# Individuals with intellectual disabilities experiences of the therapeutic relationship

#### Sarah Parker

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**Faculty of Health and Applied Sciences** 

Faculty of Health and Social Sciences, University of West of England, Bristol

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University of West of England, Bristol

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## 1. Abstract

**Background:** In the UK higher rates of mental health difficulties are experienced by those with intellectual disabilities (ID) than by those without. Despite this there is a lack of understanding about how best to support these individuals. Recently, there has been a move towards more individuals with ID being offered psychotherapeutic support. The evidence base regarding the use of psychotherapies for individuals with ID is still limited. The therapeutic relationship does appear to be important but further understanding is needed.

Aims: To gain insight into how individuals with ID experience the therapeutic relationship

Methods: 6 participants were recruited from an NHS adult ID service that provided

psychotherapeutic support. Semi-structured interviews focused on the therapeutic relationship

were analysed with use of interpretative phenomenological analysis.

**Results:** Six personal experiential themes arose from the participants' experience of the therapeutic relationship: 1) A person-centred experience, 2) The importance of adaptations, 3) 'I feel like I know you', 4) A secure base is offered, 5) Change does occur, 6) An overlap of subjective experience.

Implications for counselling psychology: This study highlights that the therapeutic relationship is an important part of psychotherapy for individuals with ID. Empathy, warmth, security and adaptations are important. Therapists working with this client group need knowledge and willingness to provide these. Participants recognised the efforts of therapists to offer considered support and this created a sense of a shared intersubjective experience. This was something which participants did not experience elsewhere, but which facilitate personal growth. This suggests that the opportunity for a new positive relationship within psychotherapy is important

for individuals with ID. This study also highlights that with some adaptations and careful consideration to ethics, individuals with ID can engage with qualitative research.

**Conclusions:** This is the first known study to directly ask individuals with ID about their experience of the therapeutic relationship. The current findings suggest that the therapeutic relationship is important for individuals with ID. The research also demonstrated that individuals with ID can engage in qualitative research. Areas for future research are discussed.

# 2. Introduction

An intellectual disability is defined as having a significant impairment of intellectual function and of adaptive or social functioning when the age of onset is before adulthood (British Psychological Society, 2010). Adaptive functioning is determined by a failure to meet developmental level for personal independence and social responsibility. Reduced abilities with reasoning, problemsolving, planning, abstract thinking, judgement, academic learning and learning from experience all determine intellectual function. ID is often divided into mild, moderate, severe and profound classifications, reflecting the variety in level of functioning across individuals with an ID. Previously these have been determined based on IQ scores across reading, maths or writing. Since publication of the DSM-V, diagnosis is based on a clinical review that considers an individual's history, academic reports and records and responses to interventions (American Psychology Association, 2013). The current study interviewed individuals with a moderate ID. Further information is given about how this was determined in the method section. With regard to the literature it was not always stated in studies what the level of functioning of participants was.

Some IDs have genetic links such as Down Syndrome, but others result from unknown causes. There are approximately 1.5 million people in the United Kingdom who are diagnosed with an ID (Pearce, 2017). The term 'intellectual disabilities' replaced the term 'mental retardation' as it is considered to be more specific, consistent, representative of current knowledge, robust and communicate more respect and dignity (Schalock et al, 2007). Globally, 'intellectual disability' has been accepted by many countries including America, Australia and Ireland. Within the UK there is no official consensus, although some NHS services and UK based journals have changed their names to reflect this term. Intellectual disability is also the term used widely across the scientific communities (Cluley, 2018). As it is hoped this research will be able to provide guidance to professionals working with individuals with ID, based on this it was felt the term 'intellectual

disability' would make it more visible amongst other search terms. Therefore, intellectual disability will be used throughout this study.

Mental health is a broad term that encompasses an individual's cognitive and social skills, emotions and daily functioning. It may affect how one copes with adverse life events or social roles and involves both the mind and body (Galderisi et al, 2017). Mental health problems are overrepresented in individuals with ID compared to the general population (Whittle et al, 2018), despite risk factors such as, stress, low socioeconomic status, lack of social support, old age and female gender, being the same in both populations (Smiley, 2005). Furthermore, it is difficult for individuals with ID to access mental health support from experienced professionals (Bouras and Holt, 2004). Recently there has been more acknowledgement that individuals with ID are suitable for talking therapies, but there is still limited literature regarding what may make it most effective (Hemmings et al, 2009). Within the general population the therapeutic relationship has been found to be more important than the modality used (Flückiger et al 2019). Therefore, this research will consider whether this is important for individuals with ID as this feels an important next step towards meeting the mental health needs of individuals with ID. In particular, being able to provide them with effective support that best meets their needs.

## 3. Literature Review

This literature review will explore the knowledge base relating to people with intellectual disabilities (ID), their mental health and the therapeutic relationship. The literature review will begin with a discussion about the experiences of people with ID in terms of their mental health and therapy. Research has shown that the therapeutic relationship is important for successful outcomes across different therapeutic approaches (Flückiger et al 2019). Therefore, this review will discuss different components of the 'therapeutic relationship' to provide a definition of what it is. Following this, research that has studied the therapeutic relationship in both the general population and individuals with ID will be reviewed. Focus will be given to research considering intersubjectivity and attachment as these have previously been considered influential within a therapeutic relationship. This review will conclude with a rationale for the current study, that considers the previous research conducted.

Searches of the literature were completed using combinations of the following search terms: intellectual disability, learning disability, counselling, psychotherapy, therapy, mental health, counselling psychology, therapeutic relationship, intersubjectivity and relationships. The following terms were also used to provide an overview of research relating to different models of psychotherapy and individuals with ID: cognitive behaviour therapy, person-centred, psychodynamic and third wave therapies. The focus of this research was on the therapeutic relationship generally, not within a specific modality. Also, much of the research reviewed regarding specific models suggested that for individuals with ID the relationship appeared more important than the model. Therefore, it was decided to limit discussion around different models and search terms are reflective of this. It is hoped this allowed a more in-depth exploration of the therapeutic relationship.

#### 3.1 People with intellectual disabilities and mental health

Bereavement is a common mental health issue experienced by individuals with ID (McCausland et al, 2021) and this is complicated by their ability to understand death and communicate about experiences of loss (Alcedo Rodríguez, 2018). Schizophrenia is also more prevalent in this group (Costello and Bouras, 2006), and they appear to experience a greater severity of negative symptoms such as blunted affect, emotional withdrawal, poor rapport and social withdrawal (Welch et al, 2011). Reasons for why this may be are not well understood but include difficulty with communication or misinterpretations behaviours as symptoms of psychosis (Adams and Matson, 2015). Anxiety, dementia and depression are also experienced (McCausland et al, 2021) which is similar to the general population within which anxiety and depression are most prevalent (McManus et al, 2016). This indicates that the range of mental health issues experienced by individuals with ID is different to the general population, and that they are more at risk of experiencing one.

Many individuals with ID also experience comorbid physical disabilities, dependency and fear of death, obesity and live sedentary lives (Hollins and Sinason, 2000, Cooper et al, 2015). This is thought to be linked to difficulty accessing health services, not having the knowledge to make healthy choices and relying on carers for communication and to recognise problems (Cooper et al, 2015). This is further complicated by their own limited capacity for solving problems and a limited ability to use appropriate and effective coping mechanisms (Royal College of Psychiatrists, 2003, Adams and Matson, 2015). In addition, adults with ID have limited social networks which is linked to a more impoverished lifestyle, and suggests they are less likely to receive emotional support from social networks (Lippold and Burns, 2009). It is not surprising then that individuals with ID may experience reduced wellbeing in response to the impact of these different adverse life events and environmental stressors. This can often be displayed through challenging behaviour or substance abuse (Wigham and Emerson, 2015). This highlights how varied the response to reduced wellbeing can be by an individual with ID and so identifying mental health problems in this population may be more difficult.

Challenging behaviour may indicate different factors such as unmet need, frustration, avoidance, sensory or environmental factors. Furthermore, within adults with ID there is a high prevalence of challenging behaviour and mental health difficulties, but no consensus regarding the association between the two in terms of causation. Bowring et al (2019) suggest that the two may interact in some way. For example, a mental health difficulty may maintain challenging behaviour, or individuals who find it difficult to express themselves verbally may find challenging behaviour offers relief to mental health problems. Despite this, they acknowledge there remains too much ambiguity around the topic to draw conclusions (Poppes et al, 2016). Professionals though, will often overlook mental health difficulties and the possible relationship to challenging behaviour in favour of working behaviourally (Unwin et al, 2016). This is an example of diagnostic overshadowing, which is when the assumption is made that an individual with ID's behaviour is due to their disability, without considering other factors (Reiss et al, 1982). It has been widely discussed in the literature as a barrier for individuals with ID accessing appropriate support because this cannot be offered if an individual's presentation is misunderstood (Javaid, 2019). Mason (2007) surveyed 220 clinical psychologists and psychiatrists working in ID services and found diagnostic overshadowing to be an important factor in the effectiveness of psychological therapy. They proposed that diagnostic overshadowing meant that individuals with ID and mental health needs were not being identified and so were not being offered support with their mental health. This suggests that there are many individuals with ID and mental health difficulties being overlooked because professionals do not understand the true nature of their problems. This may be an insight into why individuals with ID do find it so hard to gain access to appropriate services, although Mason (2007) did not ask individuals with ID who may have been able to offer their own perspective on why this is.

The difficulty in accessing services contributes to individuals with ID with mental health difficulties not getting the support they need. There is a lack of appropriate services, such as those with professionals trained in working with individuals with ID, and limited availability to the ones that do exist (Bouras and Holt, 2004, Capri, 2014). In a review of the literature, Whittle et al (2018)

found that organisational barriers, lack of appropriate services and poor quality of existing services relating to deficits in knowledge were commonly discussed barriers for individuals with ID trying to access mental health support. For example, it was commonly found across studies that professionals were unfamiliar with clinical presentations of mental health difficulties in individuals with ID and they found themselves under-resourced to work with this client group. Whittle et al (2018) also found that often for an individual with ID, they rely on a carer or family member to notice signs of mental health difficulties and to make referrals to the appropriate person. This is difficult because it places an expectation on the family member or carer to make this initial diagnosis and then to be able to navigate the complicated health system to get a referral to an appropriate service (Whittle et al, 2018). This is not necessarily easier even if individuals with ID are known to systems. Studies have found that barriers to access arise when there is a lack of service cohesion and interagency communication resulting in staff involved in services such as ID and mental health, disagreeing about who should be providing which support (George et al, 2011). In the last decade there has been a move to mainstream mental health services providing support for individuals with ID, rather than specialist services (Department of Health, 2009). However, these services have not been set up with the aim of meeting the needs of this population group and staff are not adequately trained (Rose et al, 2012). For example, the main mental health service in the UK, IAPT (Improving access to therapies), has not been developed for individuals with ID. IAPT is a stepped care model for mental health that is used widely across the United Kingdom. Chinn and Abraham (2016) found that the tightly determined eligibility criteria and written or verbal way of referrals often meant individuals with ID were excluded from this service. If they were successfully referred, the extended time they needed was not allowed within the model, making it difficult for individuals to experience much change. This demonstrates the failures of IAPT to meet the needs of individuals with ID.

In addition to the services not being adaptable, evidence would suggest that professionals working with individuals with ID feel ill equipped to do so. One study found that of the 71% of mental health staff questioned who were working with individuals with ID and mental illness, only

47% had received training on mental health issues. Those that had had training were found to be more confident, but those who had more experience did not (Quigley et al, 2001). This suggests that training may be important in building confidence in those supporting individuals with ID and mental health difficulties. Rose et al (2012) reviewed the literature and found training could be effective and enhance staff attitudes, but it was not clear how much transferred to the working environment. Weise et al (2017) suggested that the focus on educating the workforce was unlikely to produce lasting change, and that it was important to consider core workforce competencies. Interviews with mental health professionals, including nurses, psychologists, psychiatrists, occupational therapists and social workers found that communication, assessment, and intervention that followed a person-centred approach, in terms of being holistic, inclusive, and collaborative were all important. Professionals need to be able to adapt their communication style and use the preferred style of the individual they are working with. They also need to prepare for assessment and consider the contribution of mental health, physical health, the environment, communication, and skills to behaviour as would be done with a general population, instead of considering the behaviour as a part of their disability. The assessment process also needs to be individualised, involving multiple sources of information if appropriate. Professionals need to have belief their interventions will work and move away from prescribing medications, especially as overprescribing has been found to be a problem for individuals with ID (Sheehan et al, 2015). This study is unique in that it considers the competencies, rather than training needs of professionals working with individuals with ID, but it did not ask individuals with ID for their views, a common problem across the literature. It was also limited in the solutions it offered and how to implement these.

The literature needs more research using individuals with ID as a sample. The only way to best understand their experiences and beliefs is to ask them directly, otherwise decisions about support and what is best for them is being made on the assumptions of others. Hemmings et al (2009) compared the views of service users, carers and specialist health professionals involved in community services for adults with ID and psychosis. They found that all groups recognised

change was needed but differed in what they felt was important. For service users, advice and practical help was more important, whereas professionals were more concerned about relationships between different services. This suggests that professionals may be more concerned about the systemic issues impacting the service they work within, rather than the actual needs of the individuals they are working with. This highlights the importance of research giving individuals with ID an opportunity to be heard as their views are different from the professionals they are working with. Qualitative methods allow this, as they centre on the experiences of the individual and offer them the opportunity to provide their own perspective and understanding. One study that did use a qualitative methodology to explore the barriers and enablers in accessing mental health services among people with ID, identified the main themes as distance, location and accessibility. Results also confirmed the presence of diagnostic overshadowing as it was found that in addition to personal issues, challenging behaviour often resulted in a lack of understanding by professionals, who often misdiagnosed as a result (Maestri-Banks, 2020). This suggests that professionals may see the disability before the person and further highlights the need for more research with this population group as they are able to contribute to what is important for their mental health support. Barelds et al (2010) also found that the nature and type of care and services they received were important to individuals with ID. The client wanted to feel like they were being taken seriously, they were allowed sufficient time and attention and they felt listened to. However, relatives were more concerned about support costs and service delivery processes. This further illustrates a difference in opinion depending on who is asked. The evidence suggests the relationships and interactions within service delivery are most important to individuals with ID. As there is a dearth of research asking individuals with ID their views, it is difficult to conclude what it is they value from mental health services, or even their experiences of mental health. Therefore, an important part of the current research will be to ask individuals with ID about their views.

Some research has asked individuals with ID about their mental health. Lunsky (2003) completed structured interviews with individuals with ID. They found that individuals with higher depression

scores were lonelier and had higher stress levels than those with lower scores. Scott and Havercamp (2014) also found a significant correlation between stress and mental illness, regardless of level of ID, gender or place of residence. Those who lacked social support were twice as likely to have a mental illness, but adequate social support reduced this risk. This study did gather questionnaire data from individuals with ID, but only included participants who met a clinical diagnosis of a mental health problem, and this was determined by their carer. They were also unable to include anyone who could not answer most of the questions. Therefore, results may not be applicable to those with more severe ID or those with presentations that don't meet clinical level. Even so, the results do suggest that there is a relationship between stress and mental health for individuals with ID. This is worse than the general population. Hartley and MacLean (2009) found that compared to a matched sample of adults from the general population, adults with ID and depression had more stressful social interactions, experienced more stress and used fewer active coping skills. This suggests that not only is stress a factor for poorer mental health outcomes, but individuals with ID are more at risk of experiencing it. This highlights the importance of more accessible services, such as therapy to support them and teach them coping skills, such as talking to someone about their problems. It is also important to conduct research using individuals with ID, as these studies have done, so they can contribute to what effective support is best for them.

#### 3.2 Individuals with intellectual disabilities and access to psychotherapy

Individuals with ID have historically not been considered suitable for talking therapies because they do not have the emotional capacity or ability to form attachments required by such interventions. Therefore, working relationally was not considered to be successful (Greenhill 2011). This thinking has been challenged (Bender, 1993, Goad, 2022), but interventions are still dominated by the behavioural approach (Unwin et al, 2016). This is problematic because whereas behavioural interventions for challenging behaviour in those with more severe ID has been well documented (Vereenooghe and Langdon, 2013), they are felt to overlook the emotional context of behaviour (Bhaumik et al, 2011). As a result, they are not considered sufficient to help with

individuals with ID's mental health problems (King, 2005). This is not surprising as behavioural interventions also do not address the number of factors thought to underpin some mental health difficulties, such as stress, loneliness, and economic difficulties that have previously been discussed (Smiley, 2005). Although, with a growing research base and more policy papers being published, how best to meet the mental health needs of individuals with ID is now being considered.

A vision for improving mental health and wellbeing in England was specified in the 'No Health without Mental Health' strategy (Department of Health, 2011). This emphasised the importance of prevention and early intervention in addressing mental health, and the joint working between local governments, the NHS and the third sector. It highlighted the importance of including individuals with ID in mainstream mental health services and that staff have adequate levels of training.

The Green Light Toolkit (2004) aimed to improve mental health treatment for people with intellectual disabilities. Instead of just identifying that mental health services needed to do better, it suggested ways in which they could improve, and services were encouraged to use it to agree local actions. The National Development Team for inclusion (NDTi, 2012) reviewed the toolkit in 2012 and found that some changes had been made, but there was still a way to go and suggested ways for these changes to happen. They found that mental health services which were already helping staff be leaders, reflecting on things that worked and didn't work, involving families, being person centred and working together with other services were good at improving services for individuals with ID. When services weren't doing these things, they suggested the focus be on training and empowering staff, so they are better equipped to support individuals with ID and champion their rights. The report takes a top-down approach, indicating that service managers and funding bodies need to see the importance in supporting individuals with ID to make change happen.

Reasonable adjustments so that services are easier to use by individuals with ID, were further suggested in the Reasonably Adjusted Report (NDTi, 2012). They indicated the importance of

advocacy so that people with ID and mental health problems get the appropriate support; psychological therapies become more accessible, services to be educated in what they should be doing, and staff receive training to support their working with individuals with ID and mental health problems.

The National Institute for Health and Care Excellence guidelines (NICE, 2016) state that the full range of psychological therapies should be adapted based on individual need and level of disability, and available to all individuals with ID. Furthermore, the Department of Health (2009) recommends that IAPT services should also provide interventions to individuals with ID. As already discussed, IAPT is one of the most accessible interventions to the general population but adaptations are needed to make it suitable for individuals with ID, such as, easier to read information and support with understanding and gaining consent (Levin, 2011).

As highlighted, there are several reports advocating the mental health needs of individuals with ID. But a report by The Foundation for People with Learning Disabilities (2014) states that; publishing reports and guidelines does not lead to action. Survey responses from individuals with ID, their families and professionals indicated that despite the initiatives aimed at reducing stigma in mental health, many individuals with ID still cannot access the mental health services they need compared to other groups and diagnostic overshadowing was a common experience. Individuals with ID felt they were defined by their disability, were not believed, or listened to and information was not in an accessible format. Family responses also reflected these points, but also showed concern at the detrimental effects being treated like this had on their son or daughter's wellbeing. Professionals also recognised the current failings of mental health services and suggested better joint working between services and long-term support would improve this. The volume of reports published suggests there is guidance for working with individuals with ID, but there is no indication of proactive implementation. Research that considers what individuals with ID find useful about support for their mental health, based on their own experiences could help guide this.

There is also no consensus regarding whether individuals with ID should be treated within mainstream services or specialist LD services and no agreed model of integration between these (Hawramy, 2020). 50 years ago, following a process of 'normalisation', individuals with ID were deinstitutionalised and supported by community care teams (Simpson, 2018). This did result in higher care standards and an improvement of human rights and equality for individuals with ID, but it also led to overwhelming demands for specialist ID mental health services (Chaplin et al, 2009). There is no disputing that individuals with ID should have access to mainstream mental health services, but despite these teams having specialist mental health knowledge, they often lack specialist ID knowledge. Despite guidance being available to aid mainstream services (NDTI, 2017), it is strongly felt that joined up working between mainstream and specialist ID services will be most effective in responding to the mental health needs of this population. Hawramy (2020) calls for a flexible care model that utilises skills, knowledge, and expertise from both mental health specialists and ID specialists, through multidisciplinary team working. This fluid approach feels appropriate as it would employ the existing skills of specialist professionals to support each other in providing holistic support for individuals with ID.

The number of reports that have been written suggests that there is an awareness among professionals and policy makers of the mental health needs of individuals with ID, but the difficulty comes in establishing effective services to meet their needs and in making these services accessible. It is also the opinions of the professionals and policy makers that dominate the literature. It may prove enlightening to give individuals with ID a platform for their own voices to be heard about the type of support they would like to receive. There also needs to be more suggestions of how proposed changes can be actioned. Many of the reports and research discuss what is needed, but not how this could be implemented or what is needed by the client group they are discussing. Therefore, gaining insight from individuals with ID on these matters appears to be essential.

### 3.3 Different psychotherapeutic approaches for individuals with intellectual disabilities.

Over the past decade, there has been an increase in individuals accessing psychotherapy and with it more research reviewing its use across a breadth of difficulties including anxiety, depression, sexual abuse and anger (Whitehouse et al, 2006). Cognitive Behavioural Therapy (CBT) and psychodynamic approaches are most often used, (Fletcher, 2011, Vereenooghe and Langdon, 2013). More recently some third wave therapies have also been considered including dialectical behavioural therapy (DBT), acceptance and commitment therapy (ACT) and mindfulness-based therapy (MBT).

CBT aims to change an individual's thoughts and behaviours to help them manage problems by methods such as verbal thought challenging and behaviour experiments (Beck and Dozois, 2011). CBT invites the client to take an active role in the therapy process and the therapeutic relationship is an important part of this. CBT acknowledges that the therapeutic relationship will both influence and be influenced by the client responses and that these are determined by developmental history, core beliefs, attachment, and behaviour. Therefore, success within CBT is dependent on a good therapeutic relationship (Okamoto et al, 2019). This is interesting to consider regarding individuals with ID because it has been argued they do not have the emotional capacity or ability to form attachments (Greenhill, 2011). Therefore, establishing a good therapeutic relationship in CBT or any talking therapy may be difficult for individuals with ID. Although, no research has asked whether this is the case. The current research aims to address this.

CBT has been adapted for individuals with ID. Unwin et al (2016) conducted a literature review of the evidence for CBT in individuals with ID. Despite there being an overall lack of evidence for the effectiveness, some studies did suggest that CBT could be used to reduce symptoms of depression among adults with mild ID. However, many studies did not account for concurrent interventions such as medication or other therapies and only 7 studies were considered relevant for inclusion. They also found that positive changes such as reduction in negative automatic thoughts and depressive symptoms were not consistently maintained at follow up across studies. Unwin et al (2016) also compared studies using CBT to treat anxiety. Only three studies were found that were

relevant for inclusion and these found CBT offered limited improvement in anxiety symptoms and these were not maintained at follow-up. Therefore, quantitative studies do not provide a clear understanding of the effectiveness of CBT. Unwin et al (2016) also reviewed qualitative methodologies. These studies found more positive results. They indicated that clients enjoyed talking about their feelings, going out of the home, feeling supported, not judged, and respected by others. They also found improved social relationships for those engaging with CBT. This suggests that CBT may improve mental wellbeing by supporting individuals with ID to build skills that help them develop more social relationships. Furthermore, qualitative methods are an important tool for gaining personal insight not offered by quantitative methods. This is supported by the success experienced when CBT is delivered in a group format (Lindsay et al, 2015 and Marwood and Hewitts, 2013). Giannaki and Hewitt (2021) used a multi method approach to evaluate a CBT therapy group for individuals with ID. Participants attended the group with their supporter. Pre and post group questionnaires measuring anxiety, psychological distress and overall functioning were administered and post group semi-structured interviews were conducted. Questionnaire responses indicated an overall positive impact of the CBT group, with many participants experiencing a decrease in anxiety, distress and increased global functioning. None of the participants mentioned the impact of unhelpful thoughts on anxiety during the interviews. Participants did report that learning skills, the group format and being able to have a supporter present beneficial though. It could be suggested that the core concepts of cognitive therapy are less important in eliciting change in individuals with ID, but what is important is the way within which therapy is delivered or the relationships that are a part of it. Unwin et al (2016) drew a similar conclusion from the qualitative studies they reviewed, stating that it may not be the technical aspects of CBT that are important but the sense of being listened to and taken care of by the therapist. This is supported by Pert et al (2013) who interviewed 15 individuals with mild to moderate ID about their experience of CBT and found feeling valued and validated, being treated as an equal and experiencing an empathic, validating therapeutic style to be important. Therefore, CBT does appear to be beneficial based on results from studies with qualitative

methodologies. This may not be a result of the core processes underlying the approach, but because of the skills gained from experiencing a positive therapeutic relationship and indicates that individuals with ID can work relationally. It may also indicate that the core CBT needs to be worked differently with adults with ID and that therapists need to develop such skills. Delivering adapted CBT that focuses more on the relationship and skills surrounding this may be more effective and person-centred. Only two studies in the literature have considered a person-centred approach for individuals with ID. Flitton and Buckroyd (2002) found limited improvement when a person-centred counselling approach was used with children with ID. Only one teacher out of four reported improvements. Demanchick, Cochran and Cochran (2003) did find person-centred play therapy resulted in positive growth and improvements in self-expression and emotional wellbeing and these changes were seen inside and outside of sessions. However, they only had a sample size of two and no further follow up studies were conducted. It is apparent that studies that directly compare CBT with a pure relational approach, such as person-centred, are needed to gain a better understanding of this for adults with ID. There also needs to be better clarity of what a person-centred approach encompasses for individuals with ID as this is a phrase that can be used in different ways. It is dependent on the relationship between the client and therapist, therefore, by asking individuals with ID about their experiences of the therapeutic relationship, the current research may provide more insight into this.

Hurley et al (1998) developed a framework of adaptations for individuals with ID that were recommended for consideration when planning CBT interventions. These modifications included simplifying language, using activities more frequently, being flexible in style, involving caregivers and taking disability or rehabilitation approaches. Surley and Dagnan (2019) updated and extended a review by Whitehouse et al (2006) looking at how these adaptations are used in CBT and written about in the evidence base. They found, as Whitehouse et al (2006) found, that there is a lot of variability in reporting of modifications between studies and the detail with which they are reported. They also found that since Whitehouse et al (2006) conducted their review, more studies reported alterations to language used, activities, developmental level and involving

caregivers. This suggests that, more recently, professionals are giving greater consideration to the interpersonal context of individuals with ID, by adapting approaches in line with their needs and to include others in support. It appears that there is an awareness of the importance to support individuals with ID with appropriate modifications when engaging with CBT, but the variability in reporting of these adaptations makes it difficult to determine effectiveness or reliability.

There is also a question regarding how important emotional skills are for individuals with ID accessing CBT. Across the literature there is a tendency to predict an individual's success with therapy based on their emotional literacy and verbal reasoning skills (Langdon et al, 2017). Although, having a history of meaningful relationships, the ability to relate to the therapist and being motivated are all likely to predict good therapeutic outcomes (Sifneos, 1972). This is supported by Pert et al (2013) who interviewed individuals with ID having CBT. They found that it was the warm, empathetic and validating therapeutic relationship with their therapist that they valued and this validation, being treated as an equal and feeling understood contributed to positive outcomes, rather than factors specific to CBT. Roberts and Kwan (2018) also looked at the effectiveness of CBT for reducing anxiety in individuals with ID. Their study was twofold. First, they looked at whether cognitive challenging could be taught to individuals with ID and then they looked at the effectiveness of a 6-week CBT intervention adapted for individuals with ID (CBT-ID). Cognitive challenging involves systematically examining dysfunctional thoughts that cause emotional distress. It is an important part of CBT. Roberts and Kwan found that whereas individuals with mild ID were able to understand and apply it readily, individuals with moderate ID needed extensive modelling and practice before they were able to use it independently. Despite this, they still found a reduction in anxiety scores following the CBT-ID. This suggests then that CBT can still be effective regardless of the skills needed and may be effective for individuals with differing levels of disability. The CBT intervention Roberts and Kwan used involved group therapy, which, as already discussed, is thought to be an effective way of delivering CBT to individuals with ID, potentially due to the social element (Lindsay et al, 2015, Marwood and Hewitts, 2012, Giannaki and Hewitt, 2021). Consequently, the reduction in anxiety scores may have been

influenced by the reduced isolation, increased social support and shared experiences that the individuals with ID experienced. This suggests then that the ability to establish relationships may be more important than emotional understanding. When considering what is effective in therapy, the focus may be better placed on the relationships of individuals with ID, not their ability to interpret emotions, as this is often overlooked with individuals with ID (British Psychological Society, 2016). This further supports the need for the current research, which hopes to ascertain how important individuals with ID find relationships, in particular the one with their therapist.

Third wave therapies emphasise acceptance instead of trying to challenge and change internal, negative thoughts and feelings. They encourage awareness of both internal and external experiences through mindfulness practice and have been found to be effective across various mental health conditions in the general population (Brown et al, 2011). Third wave therapies have been argued to address the need for communication and abstract reasoning ability, that CBT can require and so could be more effective for individuals with ID. Patterson et al (2019) conducted a systemic review that looked at 20 studies using third wave therapies with individuals with ID to support mental health, challenging behaviour or stopping smoking. Whereas results were found to be more effective for behavioural needs, the evidence for third wave therapies improving mental health symptoms was more mixed. Although, they did increase the range of psychological skills, including non-judgment, self-compassion, and willingness to experience cognitive emotions. Overall, the authors found the evidence base to have a weak research report strength. This indicates a need for more robust methodologies that better explore the effective of third wave therapies for individuals with ID.

Psychodynamic therapy draws upon the work of interpersonal and development theorists (e.g. Klein, 1932, Bowlby, 1969), so research into it could offer insight into the importance of relationships for individuals with ID. The aim is to alleviate psychological tension by bringing the unconscious into the conscious awareness. The therapeutic relationship is considered an important part of this. It acts as an object to be scrutinised and changed. This is partially at a behavioural level; why a client forgets to attend or is late, the importance of payment and setting

of boundaries by the therapist. But also, at a more implicit level; a psychodynamic therapist will help a client become more aware of their transference patterns and consider their own countertransference, so that these can be addressed in the therapy room (Freud, 1964, Gelso and Hayes, 1998, Feltham, 1999). Therefore, within the psychodynamic approach, unconscious processes underlying the therapeutic relationship are also considered important. The importance of bringing the unconscious into the conscious raises interesting questions regarding how easy it is for individuals with ID to grasp insights into these processes and so how effective psychodynamic therapy would be for them.

In a review of the literature, James and Stacey (2014) concluded that psychodynamic therapy was effective for individuals with ID. However, they stated that descriptive case studies dominated the literature, and details about the therapy provided were lacking, so it was difficult to discern the important components of therapy. Himmerich (2020) has more recently reviewed the literature. It was concluded that methodologies were still not robust enough to draw any firm conclusions about the effectiveness of psychodynamic therapy for individuals with ID because the evidence base is largely case studies and no differentiation between level of disability is made. Some do discuss adaptations to therapy such as a more flexible frame and increased use of the environment as a therapeutic tool, but do not specify the level of disability. Therefore, it is difficult to ascertain whether change is seen due to psychodynamic components, or more humanistic ones, for example having someone to talk to for an hour, being listened to and feeling validated. These are often rare experiences for someone with an ID and something the CBT literature would suggest is important, despite previous beliefs that individuals with ID could not form attachments.

Beail et al (2005) found a reduction in psychological problems, symptoms of psychopathology, interpersonal problems and improvement in self-esteem following an average of 13 sessions in individuals with ID but did not offer insight into what components of therapy were effective.

Skelley et al (2018) also found improvements for 30 individuals with mild to moderate ID. This study had a higher level of control than some; participants were excluded if they were receiving

other significant psychological interventions and were compared with outcomes whilst on the waiting list, suggesting that it was therapy that made a difference. Results were also retained at six month follow up. The average number of sessions was 22 though which suggests individuals with ID may benefit from more prolonged therapy, rather than the shorter durations often offered. Skelley et al (2018) argue that when services are under pressure to offer less, therapy recipients may feel rejected and that it is not enough. This suggests that a shorter duration of sessions could potentially be more damaging for an individual with ID. This is supported by McInnis's (2016) case study of an adult with mild ID presenting with complex emotional and behavioural problems, which reduced following a total of 88 sessions. After completing the therapy, the therapist felt the participant's ability to cope with change had improved, was better able to form safe attachments to others, formulate and understand himself, trust the therapist to share information and discuss life goals. Despite this being a case study, the in-depth account provided offers insight into psychodynamic therapy with individuals with ID. It also suggests that longer durations of therapy overall may be more beneficial.

One explanation for this may be the time needed to build a relationship with a therapist, as studies suggest that the relationship is important, and this takes time to develop. Merriman and Beail (2009) interviewed individuals with ID about their experiences of long-term psychodynamic psychotherapy and found they viewed the relationship with their therapist as helpful. They found staff leaving or therapy ending difficult because of how much they valued the relationship.

Furthermore, Alim (2010) found relational interventions where the therapist adopted a parental stance aided therapeutic progression, as the client was able to repair early parental relationships based on the new one they were experiencing. Therefore, it appears individuals with ID can form attachments within psychotherapy and so working relationally may be important for them. The current research hopes to offer insight on this from the perspective of an individual with ID.

#### 3.4 The therapeutic relationship

It is evident from the research considered thus far that the therapeutic relationship is an important, but under researched area and so worth further exploration within an ID population. The therapeutic relationship is a complicated concept that has many definitions and components. This section aims to consider these different definitions, such as the 'therapeutic alliance,' 'working alliance' and 'real relationship' and the components underlying them. This section will also draw further insight from established literature on attachment theory, before considering the influence of intersubjectivity and how this may influence the therapeutic relationship. This section will conclude by considering how all the literature discussed may apply to an ID population and why it is worth further exploration.

#### 3.4.1 Different components of the therapeutic relationship

The importance of the therapeutic relationship has been recognised across modalities within the general population and so it is not surprising that it is also important for individuals with ID. Freud (1912) declared that the first aim of treatment was to build a bond between client and therapist, and that the 'friendly and affectionate aspects of the transference' were key to success. Zetzel (1956) coined the term 'therapeutic alliance' explaining it as the client's ability to use part of their 'ego' to engage with the therapist and tasks of therapy. Within the person-centred approach, Rogers (1951) also suggested that the patient's experience of the therapist's empathy, congruence and unconditional positive regard were all important. These views are all compatible to the extent that they focus on the shared experience of the relationship between the therapist and client, although they differ in which components are felt to be most important and how they are used, for example, the type of relationship that is established.

The term 'therapeutic relationship' is used widely and can be understood in different ways.

Greenson (1965) suggested two alliances: reserving the term the 'therapeutic alliance' to describe the bond between the client and therapist and suggested the 'working alliance' to describe engagement with therapy tasks. Bordin (1979) further conceptualised the 'working alliance' to include agreement of goals, assignment of tasks and development of bonds. These determine the quality of the alliance between therapist and client. The working alliance is now commonly

defined as 'as the emotional bond established in the therapeutic dyad, and the agreement between patient and therapist concerning therapy goals and the tasks necessary to achieve them' (Elvins and Green, 2008). It is one of the most robust factors thought to contribute to psychotherapy outcome across contexts (Cameron et al, 2020). Evidently, the 'working alliance' has undergone many conceptualisations and represents both single constructs (i.e. Zetzel, 1956) and multiple dimensions (i.e. Bordin, 1979). There are three common themes across the theoretical definitions; the collaborative nature of the relationship, the affective bond between patient and therapist, and the patient's and therapist's ability to agree on treatment goals and tasks (Martin et al, 2000). For the purposes of the current research the term 'working alliance' will be used as a single term including all three themes.

Greenson (1969) suggested that the transference and countertransference feelings between client and therapist and the 'real relationship' between them was important. Gelso and colleagues (1998, 2011) developed the concept of the 'real relationship' and argued it was more important in building the relationship than the working alliance. They refer to a 'tripartite model' in which the working alliance, transference-countertransference and real relationship are present in every therapeutic relationship. How salient the different components are, will depend on many factors, such as time point, duration of treatment or therapist's theoretical orientation. The real relationship differs from the working alliance in that it exists on a personal level and is not limited to the boundaries of the therapeutic work. Rather than focus on goals and tasks, it is the personal relationship existing between two people that reflects how genuine each is and how realistic their perception of the other is, that is important. It consists of genuineness, or being authentic, and realism, which means to perceive the other in ways that suit the other, not fit in with the needs of the perceiver. (Gelso, 2011). Both the therapist and client contribute to the real relationship. The therapist may contribute directly by disclosures of thoughts, feelings and information and indirectly, by their sense of humour, body language, office décor and facial expressions. They perceive the client genuinely and not based on their own misperceptions. The client strengthens the real relationship through engagement with self-exploration and communication that disclose

who they are. They also respond to the therapist in ways that suit them (Gelso, 2018). Therefore, a reflection of an effective working alliance may be recognition of skills or competence. In contrast, the real relationship is reflected more through connection or a sense of care for the other.

Attachment theory gives further insight into the 'real relationship' (Holmes, 1993): Bowlby (1969) highlighted the importance of a supportive caregiver for an infant to establish a secure attachment style and this has been found to be important for how children respond to stress. Mahler et al (1975) also studied children and their caregivers. They identified behaviour changes that could be linked with different emotional development stages. The behaviours change as the child transitions through each of five stages. Mahler et al (1975) described it as the children moving from biological birth to psychological birth and the final stage was met by 40 months in typically developing children. Primary carer support is needed throughout this process to ensure anxiety experienced by the child remains manageable and they can grow in independence. If a child is supported and able to reach 'individuation' then if later trauma does arise, they will be better placed to respond to it than children who experience trauma before individuation. This is supported by Spangler and Grossman, (1999) who found when presented with a challenge, securely attached children used appropriate stress-reducing behavioural strategies to communicate with caregivers and this appeared to regulate cortisol response. Insecurely attached and disorganised infants were not able to do this and had an increased response to stress. Therefore, in therapy, a therapist aims to provide a secure attachment base, characterised by warmth, safety and predictability. They will also aim to be a secure figure who is empathic, responsive, and attuned to the client's needs. It is suggested that empathy is significantly related to the strength of the real relationship. When a client feels understood it helps establish realism from the therapist and fosters a sense of personal connection. This empathetic experience is often reciprocal, so the therapist also then feels more understood by the client (Gelso, 2018). Therefore, by offering this environment and experience of a relationship that may have been missing from the client's early life, new opportunities are available to reconsider trauma and work through it (Feltham, 1999). This supports Roger's view that transference needs to be dealt with, as opposed to fostered, otherwise it risks disrupting the development of the real relationship (Rogers, 1951).

This ability of a child to be able to understand their parents' mind, and the parent to understand the infant's is due to the cognitive affective capacity of the human brain. The mutual recognition of each mental state is the basis for intersubjectivity (Auerbach and Blatt 2001). Lyons-Ruth (2007) suggested that when the infant and caregiver communicate in this way it helps the infant regulate unpleasant arousal and develop new learnings. This is further supported by Stolorow and Atwood's Intersubjectivity Theory (1992). This relational theory considered the organisation of a child's experience based on a mutually regulated child-caregiver system. They suggested it is the coming together of the child and caregiver's subjectivities that develop new principles which unconsciously drive the child's future experiences. This would suggest that infants require a supportive caregiver with whom they have mutual understanding so these exchanges can happen. When this has not occurred, and there have been recurrent experiences of misattunement, individuals may have unmet developmental needs and reactive feeling states that they unconsciously put this down to their own defect or inner malice. Future perceptions of mismatched subjective interpretations only reinforce this experience. Therapy offers an opportunity to address this, because a strong therapeutic relationship that offers intersubjective experiences may disprove previous conclusions about the self and lead to therapeutic healing (Stolorow and Atwood, 1996). Modern schema therapy (Young et al, 2003) offers further insight. 'Schemas' are internal representations that through the development of coping styles, influence external behaviour. They embody how one conceptualises oneself and their relationships with others. The basic emotional needs are secure attachment, autonomy and competence, genuine self-expression of needs and emotions, spontaneity and play and realistic limits. If basic emotional needs are not met, maladaptive schemas emerge. The individual then develops maladaptive coping styles, broadly categorised as avoidance, surrender or overcompensation. A schema therapist will empower a client to work through their maladaptive schemas, their approach

underpinned by Carl Roger's core conditions (1951). They aim to create an accepting and safe environment, so the client can form an emotional bond with the therapist. The therapeutic relationship has two features; empathic confrontation, whereby the therapist expresses understanding about the client's schemas, but confronts the importance of change and limited reparenting. This establishes boundaries to the relationships that were missing from the client's earlier primary caregiver and involves flexibility from the therapist to respond in a way dependent on the client's unmet need, for example by generating trust or providing stability. If schemas are triggered during therapy, they are worked through together. Therefore, schema therapy highlights the importance of a positive therapeutic relationship to overcome early maladaptive experiences. Intersubjective experiences may be an important part of establishing this as they may strengthen the therapeutic bond on which the work progresses from.

#### 3.4.2 Intersubjectivity and the therapeutic relationship

Intersubjectivity has also been studied within the psychotherapy literature. Freud (1912) recognised the importance of the bond between therapist and client, but he posited them as two separate beings. Kohut (1982, 1984), furthered this thinking by suggesting that interpretations of reality are relative and that any observations of the client will involve the therapist. More recently, the mutual influence of the therapist's and client's subjectivities on the therapeutic relationship are considered important. This underpins intersubjectivity within therapy (Capri, 2014).

Psychological healing results from experiencing new ways of relating to people within the intersubjective space. New principles arise from the intersubjective space which enlarge and enrich the patient's experiential repertoire, leading to more flexible and complex understanding. The integration of the two subjectivities is unique to the therapeutic dyad, and both the therapist and client make specific contributions (Fosshage, 2011). Furthermore, it is the exploration and testing clients do within this space that leads to therapeutic growth (Swartz, 2006). Intersubjectivity is defined differently depending on the theory, but they all agree that experiences of the world are shaped by subjectivity and that mutual influence and adaptation

affect the therapeutic relationship. They also recognise influences of transference and countertransference and a focus on the client's rather than the analyst's subjectivity (Swartz, 2006). Buirski, Haglund and Markley (2020) highlight that making sense together so that the client is aided to understand themselves in a new light and have new relational experiences with a therapist who the client feels deeply accepts and understands them underlie an intersubjective therapeutic experience. They suggest guidelines to aid this: The therapist needs to be open and curious to the client's disclosures and aware of their own subjectivity, they need to avoid interventions that injure the client and allow the client to set the agenda. The client's affective experience needs to be identified and articulated so that it can be reorganised. Also, personal meanings made of subjective experience need to be revealed for interpretation. Therefore, intersubjectivity is more than being able to empathise with the client. Therapists need to be able to pull out interpretations and support learnings from these.

Underlying intersubjectivity is the relational unconscious (Gerson, 2004). This influences the individual subjective experience within the dyad by controlling the engagement that is specific to that dyad. Gerson (2004) argues that without an intersubjective experience a thought is never thought, because the organisation of meaning in one's mind is guided by the reciprocal influence of other minds. Gerson (2004) continues to suggest that this should not be thought of as an exchange between two bounded individuals, but a coming together of them into a mutual partnership. The relational unconscious bonds each partner's subjectivity and own unconscious within the dyad, forming a new intersubjective understanding. This intersubjective understanding may be an important factor in determining the therapeutic relationship, and therefore, supporting therapeutic growth.

Freud (1912) believed that it was important for therapists to be immune to patient's unconscious and engaging in their own psychoanalysis would help with this. According to Ogden (1994b as cited in Gerson, 2004) this is not possible as humans strive to establish intersubjective constructions and so therapists will automatically respond to their client's unconsciousness.

Empathy has also been considered an important part of intersubjectivity. This may require

conscious insight of the therapist to ensure their own subjectivity is empathic. How the client interprets things is shaped by the therapist, and this in turn, will determine how much the client feels understood (Fosshage, 2011). This can be difficult for the therapist, who needs to 'hear' both the content and the process and differentiate between foreground and background features of the client's experience.

Considering the literature that emphasises the importance of the therapeutic relationship for successful therapy, it may be intersubjectivity that facilitates this. Even outside of therapy, relationships where individuals feel understood, respected and accepted are more positive so it is logical to suggest this relationship is essential within therapy. This may be even more important for individuals with ID, who are often deprived of such relationships early on in life (Banks, 2006). Although, intersubjectivity relies on a strong therapeutic relationship and so an ability to work relationally. There is still limited understanding of how this may best be approached for individuals with ID and so the current research aims to consider this.

#### 3.4.3 Intersubjectivity and the therapeutic relationship for clients with intellectual disabilities

Bowlby (1969) indicated the importance of stable, secure relationships for young children's emotional and behavioural development. Mahler et al (1975) offered further insight into the links between typically developing children's behaviours and emotions. Mahler proposed that until six months, children are unaware of their surroundings and others, and do not see beyond their relationship with their mother. After six months, the child begins to distinguish themselves, develop cognitive ability and communication skills. As the child grows, they begin to internalise the image of their mother. Those with a positive relationship feel supported, whereas those who don't may struggle with insecurities. Disruption in this process, Mahler argued, could lead to maladaptive behaviour. In the 1980s, similar patterns were noticed in people with ID but on a more delayed timescale (Frankish, 1992). Individuals with ID are at an earlier stage of emotional development, and so may not be as emotionally connected or attached to others. They may also have an insecure attachment style, whereby they focus on the self and when interacting with others, may display emotional or behavioural problems due to not having other skills, considered

more appropriate (McInnis, 2016). This may be linked to the suggestion that children with ID find intersubjective skills such as expressing needs or understanding an adult's emotions or intentions more problematic, making it more difficult for them to establish a secure attachment relationship with their primary caregiver (Atkinson et al, 1999). It could be suggested that if the client with ID has experienced an insecure attachment, this difficulty may also be seen in therapy when establishing a relationship with their therapist. Although, some have argued otherwise.

Frankish (1989) adapted the work of Mahler, to develop the Frankish Model of Disability psychotherapy. The Frankish Model of disability psychotherapy proposes that offering the client individual psychotherapy provides a secure physical and emotional base, from which the client can gain a sense of self and practice relating to others. This is more likely to be successful when staff are matched with the individual for characteristics, can provide long term support and they understand the needs of the person with whom they are working (Frankish, 2013). Indicating that, despite finding relationships difficult to obtain, a successful therapeutic relationship may be important for individuals with ID as it offers them a new experience and opportunity to learn new skills that may help them relate to others.

Not all individuals with ID will have experienced an insecure attachment, but for those who have therapy may be the first experience of them experiencing a collaborative and equal relationship.

Coming to terms with raising an infant with an ID can be an overwhelming experience for parents, who often lack adequate support. Not only does this create a sense of fear, but also an experience of loss of the child they were expecting to have, leading to a disconnect with their child with ID, resulting in different styles of interaction, such as reduced eye contact (Hamadi and Fletcher 2019, Potharst et al, 2012). Furthermore, increased stress in trying to meet the needs of the infant leads to decreased parental engagement (Giltaij et al, 2015). As early developmental theorists suggest, these early relationships can be influential on the young person's later emotional and behavioural development. If the child doesn't have a caregiver returning their gaze with understanding and tolerance or someone to contain their emotion, then they are unlikely to be able to regulate their own thoughts and feelings and they will have difficulty with their own

subjectivity (Linington, 2002). This disruption in caregiving is associated with distant, inconsistent or neglectful parenting styles (Mullen, 2018) and is thought to underlie the higher rates of disorganised and atypical attachment styles associated with individuals with ID (Scheungel et al, 2013). Social connectedness and warm, intimate relationships with a primary caregiver are known to be important (Mullen, 2018, Bowlby, 1973), but it appears that this is missing from early interactions for some individuals with ID. If this is considered in terms of schema therapy (Young et al, 2003), then it is reasonable to suggest that these early experiences result in an individual with ID's basic emotional needs not being met and so maladaptive schemas emerge. Through consideration of the therapeutic relationship, the current research hopes to build a better understanding of whether it is influenced by early experiences.

This difficulty with relationships persists throughout life. Individuals with ID have greater difficulty forming and maintaining friendships and experience more loneliness than a non-disabled population (Friedman and Rizzolo, 2018). It is not clear why this is. It may be that maladaptive schemas from childhood are activated when attempts are made at forming relationships, and strong negative emotions are triggered as a result (Young et al, 2003) although, no research has looked at this with individuals with ID. The social relationships of adults with ID have been found to be largely restricted to paid staff, family and other individuals with an ID (Bigby and Knox, 2009) and so it may be that their opportunities to form friendships are limited. Despite them having a desire and understanding of friendship, it often doesn't materialise (Cuckle and Wilson, 2002). Considering the importance of trust and mutual respect for friendship, it may be the lack of these being reciprocated that act as a barrier for individuals with ID building social networks (Petrina et al, 2016). This then impacts their quality of life, as having satisfying friendships leads to individuals with ID participating more in the community, having more intimate relationships and being more respected (Friedman and Rizzolo, 2018). Good social networks also appear to act as a protective factor against mental health difficulties. Conder, Mirfin-Veitch and Gates (2015) interviewed women with ID and found that it wasn't just the positive relationships with family and friends that provided happiness, but also the experiences they got from interacting with them also. Although, for some of the participants the relationships they spoke about were about the parents they lived with and who supported them, or their support staff. This suggests that for some individuals with ID, extended social networks beyond family and professionals may still be quite limited despite the importance they hold.

Attavar and Bhogal (2019) highlight the importance of finding the right fit between the patient, therapist and approach being used, for successful therapy. Individuals with ID have varying different communication needs and it is the responsibility of the therapist to ensure they meet these needs. This will then help provide a trusting space for the individuals to develop a therapeutic relationship, explore their emotional needs and improve their quality of life. It has been argued that the therapist's inability to successfully adjust their style, has resulted in individuals with ID being labelled as unsuitable for therapy (Banks, 2006). Banks (2006) indicates how it may be harder for individuals with ID to experience rejection or lack of intimacy. Therapists who take an 'analytic neutral' stance may be perceived as cold or lacking in concern. Therefore, a friendlier approach that allows for greater flexibility with timings of sessions and use of physical touch may be more successful in establishing a positive relationship. Although, he does acknowledge this may make it more difficult for the patient to express and process negative emotions in therapy. Overall, it appears that a trusting therapeutic relationship is important for individuals with ID, but it requires a therapist willing to make adaptations to the approach they use and really consider the needs of the individual for it to be successful. Therefore, it may not be that individuals with ID are unable to form relationships, but that those they are working with are not equipped to facilitate this.

Being able to adapt to their needs may affect the quality of contact with professionals. This is important for the wellbeing of the individuals with ID (van Asselt-Goverts, Embregts, & Hendriks, 2015). This is supported by research which proposes the therapeutic relationship is an important component of therapy for individuals with ID accessing therapy (Lewis, Lewis and Davies, 2016, Wills 2018). Evans and Randle-Phillips (2018) identified positive feelings towards therapists, feeling listened to and valued and feeling it was collaborative were important factors. 'Being

heard' has also been identified as being important (Mattock, Beard and Baddeley 2020). This was further supported by Weise et al (2017) who interviewed individuals with ID about their experience of mental health services and found that building rapport and trust through demonstrating their experience and respect for individuals with ID were important for them. This suggests that the relationship an individual with ID has with their therapist is highly valued and important to them. None of these studies focused on this though, so provide limited insight into what makes a therapeutic relationship positive.

Some studies have considered this but use professionals as a sample. Jones (2014) interviewed Counselling Psychologists (CoPs) about their experiences of working with individuals with ID. The therapeutic relationships emerged as being fundamental, more so than the theoretical approach used. Although, CoPs found it difficult to develop it due to client's limited experiences with relationships, the involvement of carers, the need to express reassurance and not having the necessary skills. Besika et al (2018) gathered questionnaire data also from therapists concerning their attitudes with working with individuals with ID. Overall they found a positive attitude within this population towards individuals with ID and this related to training, experiences and direct contact and familiarity with ID. They also suggested a therapeutic relationship could be established with clients with ID. Although, they do acknowledge a nonresponse bias that may indicate many therapists did not respond who don't engage with clients with ID. It may also suggest that those who have had more negative experiences working with individuals with ID did not fill out the form. These studies indicate that there are many barriers for CoPs wanting to establish good therapeutic relationships with individuals with ID, but do not compare these to the opinions of individuals with ID. Counselling Psychology is based on humanism and emphasises the role of the therapeutic relationship in achieving change (British Psychological Society, 2016). Therefore, it feels important that as a profession, CoPs are finding ways to break down these barriers for individuals with ID and involving them in this process. More research is needed to guide training and build understanding.

One study that did gain the perspectives of individuals with ID was Wills et al (2018) who interviewed clients with ID and their therapists. By interviewing both members of the therapeutic dyad, this study offered insight into whether there was a mutual understanding or not, something that is limited in the literature. This research was specifically looking at significant therapy events, but the identified themes do suggest the therapeutic relationship is important. For example, one theme centred on the uniqueness of the therapeutic relationship, referring to the client's experience of the unique nature of the relationship they had with their therapist. Within this theme being heard and building trust were identified as important. Therapists also expressed the importance of building a strong therapeutic relationship with their client. Interviewing both samples was positive. Although, because this study was focused on significant events, participants were interviewed with specific reference to one therapy session, rather than their general perception. So, answers could have been more reflective of the mood and content of that session. Furthermore, clients with ID completed a Helpful Aspects of Therapy form in the presence of their therapists, which may have also inhibited their most truthful responses. Despite this though, this study does appear to support the importance of the therapeutic relationship for individuals with ID and is one of a few studies to gain their perspectives, in addition to the therapists.

Lewis et al (2016) also interviewed individuals with ID about their experience of psychological therapy with the aim of improving service delivery for these individuals and providing a greater insight into their experiences. Of the themes identified many focused on the process of therapy, for example, making it accessible and setting it up appropriately. One master theme did focus on the therapeutic relationship though and identified collaborative working and positive feelings towards the therapist important aspects to the individuals with ID. Unlike Wills et al (2018), Lewis et al (2016) asked participants who had finished therapy about their general experience across sessions and so responses were reflective of this. However, as some participants had finished therapy almost six months prior there may have been problems with recall. Nevertheless, this study supports the participation of individuals with ID in research, because most participants were able to provide descriptive answers to all the questions, enabling themes to be developed. As

with many studies in this area, Lewis et al (2016) do not state the level of intellectual disability of participants though, so it is difficult to determine whether those with a higher level of ID had participated. Stating level of ID is important as due to the differences that can be seen, such as with verbal ability (Smiley, 2005), different adaptations may be needed.

The power balance within the therapeutic relationship has also been considered. Due to the reduced independence that ID can be associated with, individuals with ID are often surrounded by professionals and have reduced authority with their own lives (Bigby and Knox, 2009). This may have an impact on the development of a therapeutic relationship with a therapist, who they see as another professional telling them what to do. O'Malley et al (2019) found that psychological interventions with individuals with ID were underpinned by certain processes, including power within the therapeutic alliance. Although, a study using interactional analysis demonstrated that power was evenly distributed between therapist and client with ID during therapy sessions.

Jahoda et al (2009) found that clients provided a greater number of expanded responses than therapists, suggesting they were not simply answering therapist's questions, but contributing to the flow of the therapeutic exchange. This suggests then that clients do play an active role in sessions and there is a balance in the therapeutic relationship. It may also indicate that there is an intersubjective experience as the balance could represent the mutual influence of the client and individual with ID's subjectivity.

## 3.6 Rationale for study

Social connectivity is important for well-being, and this appears to be underlined by secure attachment styles and early intersubjective experiences (Mullen, 2018). Research suggests that these are experiences some individuals with ID are deprived of from a young age. Therefore, the higher rates of mental ill health experienced by individuals with ID may relate to this. Currently, the literature focuses on the problems of individuals with ID with mental health problems. It does not consider that it may be rigid systems that operate to stigmatise them. Counselling psychology prioritises understanding an individual's subjective and intersubjective experience. Understanding

can only be gained from the individuals themselves. Therefore, this research seeks insight directly from individuals with ID, with the hope that this will encourage change within systems.

For a typically developing population, the quality of the therapeutic relationship between client and therapist has been found to be the most important factor in predicting positive outcomes (Hovarth, 2001). Feeling understood, feeling safe and feeling like the therapist can interpret their communications accurately all promote better outcomes, and these are based on intersubjective and attachment functions (Cortina and Liotti, 2010). Kim (2018) suggests that by providing a secure base and empathic understanding within therapy, the client will be motivated to build a therapeutic alliance with their therapist. Although, this research has not been conducted with individuals with ID. Some of the research discussed so far would suggest that individuals with ID have greater difficulty with attachment and intersubjective functions and so may find it harder to establish a strong therapeutic relationship. Although, there is limited research that suggests a therapeutic relationship may offer new experiences for individuals with ID and opportunity for growth. This could be aided by therapists, who are trained in building relationships, so this does not cause a barrier to effective therapy. Research that asks individuals with ID about their experiences of this is needed to provide greater understanding so as a profession, counselling psychology can better meet their needs.

Within the general population the therapeutic relationship has been found to be more important than the modality used (Flückiger et al 2019). Due to the limited research, it is not possible to say whether the same could be true for individuals with ID. The literature does suggest that social relationships are important though and bereavement is commonly experienced by individuals with ID. Indicating they do form emotional relationships. The literature also suggests that individuals with ID may be less likely to form secure attachments at a young age (Banks, 2006). Therapy may provide a secure physical and emotional base, offering a space for them to gain a sense of self and practice building relationships with others. Intersubjectivity's focus on shared understanding and a balance between the client and therapist may be important, as there is no 'me and them' but a unity that individuals with ID rarely experience elsewhere. Intersubjectivity

creates a space for two people within which 'our intellectual (dis)ability, physical embodiment and artificially constructed beliefs about 'otherness' are free from reproach, ridicule and revenge' (Capri, 2014). Therefore, working from an intersubjective perspective may offer the individual with ID a new environment to explore previous experiences, such as those early attachment relationships, and build new meanings from them. Linington (2002) argues the lack of connection an infant with ID may have with their caregiver, will lead to a void in their subjectivity. Therapy offers a safe space within which the trauma of their earliest relationships can be explored, and the void fulfilled. Therapists with an understanding of internal and external experiences can be of value in helping individuals with ID think about this. Although no research has asked whether individuals with ID can reflect on their relationships within a therapeutic context or consider how they experience this, it is impossible to examine what is important for them. This research will address this.

Gaining a greater understanding of how individuals with ID experience the therapeutic relationship is necessary. In recent years there has been a move towards individuals with ID being seen by mainstream services to address health inequalities they commonly experience (NHS England, 2015). An important part of this is the services making reasonable adjustments, but without the research it is difficult to determine what these adjustments should be. Adapting communication methods has been found to be important (Weise et al, 2017), but this requires specialist training. There may also be other aspects of therapy with individuals with ID that also require adaptations, but there is no research considering this from the perspective of an individual with ID.

There is also limited research asking individuals with ID about their experiences. This is because they have previously been considered a difficult sample group to work with due to ethical concerns and questions around their ability to engage with the research. Although, there is now published guidance on best practice when working with individuals with ID in research and so they should no longer be overlooked. It is of crucial importance that their voices are captured in

the literature so that they can guide service delivery, especially because their views have been found to be different to those around them (Hemmings et al, 2009).

This study aims to use a qualitative methodology because this will allow participants to explore in depth their experiences of therapy and of the therapeutic relationship. The responses given will then be considered regarding similarities and discrepancies within the existing literature. This is important because as discussed individuals with ID have previously not been considered suitable for talking therapy, unable to articulate their concerns or form interpersonal connections. More recently these opinions are changing but there is still limited research asking individuals with ID directly about their experiences. Therefore, the qualitative approach will allow an opportunity to see whether the participants speak to any of the issues mentioned in the literature and what their experiences are of them. It is hoped this research will add to the limited literature involving individuals with ID as a sample and use their voices to offer insight to mental health support for this population.

# 4. Methodology

## 4.1 Research design

#### 4.1.1 Rationale to use Interpretative Phenomenological Analysis

This study used a qualitative methodology using interpretative phenomenological analysis (IPA).

Semi-structured interviews focused on the therapeutic relationship as experienced by individuals with ID during psychotherapy.

Important decisions and considerations were involved in selecting the most appropriate methodology for this research. These included deciding to use a qualitative approach in preference to a quantitative approach, the decision to use IPA in comparison to other methods and the barriers posed by involving individuals with ID in research and how these were overcome.

## 4.1.2 Aims of the study

The following research question was addressed:

How do individuals with ID experience the therapeutic relationship?

## 4.1.3 Rationale to use qualitative methods instead of quantitative methods

The personal, subjective experience of the client and pursuit of innovative, phenomenological methods to better understand this is central to counselling psychology (Lane and Corrie, 2006). As a result, there is an expectation that chosen models of research by counselling psychologists will align with these values. These models will allow first person accounts that capture an individual's own perspective of an experience, that promote empathy and avoid researcher interpretation or superiority (BPS Division of Counselling Psychology, 2005). This consideration of power is important because researchers may be more economically and socially privileged than their participants (Moriarty, 2011). Therefore, it is important inequalities are not repeated in research and that it improves outcomes for the participants, rather than exploiting them for the sake of

professional advancement. When working with individuals with ID this is especially important as they are more vulnerable to these inequalities, especially within academic discourse (Booth and Booth, 1996). Qualitative methodology, therefore, feels more appropriate, as it offers participants the opportunity to narrate their own experience in their own natural setting and reduce the influence of power by doing so.

Quantitative methods are best placed in research that wants to better understand behaviour through the systemic investigation of observable phenomena. They utilise hypotheses to make predictions that can then be tested in an objective manner. It often seeks to determine a relationship between variables, by explaining the frequency, degree or intensity to which they occur (Eden, 2017). As the current research question is focused on the subjective experience of individuals, a quantitative method was not considered appropriate.

Qualitative methods are concerned with the emotional and cognitive aspects of an individual's experience from their own socially constructed perspective and often require close interpersonal contact with the researcher for them to understand these. This aligns with the values underlining counselling psychology which centre on empowering individuals and appreciating their subjective and intersubjective experiences (Cooper, 2009). This feels to mirror the aims of this research which seeks to further understand the therapeutic relationship participants with ID have and so further supports the use of qualitative methods.

Qualitative methods allow understanding of an individual's experience, which is important in developing and improving the quality of mental health practice, especially for an under researched group, such as those with ID. Qualitative methods meet the aims of the current project because they seek depth of understanding from a homogeneous group of people who are engaged with the research question. They are open minded in that they do not hang off prior assumptions and so suitable in this case where there is limited knowledge about the topic.

Overall, it is felt using this approach will allow a substantial contribution to the literature about an area that offers great value for a group of individuals that are often overlooked.

#### 4.1.4 Rationale to use IPA

When determining which qualitative approach to use it was important to evaluate which one best met the aims of the research. The method needs to fit with the project's purpose, theoretical assumptions and research question to allow a logical research design (Willig, 2017). Free association narrative interview was considered. Due to the open nature of questions utilised by this approach it was not felt conducive for use with individuals with ID as scaffolding questions can help deepen responses and so will not be used. Thematic analysis (TA) and Grounded Theory (GT) were also considered in addition to IPA.

TA is similar to IPA because it analyses qualitative data to look for repeated patterns that are constructed into themes. Unlike IPA, TA does not have a specific theoretical grounding and so research questions using TA are often focused on things other than making sense of just personal experience. TA has a focus on patterning of meaning across participants, rather than such a focus on individual participants. It has been criticised as lacking continuity through individual accounts and allowing the individual voice to get lost (Braun and Clark, 2006). The philosophy underpinning IPA ensures a focus on the lived experience, a commitment to the particular and interpretation. It considers both the uniqueness of a participant and patterns of meaning across them. TA can also have larger data sets that are more heterogeneous in nature (Braun and Clarke, 2021). This study aimed to gain an in depth understanding of individual experience following a phenomenological and ideographic approach. This was important to give voice and gain insight into an area that has not been considered in this way or asked individuals with ID directly before. It was felt this would be better achieved by focusing on a smaller, more homogenous sample group and so TA did not feel appropriate.

The overall aim of GT is to develop a theory based on the range of participant's experience and research questions often centre on social patterns and structures. As the current study did not intend on developing a theory and social processes were not the focus, GT was not considered the right method to use.

IPA offers an opportunity to hear the voices of individuals with ID and understand them in the context of the interpretative lens of a researcher. This interpretation will be grounded in the context within which it is said and who has said it. Therefore, IPA can contribute to the development of understanding about the needs of individuals with ID having therapy because it is asking the individuals who are experiencing it. This study will use IPA as it offers a platform for individuals with ID to have their experience heard and understood in depth.

# 4.2 Epistemology of IPA

IPA aims to explore how participants make sense of personal experiences and helps discern individual's understandings of situations (Smith 2022). Hence, IPA is important for this research where a deeper understanding of clients with IDs experiences is sought. IPA is theoretically rooted in critical realism which accepts that there are stable features of reality, independent from human conceptualisation. But, due to the different experiences' individuals have of reality, they attach different meanings to it (Bhaskar, 1979, 2008). Therefore, IPA appreciates that despite certain aspects of reality being stable, how these are perceived and understood by individuals may be different. This is further understood by considering IPA's underpinnings in phenomenology, hermeneutics and idiography.

Through its phenomenological approach, IPA does not seek objective statements but is interested in an individual's personal account of experiences or objects (Smith and Osborn, 2003). So, it is less concerned about facts, and more concerned about how an individual perceives an experience or situation in their own mind. This is important in the current research where it is the individuals with ID understanding and interpretation of an experience that is sought.

IPA is influenced by hermeneutics; to understand the meanings individuals place on their experience, researchers must be able to engage with and interpret their statements. Being able to offer this interpretation of an individual's subjective experience, is central to the approach. Of course, the researcher will bring their own presumptions to the research and so will need to be reflective to recognise this and bracket them (Smith et al, 2022). This task of the researcher to

make sense of an individual, who in turn is making sense of their own experience has been termed a 'double hermeneutic'. IPA has a second double hermeneutic in that it combines an empathic hermeneutic, whereby the researcher fully tries to understand the view of the participants, with a questioning hermeneutic, whereby the researcher must ask critical questions of the data from participants such as 'What was the person trying to achieve here?' Therefore, the IPA researcher has a dynamic and reflexive role (Smith and Osborn, 2003) and this embraced in the current research.

Idiography is important as IPA focuses on the particular not the general. It displaces causality with a focus on in-depth understanding of an individual's life. Therefore, IPA analyses the individual independently before trying to cross analyse cases. These underpinnings ensure that an individual's lived experience is captured completely including the individual's wishes, desires, feelings, motivations, beliefs and how these manifests themselves in behaviours. By taking this idiographic approach, IPA directly addresses the subjective and intersubjective intricacies of human emotion, thought and action and this provides great insight into the research topic (Eatough and Smith, 2017). This is relevant to the current study as it feels important to capture both the convergences and divergences of the responses of individuals with ID.

The main aim of this research was to understand a particular group of people's experience of the therapeutic relationship. To best understand this, a process of interpretation was required that considered the experiences of the participants but was also mindful of the researcher's own assumptions. Therefore, IPA was selected as it was felt to best meet the needs of the research design.

# 4.3 Overcoming barriers to using individuals with ID in research

The voices of individuals with ID are lacking in research. Challenges including 'inarticulateness, unresponsiveness, a concrete frame of reference and problems with time' (Booth and Booth, 1996) have meant researchers often seek input from those supporting the individual with ID, not the individual themself. Although, if these challenges are experienced in research, then they are

also likely to be faced during therapy. Therefore, research may offer solutions for overcoming them, and this group should be viewed as an important, insightful sample group. By considering the challenges faced when using this group as a sample, it may be more possible to overcome them. This was an important consideration in the current research.

When working with individuals with ID, obtaining informed consent needs careful consideration. Informed consent does not only require individuals to agree to participate in a study but also demonstrate that they are aware of what they are consenting to and be able to ask any questions they may have. This can be hard to confirm with individuals with ID (Coons and Watson, 2013). Although, this can be addressed if researchers dedicate more time to obtaining consent and ensure all information sheets are adapted appropriately (Cameron and Murphy, 2006). Process consenting, whereby consent is revisited with the participant throughout the research (Munhall, 1988) can help ensure a collaborative approach and remind participants of their right to withdraw throughout. To ensure informed consent, I developed adapted information sheets (Appendix D), used a two-stage test of capacity (please see ethics section) and used process consenting.

A further barrier is communication. Individuals with ID can find expressive and written language difficult, in addition to having poor memory of events, difficulty with abstract concepts and offer confabulated responses (Coons and Watson, 2013). This indicates a need to consider the types of interview question used. Often, qualitative interviews will use open questions. Although these are not suitable for individuals with ID who will benefit from more structured and concrete responses (Rose et al, 2019). Having considered this, I wrote the interview schedule with scaffolding questions to assist comprehension during the interview process. To aid memory recall, participants had to currently be having therapy on at least a fortnightly basis, rather than having finished therapy previously.

It can also be valuable to have someone present who is able to interpret the meaning of a response, such as a support worker or parent. I offered this during the study and two participants opted for it. I also considered a multiperspectival approach to IPA. This is when analysis combines two or more perspectives so that the 'relational, intersubjective and microsocial dimensions of a

given phenomenon' can be considered (Larkin et al, 2019). For the current research this may have meant interviewing the therapists or main caregiver of the person with an ID. Analysis would have still focused on one case at a time, but interpretation would have moved across samples also. This research decided not to use this approach because there is already more research available giving voice to those around the individual with an ID, but very little research that focuses on them exclusively. It was thought, to involve others, would risk diluting the experiences of individuals with ID. Multiperspectival IPA also did not seem appropriate for the research aim which focused on the therapeutic relationship between the individual with ID and their therapist, not a third person.

It is important to highlight that the participants in the current study were all at a moderate level of functioning and were able to speak verbally. Therefore, the adaptions used are aimed at this group of individuals and the data presented in the results section is representative of this group. Without further research with a different sample group, it is not possible to generalise the results from this study to a group of participants with a different level of functioning. Different adaptions would be needed dependent on the level of disability and how this presents. Furthermore, it was apparent in this study being able to talk about difficulties verbally was important for participants in building a therapeutic relationship, so this may be different for individuals who are non-verbal.

## 4.4 Participants

## 4.4.1 Sampling procedure

A purposive sampling method was used to recruit participants. The researcher approached an NHS Adult Intellectual Disability service to whom she was introduced to through a colleague within the team she worked in at the time. Therefore, the sample was also due to convenience. The NHS service supports individuals with ID within the community through a range of disciplines, including occupational therapy, community nursing and physiotherapy. This study was focused on individuals receiving support from the psychological therapy team which was made up of assistant psychologists and clinical psychologists. The term 'therapist' will be used throughout the study

that encompasses both. Six participants were recruited to the study. As the research question was focused on the in-depth experiences of individuals this number is considered appropriate for doctorate level research. A larger number would not have allowed the same level of in-depth exploration (Smith et al, 2022).

# 4.4.2 Inclusion and exclusion criteria

On page 46 table 1 shows inclusion and exclusion criteria for the participants.

Table 1: Inclusion and exclusion criteria for recruitment of participants

Criteria	Client	
Inclusion	Identified as having mild to moderate ID	
	Considered by therapist to have reasonable expression and	
	comprehension skills to be able to consider the therapeutic	
	relationship	
	Over the age of 18	
	Having individual therapy with a qualified or trainee psychologist	
	or an Assistant Psychologist receiving regular supervision from a	
	qualified Psychologist	
	Having individual therapy	
Exclusion	Client has a severe ID	
	Client judged by researcher or referring psychologist to be	
	unable to give consent	
	Having group or couples therapy	

#### 4.4.3 Participant information

Of the 6 participants recruited to study, 3 were females and 3 were males. 2 participants opted to have a family member present with them for the interview. Participants were in one to one therapy with a psychologist or assistant psychologist and were offered sessions for up to a year. They had all been having therapy for longer than six months. The therapist's model was based on adapted CBT. The mental health presentations of participants were varied but included depression, anxiety, bereavement and social anxiety. Participants were aged between 23 years old and 46 years old (M= 35, SD= 8.5).

## 4.4.4 Homogeneity of sample

The idiographic underpinnings of IPA call for a small, homogeneous sample that offers access to a particular perspective of the focus of the study that can be interpreted at an in-depth level. The use of a homogeneous sample ensures that the research question is meaningful to participants (Smith et al, 2022).

To ensure homogeneity of the sample this study ensured that all participants had a mild to moderate ID. This was determined by the NHS ID service using an Initial Service Assessment Checklist – Adults (ISAC-A). This assesses 7 categories (education, reading/comprehension, activity, self-care, access to community and risks) giving a rating of A, B, C or D. Scores of A indicate a more moderate ID whereas D would suggest minimal ID and they would be unable to access support from the ID service. All the participants in the study had scores of As and Bs across the categories. The NHS ID service requested this questionnaire was not shared due to copyright. Participants also had to be having one to one therapy because the study was interested in the therapeutic relationship between therapist and client. It was felt this experience would be

therapeutic relationship the bond extends to include them. This research was focused on the exclusivity of the bond between one client and their therapist.

different for those in group or couple therapy. This is because when additional people enter the

Consideration was given to whether the participants needed to present with the same diagnosis of a specific type of ID because it was acknowledged that there can be differences in relational and comprehension skills across diagnoses. Smith et al (2022) highlight that the extent of 'homogeneity' will vary across studies and should be given both practical and interpretative consideration. Therefore, the decision was made to not limit the sample to one diagnosis. This was made for several reasons. The ID service based clinical decisions on level of ID using the process already discussed, not type of diagnosis and so it felt appropriate for this study to do the same. Also, following a conversation with the lead psychologist of the service it was apparent that differentiating based on diagnosis encouraged less consideration of the individual's needs, and more of what should be expected due to their diagnosis. Finally, recruiting individuals with ID is a difficult task and to limit the sample further would have restricted sample numbers and offered less insight. In the current study, despite having 11 names put forward by psychologists, only 6 interviews were arranged and completed. This was either due to participants changing their minds prior to interview or lack of response from 'gatekeepers', for example support workers or parents through who the researcher had to organise a time with. To have further limited the sample based on diagnosis was not deemed worthwhile enough to risk a smaller sample size.

#### 4.5 Ethical Considerations

#### 4.5.1 Ethical approval

Health Research Authority (HRA) approval was applied for using the Integrated Research Application System. Following a panel interview, a favourable opinion was given from the Research Ethics Committee (REC) (Appendix B). The sample was being recruited from Sirona, which is a not-for-profit social enterprise that is funded by the NHS and local authorities. As a result, HRA was granted (Appendix C) and HCRW Approval was not required for this application. The participating management of the Sirona organisation then confirmed their capacity and capability, and the research was able to begin. The British Psychological Society (BPS) Code of

Ethics and Conduct (BPS, 2009), and the BPS Code of Human Research Ethics (BPS, 2014) were adhered to throughout the study.

## **4.5.2 Informed Consent Process**

Informed consent is an essential part of ethical research as it protects the rights of the participants. There are multiple definitions, but they all acknowledge the importance of the prospective participant's voluntary agreement to participating in a study after being informed about all relevant and appropriate aspects of the study, in a way they can understand. This is most often by a written, signed and dated informed consent form (Hardicre, 2014). The most essential components to consent are adequate information so participants are fully aware of what they are consenting to, voluntariness so participants feel in no way coerced to participate and competence, the participant must have capacity to make a free and informed choice (Beauchamp and Childress, 2013). It is these essential components that provide the greatest challenge for psychologists conducting research, as they are required to determine the appropriate level of information, ensure whether the participant does understand and determine how best to ascertain this (Barnett et al, 2007). This can be further complicated when conducting research with individuals with ID and special consideration needs to be given to this. It is assumed that adults with ID have the capacity to make decisions, whether wise or unwise and this includes the ability to consent to research and in cases where this may not be the case it must be assessed on an individual basis (Mental Capacity Act, 2005). Although there is very limited research suggesting the best way to assess this (Coons and Watson, 2013), despite the clear need as individuals with ID are thought to be more easily coerced into participation without fully understanding (Roberts and Illardi, 2003). After reviewing the literature, Coons and Watson (2013) made the following recommendations for obtaining informed consent from individuals with ID: take time obtaining informed consent and plan for it in the initial stages, considering the needs of the individuals; be prepared to adapt information sheets and consent forms; provide one on one instruction using familiar language to the individual and check for comprehension; and consent should be viewed

as an ongoing process as this allows participants an active role in decisions about their ongoing involvement in the study. This also has the benefit of ensuring the participant is aware of their right to withdraw at any time.

When the current study was designed, the research considered the issue of informed consent with individuals with ID. A consent procedure based on Wills (2018) was followed as similar samples and methods were used. All participants went through a two-stage test of capacity (Mental Capacity Act, 2005). This assesses whether the individual understands information, retains the information for long enough to decide, weighs up information to make a decision, and is able to communicate their decision through any communication methods. For this study this involved the following: Therapy dyads were identified through liaising with therapists. Therapists were asked to ask their clients whether they would be happy for a researcher to contact them about participation in a study. Therapists understood what was involved and so were able to give the clients information about participating in the study. As the therapists had already been working with them, they were familiar with the most appropriate way of communicating with them and were able to share this with the researcher. The therapists also had an adapted participant information sheet (Appendix D) that they shared with the clients and explained the researcher would also go through it. If clients were happy to continue, they completed a 'consent to contact' form (Appendix E). The therapist read through the form with the client to ensure they understood what they were initially consenting to. The therapist then passed on contact details to the researcher who arranged a meeting with the client to provide further information about the study. This was either by a phone call, online or in person. The participant information sheet was read through with the client, and they were asked if they understood what the study was about and if they had any questions. If, following this, the client agreed to participate they completed a participant consent form (Appendix F). This process was repeated for each client separately. All participants consented to be contacted and to participate.

#### 4.6 Researcher Reflexivity

The researcher has an important role in qualitative research as they utilise their own perspective, identity and experience to construct knowledge (Howitt, 2010). Therefore, as the researcher, I will acknowledge my experiences, interests and beliefs in this section, in order to consider how they may influence the research process.

I am a trainee counselling psychologist with experience working therapeutically with individuals with ID. These experiences have highlighted how difficult it can be for individuals with ID to access appropriate services for their mental health because their mental health needs are often overlooked by professionals who are more focused on their behavioural needs. I am also aware that individuals with ID are rarely given the opportunity to speak about their own needs and offer perspective. It is these experiences that motivated me to do this research study as it was hoped it would offer individuals with ID an opportunity to be heard.

I am a white female in my thirties, who was undertaking my own personal therapy throughout the research process. Most of my experience is with children with ID, but I have also supported adults with ID in the community. It is therefore important for me to distinguish between my role as a trainee counselling psychologist on placement supporting individuals therapeutically and my role as a researcher. I acknowledged I may have had preconceptions from working with an intellectual disability service and experiences from counselling psychology placements and so reflexivity throughout the research process was important. For example, I entered this research with some awareness already of what individuals with ID found difficult in therapy due to my own experience working with his group. Although, by being aware of my prior experiences, I was able to bracket my own opinions and focus on those of the participants so that I interpreted them in a way true to what they were saying, not what the I personally believed. This was made easier by it being a different ID service from the one I worked within and being a different age group. This differentiation meant it was possible to embrace the role of researcher, not psychologist.

Despite bracketing my opinions, due to the qualitative nature of this research it was important to not disregard personal experience completely. The experience working with individuals with ID increased my awareness of presumptions others can inflict on individuals with ID. For example, people may underestimate or belittle their ability due to their ID. I was aware, therefore, of the importance of treating each participant as a unique individual and was prepared to adapt the approach dependent on need. For example, some participants preferred visual prompts whereas others didn't need these. I was also aware that some of the participants may have found the situation intimidating. Steps were taken to avoid this, such as offering a meeting or phone call with participants prior to the interview so they could familiarise themselves with me. Participants also had the option to have a support person in the interview with them and ask any questions they wanted to, although I did not automatically presume this would be needed.

Power imbalances during therapy for individuals with ID have been considered within the literature (Jahoda et al, 2009) and this was something I considered. It was important to me that this research promoted the voices of the otherwise overlooked in the literature. This felt essential when considering what good support is. To not do this and bias the opinions of those in more powerful positions, is to ignore a valuable and crucial source of knowledge. It also means the support options available are based on assumptions and not actually what is needed or wanted, as demonstrated by the historical belief that individuals with ID couldn't access psychotherapeutic support (Greenhill, 2011). I was aware of my position of academic power and the influence this may have had on participants. To address this, I provided opportunities for the participants to take control. Participants specified where and when they wanted the interview to happen, and they were able to ask questions throughout. I was also happy to engage in 'general chit-chat' lead by the participants. For example, prior to the interview one participant asked me about her pets. Another participant proudly showed me her artwork. This was thoroughly enjoyable and helped established a level of balance between myself and the interviewee that it was hoped would address issues in power. I also felt it was different to the typical therapeutic relationship held with a client, where boundaries felt tighter. This more relaxed approach helped build a bond between

us. This helped me gain a sense of who the participant was which made it easier to immerse myself in the data during analysis as I had connected with the personality behind the voice.

During the earlier interviews I did experience a sense of concern that the participant responses would not be rich enough for the level needed for IPA. I found myself tempted to extend interviews and repeat questions to try and get a longer response but did not do this. I found by transcribing each interview immediately after it had occurred this offered a space for immediate reflection on what had been said. Despite some of the responses being limited, due to the structured questioning, when several lines of the interview were considered, they did offer something to explore. I was further reassured by research that suggested that when doing IPA with individuals with ID, it can be productive to produce interpretative commentary across multiple exchanges between the researcher and participant (Rose et al, 2019). Therefore, with the later interviews I felt more relaxed and was not looking for long responses during the interview.

Despite my initial concerns regarding my own assumptions biasing results, I did not feel this was an issue. Supervision with my first and secondary supervisor helped with this, especially as neither

of them had worked with individuals with ID and so did not have the same pre-assumptions I did.

This extra insight and consideration offered me confidence that my themes were representative of what was said by the participants in the interviews.

## 4.7 Procedure: Implementation of the methodology

## 4.7.1 Development of the research instruments

The following research instruments were used: Easy read study information sheet, easy read consent to contact sheet, easy read consent form, visual emotion cue cards, visual activity cue cards and the interview schedule.

These instruments were developed with the participants in mind and based on advice from the literature. Abstract language was avoided, and a simple sentence structure was used. Pictures were also used. Following completion of an initial draft they were shared with some individuals with ID from the ID service to gain their feedback. This resulted in using a bigger font size, larger pictures, and with the suggestion that the forms are offered to be read to participants.

Participants were also asked to confirm their comprehension of the sheets prior to participation.

## 4.7.2 The interview schedules

The same interview schedule was used for all participants (Appendix A). The interview schedule was broken down into two sections: general experiences of therapy and then more specifically the therapeutic relationship. It was designed to be used flexibly so that the researcher could follow the participant's lead, but also have scaffolding points if required.

For each section there was one open question and then supporting questions which were more concrete and structured. The open question offered a way for the researcher to assess the participant's ability to answer less structured questions and helped direct the level of language used in the interview. Having worked previously with individuals with ID, the interviewer was confident in doing this. Most of the participants were able to respond appropriately to the open questions, but some responses were limited. Participants went into more depth when further scaffolding questions were asked.

#### 4.7.3 Recruitment

The NHS adult community ID team participants were recruited from covers Bristol, South and North Gloucestershire. Therapists working within the team were asked to consider anyone that meets the eligibility criteria, including whether they felt potential participants were able to consent to research. It was important the participants were willing to share their experiences and give opinions.

An email was sent to the lead psychologist who responded and said they were keen to be involved. A meeting was then arranged for the researcher to explain the study to the lead psychologist, answer any questions, explain inclusion and exclusion criteria, and explain the recruitment process. The lead psychologist then shared this information with the rest of the team and asked them to consider potential participants. Once a psychologist had identified a potential participant, they briefly explained what the study involved, shared the participant information sheet (Appendix D) and asked the client to sign the consent to contact form, ensuring they had understood what was being asked through comprehension questions. Following successful completion of the consent process outlined above, the research arranged a time and location for the interview with the participant.

## 4.7.4 Interview Process

Participants were either interviewed in their home or online via Microsoft Teams using a secure NHS account. When interviewing in a participant's home, the researcher ensured that this was a normal place for them to see their therapist and that an appropriate risk assessment had been done. Due to Covid-19 restrictions in place at the time PPE was also worn when attending an interview in person.

All interviews were audio recorded. Consent was gained for the recording at the beginning of the interview. Consent was also gained for participation and participants were reminded of their right to withdraw at any time. Data was collected by conducting semi-structured research interviews with each participant. An interview schedule acted as a guide to the researcher, but due to the

nature of the research the researcher tried to be led by the participant's answers. Hollomotz (2017) highlights that individuals with ID may not be able to concentrate for lengthy periods and so interviews aimed to be around 30 minutes long. Even though, this was led by the participants, some who spoke for slightly longer and others who finished earlier. This was to ensure interviews were not demanding to participants. Visual aids were available to the participants.

Two of the participants opted to have a family member with them during the interview. For one participant this was due to difficulty with his speech that made it hard to understand him. Despite this they were still able to answer all the questions fully.

## 4.7.5 Transcription and Data Analysis

The participant interviews were transcribed by the researcher. Following transcription, they were checked against the original recordings for accuracy. Orthographic transcription was used as it captures what is said, repetitions, hesitations, and false starts, but not other noise such as background noise. This was appropriate because IPA is not concerned with an in-depth understanding of how words are said, but what the participant has to say. The decision to not outsource the transcription was made as it allowed the researcher to fully engage with the data, an important part of IPA.

For the researcher to gain meaning of the content and complexity of participant's responses, she engaged with the transcript in an interpretative nature. Following transcription, the transcript was read through a few times. Whilst reading, anything of interest or that felt significant was annotated in a left-hand margin. Once completed, the researcher returned to the start of the document and looked for any experiential statements. These were based on the initial notes that were then made into more concise phrases to capture the essence of that part of the text. The link with what the participant said is apparent. Once experiential statements had been identified from the transcript, connections were made between them. Throughout this clustering, the original source material was checked to ensure connections were relevant to what was said originally. Throughout analysis there was a balance between interpretation to make sense of what

is said and checking this against what was originally said. The themes produced were then ordered logically in a table and the clusters were given names. These are the personal experiential themes (PETs). An identifier was added to each theme which indicated where examples of each theme could be found in the transcript to facilitate finding the original source subsequently. The identifier included a few key words and the page number. During this organisation, some of the PETs were discounted if they didn't fit with the resulting structure or did not have much evidence within the transcript. For the following transcripts, existing themes were held in mind, but the data was treated independently. Smith et al (2022) highlight the importance of researchers being disciplined to distinguish repeating patterns and identify issues that are found from subsequent transcripts. Identifying both convergences and divergences were important within this process, as similarities and differences of the participants was important.

Once analysis of all the transcripts was completed, a final table of PETs was produced. This involved selecting the most relevant by considering the richness of the certain passages to support themes and how themes help highlight other aspects of the account. Once this was complete the themes were written up into a narrative account, with verbatim extracts to support each account. There is a clear distinction between what the participant said and the researcher's interpretation.

# 4.7.6 Data Protection

All data generated during the study, including audio recordings of the research interviews and transcribed interview data, was kept anonymised and confidential via secure storage facilities and password protection. Any records that could identify individuals were destroyed (Ramcharan and Cutcliffe, 2001). All data was stored in line with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Participants and those referred to by name within the interview were given a pseudonym to ensure complete anonymity.

# 5. Results

Interpretative phenomenological analysis (IPA) was used to analyse the 6 interview transcripts. To illustrate how themes were identified from interview transcripts, see appendix G for an annotated transcript from each participant's interviews. See appendix H for a map of initial PETs for Josh and appendix I for a table of initial themes for Josh. Appendix J shows a master table of PETs for all participants.

The following sections will present the focus of the research interviews, the elements of the therapeutic relationship that arose from participant responses. These will be illustrated by the personal experiential themes (PETs) that developed from compiling corresponding experiential statements from the participant interviews.

To illustrate each of the PETs, direct quotations are presented from the interview transcripts. A key to supplement the direct quotations and explain abbreviations is given on page 59 in table 2.

All client names have been changed to provide confidentiality.

Table 2: Key to abbreviations used in transcripts

Key to abbreviations	
PM	Mother of participant
ТСР	Trainee Counselling Psychologist / Interviewer
[Inaudible]	Indicates where a participant's speech could not be understood
[Laughs}	Laughter
[Therapist]	Indicates where therapists name has been omitted
[Support worker]	Indicates where a support workers name has been omitted

# **5.1 PETs and experiential statements**

Six PETs were identified from analysis. Table 3 on page 60 and 61 provides an overview of PETs and experiential statements.

Table 3: Personal experiential themes and experiential statements

Personal Experiential themes (PETs)	Experiential statements
1. A person-centred experience	a. Unconditional positive regard
	b. Empathy
	c. Trust underlying congruence
2. The importance of adaptations	a. Therapist is prepared to flex the frame
	b. Disregarding professional titles
	c. Abstract concepts are difficult but
	aware of good relationship
	d. Combating comprehension difficulties
	with concrete tools
3. 'I feel like I know you'	a. Sense of familiarity
	b. Being able to talk openly
4. A secure base is offered	a. Therapist is responsive to client's
	needs
	b. Therapist offers warmth and
	boundaries
	c. Knowledge offers reassurance
	d. Safety and predictability – clients
	know what to expect
5. Change does occur	a. Talking to the therapist results in
	change
	b. Therapy is support with mental health

	c. Regularity is important to maintain
	change
6. An overlap of subjective experience	a. Ability to form attachments
	b. Third dimension to the therapeutic
	relationship
	c. Positive intersubjectivity, despite
	previous negativity
	d. Building new meanings from difficult
	experiences
	e. Rethinking the 'bad'

## 5.2 Presentation of the PETs and experiential statements

This section provides a detailed presentation of the PETs and experiential statements, with direct quotations.

#### PET 1: A person-centred experience

The first theme encapsulates the experience the clients had within therapy with their therapist.

Many of the participants spoke about things that made it apparent the core features of a personcentred approach were present including the core conditions and active listening. They also spoke about situations outside of therapy where these were missing.

# Experiential statement 1a: Unconditional positive regard

This subtheme reflects the non-judgemental nature of the therapist indicated by how the clients felt that their therapist *wanted* to listen and help regardless of how they perceived the situation. This was not something they experienced with everyone and seemed to make a difference for the clients. For example, Josh spoke about feeling like his difficulties had previously been treated like 'burdens' and so people did not want to help as a result;

"Like other people, they don't like burdens. They say oh, you're weird. Nah, don't want anything to do with you, why should I help you" (Josh, 1.92)

For Josh, it was also apparent that therapy offered a space where he didn't feel judged as a 'weirdo' as he did by others. As a result of not feeling judged he felt the therapist wanted to help.

Whereas for Alex there was a clear sense of embarrassment around something he had previously done that had been labelled as 'silly'

"TCP1.16 Great and what kind of stuff do you talk about?

Alex, 1.16 Urrrr, feel in the past I've done something silly"

Even so, being able to talk about this with his therapist indicates that he feels it is a safe space to talk where he will not be further judged for what he considers 'silly'. This was also true for Lenny,

who recalled a time when he attempted to share personal information with a colleague only to be yelled at and judged as inappropriate;

"Wait, wait, are we still on how I want to talk about my problems, because a different – in June this year, I spoke to a work colleague urm, urm, urm, who I was working with [inaudible] to the first of June this year and the morning I arrived into work, I remembered she yelled at me and she wasn't [inaudible]" (Lenny 1.53)

Lenny had assumed he would be treated in the same non-judgemental way his therapist treated him, but this wasn't the case. Thus, despite the non-judgemental nature of the therapist being positive, without the appropriate conversational boundaries in place, some clients found it difficult to know who would and wouldn't judge them for sharing their problems.

#### **Experiential statement 1b: Empathy**

An important feature for all was a sense of being understood without judgement, despite many finding it hard to articulate why in particular. Josie was considered in answering that they found their therapist understanding and that they recognised eye contact to be an important part of this.

"Urr. Long pause. I think she is understanding, and I think she keeps eye contact as well."

(Josie, 1.11)

Shortly after saying this Josie articulated a connection with the therapist despite finding it hard to explain why.

"I don't know why but I just feel like I connect with her" (Josie, 1.16)

Often individuals with ID find many people don't understand them, so it may be the understanding that Josie experiences, that is not commonly experienced, that leads to this sense of connection.

Reading body language was also helpful in making Josh feel validated in what they shared with their therapist.

"Well, I guess what you can see in her face, her facial impressions that she is taking it seriously." (Josh, 1.42)

Considering Josh's experience of feeling like a 'burden', being taken seriously by his therapist was a new and important experience for him. Lenny also shared they had a good relationship with their therapist and listening and understanding was an important part of this.

"Who listens and who understands" (Lenny, 1.44)

This is not surprising as it is Lenny who had experienced being yelled at when trying to talk to others about his problems.

## Experiential statement 1c: Trust underlying congruence

Another key experience that featured for most of the clients was holding a trusting relationship with the therapist. For some, this experience had developed when a third party, such as a social worker, had stopped participating in sessions. This is likely the result of the clients feeling more able to be themselves with the therapist and have this realness returned. For example, for Josh there was a clear sense of trust with the therapist and that it was unique to the therapeutic relationship.

"Sometimes, I ur, the only person I can trust is her, she keeps mine and her conversation private" (Josh, 1.17)

There is also a sense of unity between the pair 'mine and her.' Despite this, their session initially started with support workers also in the room. Although, the congruence of the therapist made them recognise the client's needs and close the sessions to external individuals.

"Well she thought I was ready. These guys weren't really involved, it was just me and her.

It's not their session." (Josh, 1.76)

This was important for Josh, who held an ownership of his sessions that he shared only with the therapist. There was some suggestion for Josh though, that the congruence was not present from

the start as the trust took a while to build. They did initially find some topics hard to talk about but had now forgotten what these were.

"TCP1.88: Yeah. Is there anything you find tricky, to talk to her about?

Josh,1.88: few things. Yeah but to be honest I have forgot."

This indicates this was a while ago and that they were now open to talk about anything.

Furthermore, the openness in the relationship meant they also felt they'd be able to be honest with the therapist about their feelings towards her.

This indicates a balance within the relationship and a level of strength that suggests even uncomfortable topics can be managed. Congruence was also present for Sandy, who was able to "Tell her what I'm feeling and that" (Sandy, 1.11) within her therapy sessions. The trust to do this arose from the therapist recognising the need for confidentiality within the therapeutic space.

"And she knows that if I told her, if I don't like her, I will tell her. [Laughs]" (Josh, 1.48)

"Cause if I tell her anything she keeps it to her and me" (Sandy, 1.13)

'her and me' also creates a sense of exclusivity between the two and suggests that when they are together the therapist is completely engaged and this is what Sandy needs.

For some of the clients the sense of congruence was less apparent. Josie's therapist offered her reassurance that her problems would be heard:

"Well, I know for a fact I can talk about my problems with [Therapist]" (Josie, 1.33)

Which felt important for her, although she was hesitant using the word 'trustworthy' despite

'friendly' coming readily to her.

"Yes, definitely friendly. Urm... to my mind I'm not too sure, I might be wrong, but trustworthy." (Josie, 1.54)

So, the sense of a friendliness was apparent, but it was harder for Josie to articulate trust, despite there being an awareness she could speak to her therapist about her problems. Alex also found it

hard to articulate why they felt they trust their therapist, despite recognising that trust was present.

"Don't know really. Trust her.... Oh my god... trust her.... It's hard to say isn't it? Urmmm, trust [Therapist]... What she saying?" (Alex, 1.65)

Overall, all the participants found trust within the therapeutic relationship. This occurred because the therapist was able to be congruent to the needs of the client, something that was not always present for them. Creating this conceptual wall around the dyad, by not involving support workers or parents, appeared to offer reassurance to the client that what they said would be kept confidential.

## PET 2: The importance of adaptations

There were apparent barriers within the therapy sessions that clients spoke about, but these were almost always overcome by adaptations by the therapist. This is particularly important for this group of individuals, because the transcripts suggest a difficulty with more abstract concepts and so by overcoming these more the clients had more opportunity to express themselves. Also, by being willing to adapt the therapist was demonstrating a willingness to enter their world by communicating in ways they better understand

## Experiential statement 2a: Therapist is prepared to flex the frame

This subtheme encapsulates how some therapists were willing to go beyond the standard four walls of a therapy room or adhere strictly to any method. For these clients, being able to go outside was of benefit and the therapist recognising this is evidence of their understanding of what may help the client. Josie recalls a time she and the therapist went to the park and later speaks about enjoying it:

"Urm, once she came here but we went to the park." (Josie, 2.02)

For Tilly going out sounds like a more common occurrence during therapy, suggesting she benefits greatly from it:

"Urm like. We go out." (Tilly, 1.42)

Many individuals with ID can feel isolated and so by flexing the frame in this way it offers them the chance to do something they are not usually able to do. This is beyond traditional therapy but highlights the therapist recognising the unique needs of this client group.

For Josh the importance in flexibility of the therapist in that they were able to move between methods until one was found:

"Well, she tries trying different methods with me." (Josh, 1.94)

Considering he had previously spoken of feeling like a burden, the recognition that the therapist wasn't prepared to give up suggests this is something important to him.

## Experiential statement 2b: Disregarding professional titles

Across clients there was a difficulty with understanding the word 'psychologist' during the interviews. This suggests that the psychologists who worked with the clients had disregarded this title in favour of using their first names instead. For example, Alex had no awareness of what a psychologist was,

"TCP1.12: Ok great, so could you just start by telling me about your experiences of working with your psychologist

Alex1.12: What is that?"

Suggesting that it was not a term used regularly by his own psychologist. This felt important as some clients struggled with the complicated jargon, such as Josie:

"Well I get confused with that word. I know, it's a long word, but its hard for me to remember that" (Josie, 1.91)

Josie has many different professionals involved in her care and keeping on top of all their titles is quite difficult for her.

Using complicated titles may pose a threat to the therapeutic relationship as they create a sense of unfamiliarity. Also, titles often hold implications of what one can and can't expect which may result individuals feeling limited in what the relationship can offer. It appears the psychologists working with these clients did not often refer to themselves as such, and this was likely because it wasn't important. The more important thing was offering themselves as a person the clients could connect to.

Experiential statement 2c: Abstract concepts are difficult but aware of good relationship

Alongside the titles used, it was apparent consideration was given to the language used. Many of the clients had difficulty with more abstract concepts. This was apparent through their interview responses, often finding articulating in more depth difficult.

Alex uses laughter and then later self-depreciation in response to questions he finds hard to answer due to their more abstract nature.

"TCP1.39: What makes her good?

Alex1.39: Laughter, urm, it's a bit hard to say

TCP1.40 Yea? I've got some prompts would you like some prompts? I can help you a little bit

Alex1.40 Yea, go on then, yea"

The laughter is used here as a defence mechanism, suggesting there is a shame with not knowing what makes his therapist good. They may feel like they want to validate the strength of the relationship but don't have the words to do so and so use laughter to cover this. They do accept the help of prompts though.

"Flipping hell, laughs, urrr, can't think right now. My head it's not very good" (Alex, 1.53).

The feeling of discomfort has now developed and there is a level of frustration. This time Alex blames himself for his head being 'not very good', demonstrating the difficulty with answering the

question. Tilly also has difficulty describing their therapist, indicating the relationship building process is more unconscious for them.

"TCP1.26 Important yea? And how would you describe [Therapist}? So you said helpful.

What other words can you use?

Tilly1.29 Don't know. [Laughs]"

Laughter is used as a defence mechanism to hide some potential shame they have in not being able to answer the question. Josh also used laughter in response to finding the question difficult, but wanted to show reassurance that even though they couldn't verbalise it there were a lot of good things about their therapist:

"Urm. Bloody hell, anything else.. \*laughs\* urm, a lot of nice things, a lot, can't think anything nice about her, but there's a lot of words." (Josh, 1.44)

Thus, it is apparent that one does not need to be able to articulate something for it to be felt, and it may be that the strength of the relationship is more experiential, and this is what the clients benefit from. Although it is important to consider the impact of the difficulty around abstract concepts and how these should be avoided within the therapy session.

Experiential statement 2d: Combating comprehension difficulties with concrete tools

A response to the difficulty with abstract concepts was the use of concrete tools. This subtheme encapsulates the importance of using more concrete tools with the clients, such as worksheets or pictures. This was something all participants spoke about and highlights the efforts of the psychologists working with them to make the sessions as effective as possible. This was apparent for Sandy who found words were not enough, but worksheets about emotions helped them feel understood by their therapist.

"TCP1.38: Yea? How does she show that she understands you?

Sandy1.38: Cause, she does like pieces of paper about how I am feeling.

TCP39: That's really good. And do you feel like you work well together? \$1.39: Yea"

This indicates how by being receptive to the client's needs and making appropriate adaptations, the therapeutic relationship was strengthened.

For Lenny, social stories were effective in eliciting change. Something that commonly help individuals know what to expect, these visual representations supported this individual with their anxiety.

"PM1.43: She did you lots of social stories as well to help, didn't she?

Lenny1.52: Yea"

It also demonstrates the effort of the therapist to provide these for the client. Social stories are usually written for specific situations, so these will have been done by the therapist outside of session time.

For Josie, writing was effective, suggesting that in the moment recall is difficult and having something to refer to helps this client.

"I mean I do sometimes write down what I want to talk about" (Josie, 1.58)

Whereas for other clients, being given physical distraction exercises or items was more effective.

This enables the clients to do something concrete and experience a change, even if they find it hard to articulate what that change was. Tilly enjoyed the use of fidget toys:

"Yea, a poppit yea (starts pushing the poppit)" (Tilly, 1.62)

And Sandy enjoyed more physical tasks:

"Like do something, like spend time with [pet] and like do some housework, do things like that." (Sandy, 1.29)

This demonstrates how the therapists also adapt the interventions to suit the interests of the client. Thus, the impact of using concrete tools is two-fold. Clients are offered an alternative way

of understanding and so can better engage within sessions. But also, the therapeutic bond is

strengthened as by offering adaptations the therapists are showing awareness of the client's

needs and responding to this.

PET 3: 'I feel like I know you.'

There was a sense from the clients of a familiarity towards their psychologist and this contributed

to the ease with which they were able to speak with them. This is encapsulated by this subtheme.

Experiential statement 3a: Sense of familiarity

For most of the participants familiarity was an important part of being able to connect with their

psychologist. For some this was the result of having worked with their therapist for a while so a

relationship had been established, for others this was due to feeling like they already knew them.

For example, Josie spoke positively about how she was able to share with the therapist because

she reminded her of a previous support worker she used to have.

"Josie1.2: Mmm well rather lovely actually, she reminds me of someone

TCP1.3: She reminds you of someone?

Josie1.3: Yah

TCP1.4: Who does she remind you of?

Josie1.4: She reminds me of a member of staff that I used to have"

This transference enabled the client to speak with her therapist more readily, as she felt like part

of the relationship had already been built.

Alex had worked with many individuals, but the only name he was able to recall was that of his

therapist and that this was the person he trusted with his secrets.

"Alex1.67: Just trying to think now because we have had two people with [Therapist] as

well

TCP1.68: Ok. do you know who they were?

71

Alex1.68: No. there was [Therapist], but I don't know who the others were

TCP1.69: ok and did you talk to them as well?

Alex1.69: No, no, no not often

TCP1.70: Ok, so it's just [Therapist] you talk to your secrets about?

Alex1.70: Yea"

Rather than be open with everyone they worked with, this individual was only open with the individual he was most familiar with. This was also apparent in how comfortable Alex felt being open during the interview.

"Because, yea sorry I've never chatted to you before, have I?" (Alex, 1.59)

Having only spoken previously on the phone, this individual found it difficult to place who I was and therefore held back with what he spoke about. Although for Sandy it was the similar personalities of the therapists she'd had, rather than the specific person.

"TCP1.02: Aw got you and does the relationship with [Therapist] feel like the same with the other psychologists or different?

Sandy1.02: The same

TCP1.03: Yea? What makes it the same?

Sandy1.03: They are always kind and nice and bubbly"

This resulted in a sense of familiarity that made it easier for her to speak with them, but also indicates that it is not a specific person who Sandy finds important. Therefore, therapists need to be in some way familiar to the clients. This may be through familiar personality traits or appearance. By establishing this, clients are more able to relate and be open.

Experiential statement 3b: Being able to talk openly

Familiarity contributed to the clients being able to speak openly. This subtheme reflects this ability to talk openly. Alex described being able to talk about anything he wanted to in therapy:

"I talk about me. I talk about horses and I talk about things to do at home" Alex, 1.90

This suggests a freedom to use the sessions how they want that was unlike the freedom to do what he wanted in other areas of his life. Alex also highlighted how unlike his therapist, other professionals did not want to listen to him, despite attempts at trying.

"Alex1.96: Just [therapist], but I do sometimes speak to him, [support worker], he doesn't want to listen anyway

TCP1.97: he doesn't want to listen anyway. Ok, but it sounds like [therapist] is good at listening

Alex1.97: you bet she is"

This client also recognises that people have a choice about whether they listen to them and his support worker has chosen not to, but his therapist has. This also creates a sense of not being wanted across all settings.

Josie was certain in how she felt listened to:

"She certainly listens to me." (Josie, 1.10)

This reassurance enabled her to be more open. Whereas for Josh, it was the sense of being understood that was important, and this was reliant on it just being 'me and her.'

"It's just, it makes us understand things better, just me and her" (Josh, 1.77)

The use of the word 'us' suggested a shared experience of both being heard, and a merging of subjectivities to create an intersubjective space. Thus, feeling listened to offers a freedom to speak that results in feeling understood and this is helped by feeling like they know the therapist well.

#### PET 4: A secure base is offered

For all the participants the therapist held many roles, and these contributed to the high level of support and understanding the clients experienced. These roles centred on what could be expected of the therapist and how the therapist was viewed within their role. By offering so much to the clients the therapists were able to establish a secure base upon which effective therapy could occur. The clients rarely spoke of their own roles, but the strength of the relationship was felt to be based on how secure they felt.

## Experiential statement 4a: Therapist is responsive to a client's needs

Clients acknowledged when their therapist was responsive to their needs and did something for them. For some this was a physical act, for example Josh spoke about how his therapist helped with things around the house:

"So urm, just recently, she said any stuff here \*gestures around room\* she will help out and that and obviously she knows my social worker, she helps with that as well," (Josh, 1.9)

This was clearly something that set the therapist apart from other's they'd met because they shared it hadn't been the same with all therapists:

"Well she does stuff and she actually makes it happen, so if she says she's going to do something she actually does it compared to the rest of the therapist I've met." (Josh, 1.8)

And had resulted in him previously walking away from therapists:

"Well, it's not, I dunno, if they I dunno, I dunno, make no effort to help you at some points.

Go see you, let's walk away, get another one." (Josh, 1.29)

It was important for this client to feel like an effort was being made, as without this experience they were prepared to walk away and 'get another one'. This suggests that this client thought of psychologists in plentiful supply.

For other's they found the therapist's ability to offer solutions to their problems important. For Lenny his therapist offered a knowledge base and ability to solve problems they did not feel they had themselves. Therefore, the therapeutic space offered another perspective that helped with problems:

"Well she was knowledgeable and she was a very, very good problem solver." (Lenny, 1.49)

Lenny also suggests that instead of solving the problems together, the therapist solves them for him, because he does not have the knowledge. Alex also relied on his therapist to do things for him:

"I wish she could have said it to you, I don't know why she didn't" (Alex, 1.27)

There is more of a reliance on the therapist and an expectation of them to speak on their behalf.

This was regarding a situation where the client felt they had done something 'silly.' They had been able to share with it the therapist but sharing it during the interview was too difficult. This implies that Alex needs his therapist to support him through difficult situations. Whereas for Sandy the problem solving appeared to happen more in a partnership. Sandy speaks about the therapist helping her understand things together.

"Helps me understand why he didn't turn up, why he never turned up, things like that." (Sandy, 1.56).

This may indicate an overlap of two subjectivities, where one is trying to understand the other and then offer another perspective to help.

The differences in how therapists respond to client's needs may mirror where they feel a client is at in therapy. Clients like Sandy may be more able to problem solve alongside the therapist, whereas Lenny and Alex may benefit more from this being done for them. The difference in approaches highlights how important it is for therapists to be responsive to the specific needs of the individual client and a 'one size fits all approach' is not appropriate.

#### Experiential statement 4b: Therapist offers warmth and boundaries

Another aspect to the 'role' taken on by the therapist was the perceived level of friendship and how balanced the relationship felt. For many of the clients a friendship was experienced but this was one sided suggesting the therapist had established certain boundaries around the relationship. For example, when talking about the relationship Josie spoke about how despite being aware of it being one sided, she still experienced the relationship like a friendship:

"She might not think that, I think so for me" (Josie, 1.56)

Josie also spoke about being given homework to do, just as a teacher would to a student:

"I have actually noticed that she sometimes, she can give me a little bit of homework to do." (Josie, 1.25)

This suggests the client holds their therapist with a more authoritarian view and so may not feel the friendship is two sided but does experience warmth towards the therapist.

Alex also recognised their therapist was not a friend, but also acknowledged the help they received was not dependent on this and didn't seem to mind.

"She's not a friend but she likes to help me anyway." (Alex, 2.41)

This comment indicates that Alex understands the boundaries around the relationship.

For Lenny, he did perceive a friendship that was returned, and this helped him build a bond:

"Urm, urm, because I think that that they are a friend to me." (Lenny, 1.42)

Although, the use of 'they' still suggests a distance with the therapist that may be because Lenny easily finds friends in people. Whereas Sandy didn't mention friendship but did show a warmth and allude to a balance in the relationship:

"We get on really well together." (Sandy, 1.40)

And

"She is always pleased to see me, every week." (Sandy, 1.33)

The use of the word 'together' binding both together and suggests the warmth is returned. Also, there is a clear sense that Sandy feels welcome.

Therefore, there is divergence across the clients about how they perceive boundaries within the therapeutic relationship. Although, this does not impact the therapeutic relationship and the work client and therapist do together. It does appear to contribute to the secure base offered.

## Experiential statement 4c: Knowledge offers reassurance

Some of the clients felt reassured by the skillset of their therapist. This helped set them apart from others. For Josh, the level of training the therapist had, was important and gave him reassurance that she would be better than the rest of them;

"Basically everything, everything around her job. Training wise, she is better than the rest of them," (Josh, 1.34)

The therapist's level of training set her apart from the rest and Josh appeared to idolise her as a result. For Lenny the qualification offered a clear distinction for who he could and couldn't talk to and this was supported by the knowledge he perceived his therapist to have.

"PM1.50 Yea ok, so I think he has learnt from that that you talk to people who are qualified to discuss his sort of worries shall we say to help him

Lenny1.51 Urm, urm, urm urm, I think it was her knowledge of stuff"

This indicates that as much as a therapist can be someone who listens, it was important for Lenny to also be able to get advice from them.

Thus, there was a sense that being qualified set therapists apart from other individuals, and helped the client's feel their problems would be held or solved. Much like a child will look to their main role model to provide them with guidance, it appeared clients were also looking to their therapists for this.

#### Experiential statement 4d: Safety and Predictability – clients know what to expect

Clients spoke about problems in a way that they could be passed on to the therapist and held by them. This was both a motivation for being open with the therapist, but also a reassurance that they would be there for them. Speaking to their therapist seemed to release their problems from the prison of their own head. For example, Alex was motivated to be open as it got the problems out of his head.

"TCP1.33: Yea and what is it about [Therapist] that makes it easy to talk to her?

Alex1.33: Get things out of my head."

For Alex, the therapist offered a space within which the problems could be held and taken out of his head. For Josh, recognising the problems were in his head with the support of his therapist meant he no longer pushed them away as he had at the start:

"Well, it's kinda in my head as well, cause when we started I wasn't, I was pushing it, pushing it away at the start." (Josh, 1.54)

As therapy progressed, with an ally by his side to also tackle the problems, he was able to trust more and confront his difficulties. Whereas for Lenny, he recalled an experience where he'd forgotten to talk to his therapist about something and as a result felt threatened and unprepared:

"Urm well back in November 2018 I went to see a band called Basement. Now, this was earlier before the gig, I forgot to tell [Therapist] about this so, I urm, urm, urm so on the evening my support worker, [support worker] took me to see Basement, I remember saying to him 'Phone [Therapist]!' 'Phone [Therapist]!' because I forgot to mention this to her and I should have done and when I knew I hadn't I just felt scared and threatened and urm urm urm about what might happen to me when I went to Dingle with [support worker] – and the forest yea? Felt more threatening than it was" (Lenny, 1.54)

This indicates Lenny had a strong reliance on his therapist, to the point where because he had not shared his problems with her, he did not feel able to tackle the problem. Although, he did seek to

solve the problem by calling her in the moment, suggesting that offloading may have provided immediate relief.

Thus, an important part of the therapist's role appears to be their ability to 'hold' onto a client's problems, as if they are a vessel waiting to be filled. By knowing they can expect this of the therapist the therapeutic space feels safe and predictable to clients with ID.

#### PET 5: Change does occur

Among the participants there was a clear sense that having therapy sessions did result in change. Many experienced this as a change in their mental health, often naming a diagnostic label. For some, the therapy needed to occur frequently as positive effects were short lived, indicating how beneficial it was for individuals to be able to have someone to talk to. For all though, there was change. This is important because individuals with ID are often considered not 'appropriate' for talking therapies and it deemed inaccessible.

#### Experiential statement 5a: Talking to therapist results in change

All clients recognised a positive change because of speaking to their therapist. Very few spoke of specific tasks or activities they'd completed together in the first instance that had been useful. Many also found it hard to articulate what exactly caused the changed, but recognised it, nonetheless. Josh felt change had occurred over a relatively short space of time but found it hard to articulate specifics:

"Bloody ell, a lot of stuff. We haven't been seeing each other that long but, we've made some progress." (Josh, 1.13)

Although, he did articulate that talking was effective:

"Yes, she is. Yeah. Well talking about it helps as well." (Josh, 2.22)

Therefore, for Josh change started fairly quickly and he did find talking beneficial without the need for other activities.

For Josie success experienced during therapy appeared to come as a surprise, suggesting an initial scepticism with how effective they were expecting to find it:

"O well funny enough, whatever I talk about with [therapist], I come back and it actually happens" (Josie, 1.40)

Despite this, Josie makes a direct link between talking with their therapist and change happening, clearly holding their therapist as an important part of this.

Lenny was able to identify a specific moment when he no longer felt like he needed his therapist guiding him through difficult moments and experienced a change:

"Yea yea when we got to the gig I felt like I didn't need [Therapist] by my side that night, that evening, I had a nice time that evening and yea." (Lenny, 1.45)

And that a change in confidence resulted in this:

"No, no I've got more confidence in myself" (Lenny, 1.83)

Therefore, this suggests that for Lenny there was learning within the therapeutic space that relied on his therapist, but he noticed the change when he was able to apply that learning to the outside and do things on his own. Sandy also recognised change because she hadn't experienced any anxiety:

"Cause my anxiety hasn't kicked in once." (Sandy, 1.50)

For Sandy, it appears that anxiety is something she feels is on or off and throughout therapy she has been able to keep it off.

For the two clients who had been interviewed with their parent present, a change had also been noticed by them, indicating that the changes were not only experienced internally by the clients, but noticed by others too.

"TCP1.10 Talking about things, so has that been useful?

Tilly1.10 Yep

PM1.2 She a lot better, you're a lot better than you were before

Tilly1.11 Yea"

Lenny's Mum: "She was actually very very helpful, I've got to say, she moved him on"

(Lenny's PM, 1.41)

Therefore, not only is change experienced by individuals on the inside, but it is noticed by those

close to them on the outside also. This highlights how talking therapies can lead to change for

individuals with ID.

Experiential statement 5b: Therapy is support with mental health

Many of the participants spoke about recognising a change with specific mental health difficulties

they'd been experiencing since having therapy and referred to the diagnostic labels rather than

the associated feelings. For example, Josie spoke about no longer feeling depressed since starting

therapy, despite some surprise in their voice at the change, as if she hadn't considered it.

"Josie1.62: Muttering... I wasn't depressed because of meeting [Therapist], I was

depressed because of other things.

TCP1.63: Ok, so you were depressed about other things and then you met Sam. So how do

you feel now?

Josie1.63: Urrr, well I feel alright actually"

Interestingly, Josie does not disclose her reasons for being depressed, suggesting she views it as a

private matter. Although, she is quick to assure that it is not due to meeting her therapist that she

feels depressed. This highlights that Josie recognises a certain way of feeling and associates it with

depression.

Sandy had once felt defeated by anxiety, this was no longer the case:

"Try to sort my anxiety out" (Sandy, 1.19)

Having the therapist as an ally to overcome this resulted in them getting their independence back:

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"Like when it's all, what's going on, I admit defeat that I dunno what's going on and I had to, and my anxiety was really kicking in and I had to stay with my mum for three months" (Sandy, 1.21)

Like Josie, Sandy also labelled as feeling a certain way with a diagnostic label and for Sandy, her experience of anxiety was overwhelming.

Some participants also built on the experiences they had within the therapy room and applied them outside. For example, Lenny found talking in therapy made it easier for him to talk to others about his problems:

"And, and I was quiet about it at first but when my third respite came in October last year
I was really anxious about it, I opened up beautifully to my support worker [support
worker] about it and ur ur ur the lady who was taking me there urrr, her full name is
[support worker] urm, urm, urm" (Lenny, 1.78)

By feeling more confident in talking to other individuals outside of the therapy room, Lenny was better able to manage his anxiety. This further supports that the positive effect of talking therapies extends to outside of the therapy room.

# Experiential statement 5c: Regularity is important to maintain change

This subtheme encapsulates the importance for many of the clients of having regular sessions. For example, Josh spoke about finding it difficult when his therapist was ill:

"She said that herself, and I agree with that. [Laughter] Cause she was ill for a while and I do ask for her, cause I urm, I need to talk to her really bad sometimes. [Laughter]" (Josh, 1.16)

This suggests that therapy is his main way of managing his problems, and they don't have someone else who they can speak with. Josh also stipulated the effects of therapy being short lived:

"Yea... but it doesn't ever last for long" (Josh, 1.23)

This suggests they may have difficulty generalising the work across contexts.

For Lenny the experience of loneliness was also present when not in therapy.

"Yes, I feel less lonely when they are around" (Lenny, 1.41)

Despite feeling more confident to talk outside of sessions, it appears Lenny continues to feel isolated unless in a session. Interestingly, Lenny had a large network of support workers, but did not mention any peers within the interview. It is possible that despite being surrounded by professionals there is still a limit to the connection he has with them. Although, this changes when he is with his therapist as he experiences less loneliness.

Thus, for all the participants, having therapy sessions resulted in change. There is variation between clients regarding how far this applies outside of sessions, but there are benefits, nonetheless.

## PET 6: An overlap of subjective experience

For all the clients, experiences outside of the therapeutic relationship affected the way they acted within the relationship. In most cases these were quite inhibitory, and it took the participants longer to feel able to trust or be open. For some, their experiences also altered the way they spoke about situations, having previously been told certain things were right or wrong. For all the clients these rules did not apply in the therapeutic space. It felt there was a mutual understanding between psychologist and client that enabled a trusting space for the problems to be shared.

#### **Experiential statement 6a: Ability to form attachments**

1.69)

It was apparent from the interviews that clients were able to form relationships with others. This was apparent by them talking about other individuals they were close to. Friendship was valued, although for some they were unable to see them too often. For example, Josie spoke of friends but how they were spread around the country:

"Urm. Long pause. Yes I do. Urm. MY friends are mostly dotted around the country" (Josie,

but this didn't prevent them having more intimate relationships,

[Big breath in] "I do have a boyfriend." (Josie, 1.70)

Indicating an ability to form close connections with peers despite not seeing them too often.

Although Tilly spoke vaguely of friendship: "Got [friend], yea" (Tilly, 1.40) suggesting that she didn't think anything special of having a friend.

Sandy found trust easy:

"TCP1.46: ...everyone, you find it quite easy to trust people or tricky?

Sandy1.46: Easy"

This resulted in an ease being able to talk to others about difficulties:

"TCP1.43: Ok that's really great. And do you have a similar relationship with anybody that

you have with [therapist]? Is there anybody else you talk to and trust?

Sandy1.43: My Mum, My brothers"

This demonstrates a similarity for Sandy between the therapeutic relationship and the familial one. Having a strong family bond established prior to starting therapy, may have made it easier for Sandy to form a relationship with her therapist. Thus, this would suggest that individuals with ID are able to form attachment relationships and it is not surprising that they all also formed a relationship with their therapist so readily.

Experiential statement 6b: Third dimension to the therapeutic relationship

Despite working primarily with one therapist, most of the participants also spoke about other professionals involved in their support. The relationships amongst the clients with these professionals varied. For some the trust was apparent and the relationship felt as valued as that with their psychologist. For example, Lenny shared a list of names when speaking about people they trusted:

"Lenny1.54 and [support worker]

PM1.48 Yea [support worker] or [support worker]

Lenny1.55 and some support workers, [support worker] –

PM1.49 yea, yea people who are support workers

Lenny1.56 And another support worker called [support worker]"

He didn't seem to mind having so many people involved in their support and felt it important to acknowledge them all.

Sandy mentioned her support worker ahead of their family when asked who they trusted:

"TCP1.15: Is there anyone else you trust?

Sandy1.15: My support worker, my family"

This suggests that they trusted them greater than, if not equal to their family.

Although, some clients did not trust their support workers and their presence inhibited what could be shared within the therapeutic space. For this Josie found it difficult to answer some questions during the interview due to the support worker being in the next room, indicating that her presence felt unwanted:

"Whispers quietly – I'm just a bit wary about [supporter worker], I don't want her to listen" (Josie, 1.52)

For Josie, being open was not something she felt comfortable doing in front of everyone and her support worker had not earnt the trust needed to be allowed to listen.

Josh also spoke about feeling uncomfortable having therapy sessions with support workers in the room:

"Well it was a bit nerve wracking, bit pressure. Do I want to talk about that in front of you? Well not really," (Josh, 1.80)

Josh felt strongly about not feeling able to talk about certain topics in front of certain people. By feeling pressure within the session, they were limited on what they could say.

Interestingly, it was the clients who did not have the support workers in their therapy sessions that appeared to have more trusting relationships with them. This suggests that it is important for the clients to feel like different professional boundaries are maintained, and despite some trusting their support workers, this does not necessarily mean they feel able to speak to them in the same was as their therapist. Adding a third dimension to the intersubjective space inhibits the learning that may occur.

#### Experiential statement 6c: Positive intersubjectivity, despite previous negativity

Most of the clients were accustomed to being let down by others close to them in both professional and personal contexts. Speaking about these it was apparent it impacted the way they related to individuals outside the therapeutic space. For example, for Josh being let down suddenly was a common occurrence and he seemed to expect it from those supposed to support him:

"Pfftt, which one now? One bloke I met, he, he I was seeing him for ages and then he just disappeared" (Josh, 1.5)

Despite 'seeing him for ages' referring to his previous therapist as 'one bloke' indicates this client felt scorned by the experience and has depersonalised it. The same client also shared another experience in which a therapist walked away.

"Oh, just like \*laughter\* pissed off. I don't want to talk to you, just walk away" (Josh, 2.7)

Josh appears to hold some responsibility for having 'pissing off' the therapist, suggesting he holds a level of blame for the breakdown in the relationship.

Not being able to rely on people was echoed across clients. Sandy was confused and hurt by a friend who had let her down:

"Like, my friend was coming down and he never turned up" (Sandy, 2.54)

and used the therapeutic space to explore this: "Very upset. Dunno why they have to, let me know if they can't make it" (Sandy, 2.60)

For Sandy, being let down appears to be a confusing situation and it is not understanding why that causes her difficulty. For Lenny, whose parent was present in the interview, it was apparent that being shut down was a common and frustrating experience.

"Lenny1.13: Yea, yea but I ...

PM1.12: you don't have to go into detail

Lenny1.14: No, no no

PM1.13: Keep your voice down"

Even when Lenny starts to protest his mother's interruption he is further reprimanded. This indicates how outside of the therapeutic relationship being shut down is a common experience for this client group.

Thus, clients commonly experienced some form of being let down in their lives that did not transfer to the therapeutic space. This suggests that the empathy and reliability of the therapist offers a space where they do feel validated and more able to confront their problems, away from a third individual.

#### Experiential statement 6d: Building new meanings from difficult experiences

This subtheme encapsulates how therapy was used by clients as a space to build new meanings from difficult experiences. A common feature of all the client interviews were them recalling negative experiences that they had shared with their therapist. There was a sense that these had all had lasting impressions on the clients and that they held themselves responsible. For example, Alex was very hesitant in sharing something from his past in the interview that he held himself responsible for and seemed slightly embarrassed by:

"Urrrr, feel in the past I've done something silly" (Alex, 1.16)

This was something he had been able to speak openly about during therapy.

For Josh, previous negative experiences had led to him finding it difficult to trust others:

"TCP2.18 But It sounds like you can't trust all the people.

Joshh2.18 No, that's yeah, that's the part of me and then I never got rid of"

This was something he really felt was a part of who he was, but he was trying to get 'rid of' it, despite not managing to yet. Even though, he was able to trust now within the therapeutic space, suggesting he was learning it was possible

For other clients there was a common theme of losing people close to them suggesting the therapeutic space is used to work through grief. For Lenny there was clear sadness about the loss of two people, he hesitantly acknowledged as friends. It felt that it was hard for him to recognise that those he'd lost, had been friends:

"Over the last year I lost two to Covid and urm, urm, my two friends." (Lenny, 1.12)

This also felt difficult for him bringing up during the interview but had been something he'd been able to speak about during therapy.

Sandy was still working through the loss of a family member from over a year ago:

"Like not very long ago, last, not this Christmas, last Christmas, Mum told me my nan passed away." (Sandy, 1.03)

This highlights how long some of the clients held on to feelings of grief, rather than grieving in the moment. It may be that grief is hard for them to explore on their own and therapy could offer a place to work on this. Although, for Alex, they'd been able to channel their sadness into a new hobby (horse riding) as it reminded them of their friend:

"I'm a bit addicted to it. My friend Carrie she passed away, and I did it for her anyway"

(Alex, 1.84)

Indicating that the goal for this client was not to move on from his grief but find positive ways in which he could remember her.

Overall, there was a sense of loss amongst the clients when they recalled negative experiences. Whether this be the loss of their self-esteem or trust due to doing things they hold themselves responsible for, or the more concrete loss of a person close to them. For all the participants the therapeutic space was used as a place to process these experiences. They looked to their therapist to provide them with solutions to make them feel better.

## Experiential statement 6e: Rethinking the 'bad'

Some of the clients were influenced in their responses by what they felt was 'good' and 'bad'. There was the impression that they'd previously been told this and as a result had a very concrete understanding that offered no flexibility. There was a sense that anything 'bad' should not be spoken about, although therapy appeared to be a space, they were able to break away from this. This suggests that their psychologist helped them think their understanding of 'bad' things so that they were able to talk and process it.

For Alex he didn't have autonomy over what they spoke about, and it led to confusion about what he could and couldn't say:

"I'm not sure whether I'm allowed to tell you or not, not sure" (Alex, 1.17)

Despite being reassured they did not need to share anything they didn't want to Alex chose to share more about the topic he was finding difficult.

"And she was giving me a cuddle. But I don't know why she was giving me a cuddle, but I hugged her in a good way like not in a bad way. The second time, the next time she was up here again and she was on my B. E. D" (Alex, 1.22)

Even so, this was difficult for them as they were unable to say it out loud, but spelt it instead, suggesting a level of shame around this topic.

For Lenny the concept of right and wrong applied to who they could speak to about their problems.

"She yelled at you – yea she wasn't the person to tell your problems to, she didn't know you very well. You talked to the wrong person basically." (PM1.45)

Clearly finding conversational boundaries difficult and that the experience of being able to be open within the therapeutic space, something they want to be able to access with others also.

Lenny's mother had to explain this to them in the interview, indicating it was still something they were confused about. Despite finding conversational boundaries difficult, Lenny did have an awareness of being shown inappropriate images:

"Urm urm, yea, urm yea. A bit about that urm urm, what helped with that was the latter half of, back end of 2009 and early part of 2010 I was in a classroom where I didn't want to be. I went on a pamper week, with people I didn't want to be around and then all of that urm made me look at inappropriate images" (Lenny, 1.21)

Recalling this experience caused a sense of discomfort within the interview, suggesting a level of shame that he was working on during therapy.

There was a sense with these clients that there understanding of good and bad had been influenced by someone else. Perceiving things as 'bad' caused shame amongst the clients. This made it uncomfortable for them to recall in the interview. Although, it did indicate the therapeutic space was unique in that it was somewhere they felt safe enough to talk about them.

# 6. Discussion

The research question of the current study was: How do individuals with ID experience the therapeutic relationship? The findings related to this research question are discussed within the context of the existing literature. Following is a discussion indicating the lessons learned and considerations regarding involving individuals with IDs in research. The quality of this qualitative research will be assessed by considering credibility, applicability, consistency and transparency (Kitto et al, 2008). Implications of the study findings for counselling psychology will then be discussed, before closing with a discussion of the limitations of the study and recommendations for future research.

# 6.1 How do individuals with ID experience the therapeutic relationship?

There is limited research documenting the experiences of individuals with ID who have therapy (Evans and Randle-Phillips, 2020). Of the research that is available there is an emphasis on using professionals or family members as samples. Very few studies include the voices of individuals with ID (Lewis et al, 2016). The findings of the current research will be situated within the existing research including that which uses professionals and family members as a sample.

#### 6.1.1 A person-centred experience

The current research found the experiences of people with ID in therapy were consistent with the person-centred views of the relationship regarding unconditional positive regard, trust and empathy. This indicates that individuals with ID did feel understood by their therapists and that their difficulties were validated. This has been found to be important previously for individuals with ID but within the context of using CBT (Pert et al, 2013). No participants referred to any model of therapy, suggesting that the client's perception of interpersonal processes appear to be independent of modality. This supports evidence within the general population that the

therapeutic relationship is more important than the modality used (Flückiger et al, 2019) and further supports the decision to not focus closely on modality in the current research.

The results suggest that participants felt able to talk about anything with their psychologists because they did not experience any judgement from them. Participants had previously experienced being treated as 'burdens' and 'weird' and so the unconditional positive regard was unfamiliar to them. Many spoke about sharing experiences where they had been judged or belittled with their psychologists and how they received support with these. There is no previous research that considers the usefulness of unconditional positive regard for individuals with ID. As many have experienced judgement and can be led by others' interpretations of events, being able to offer unconditional positive regard may be beneficial for clients with ID.

These findings also support that empathy and someone who 'listens and who understands' is important in ensuring that individuals with ID feel understood, as has previously been discussed with this population (Fosshage, 2011). Empathy is an important part of intersubjectivity (Buikski, Haglund and Markley, 2020) and so it is possible individuals with ID do experience an overlap of subjectivities during therapy and this betters their therapeutic experience. This is supported in the current research as some participants speak about how the feeling of being understood is unique to their therapist rather than other relationships, supporting the speculation that therapy may be the first experience of an individual with ID experiencing a collaborative and equal relationship. It is this experience of being understood that aided a sense of connection for some of the participants. Some of the individuals were unable to explain why this was. This may have been due to difficulty articulating it or it may have been an unconscious experience as they did acknowledge the connection, but they were unable to explain why. Therefore, predicting an individual's success based on their emotional literacy skills as is prevalent across the literature (Langdon et al, 2017) may not be appropriate. Individuals with ID may be able to acknowledge implicit experiences within therapy that contribute to a better therapeutic relationship, even if they are unable to explicitly state what these are.

Congruence was also important for participants, and this facilitated trust. This supports existing literature that has found therapy improves trust for individuals with ID (McInnis, 2016, Petrina et al, 2016, Weise et al, 2018, Wills et al, 2018). It also adds to the literature by indicating the importance of congruence to develop this. This trust was held between the therapist and client and there was a sense of exclusivity to this. Participants knew that what they talked about would be kept confidential by their therapist and this was very important.

The importance of a person-centred approach to therapy regarding Roger's (1951) core conditions for individuals with ID is only discussed briefly in the existing literature (Schoen, 1995) and there are limited studies that have researched this approach with this population group (Flitton and Buckroyd, 2002, Demanchick, Cochran and Cochran, 2003). The results from the current study indicate that all participants have had experiences of being misunderstood, felt let down or judged by others. The empathy, unconditional positive regard and congruence that underline a person-centred approach oppose these experiences and so may be particularly important for individuals with ID. A person-centred approach is felt to increase self-esteem, confidence and reduce emotional dysfunction (Rogers, 1951). Participant's responses in the current study did indicate the presence of the core conditions within their therapy. Therefore, it is possible the positive change they spoke about such as "I've got more confidence in myself" or being "better able to manage emotions", was a result of their psychologists displaying signs of the core conditions during therapy. Therefore, working with a therapist who is mindful of person-centred values may prove beneficial for individuals with ID.

#### 6.1.2 The importance of adaptations

The existing literature indicates that it is important to use adaptations when working with individuals with ID. These include adapting the language used, involving activities, and involving caregivers (Whitehouse et al, 2006 Lewis et al, 2016, Surley and Dagnan, 2019). They also like to 'try different methods' with clients. The importance of adaptations has also been indicated as important by different reports and guidelines (Department of Health, 2009, NDTi 2012, NICE, 2016). Although, some have argued this does not lead to action (The Foundation for people with

Learning Disabilities, 2014). The responses from participants in the current research suggest that some professionals working with individuals with ID therapeutically do consider adaptations and use these where appropriate. Although, this may be because the psychologists in this study worked within an ID team and so had the skillset needed to recognise this need and offer it. If individuals with ID are not accessing support through a specialist service, then the necessary adaptations may not be offered. A more cohesive approach between specialist and mental health services may improve this as suggested by Hawramy (2020).

Many of the participants in the current study felt the adaptations were an indication their psychologist understood them. Also, there was a sense participants felt frustrated or embarrassed when they did not understand abstract concepts and used defence mechanisms, such as laughter, to hide this. By avoiding difficult language, therapists spare their clients these experiences of shame which may make therapy less positive. This supports Schepers and Kerr (2019) and Banks (2006) who indicate the importance of the therapist being able to adjust to the varying communication needs of individuals with ID and how this contributes to a trusting space for them to explore their emotional needs. Therefore, adaptations are not just important to aid comprehension, but as an empathetic gesture that strengthens the therapeutic relationship.

This study also offered the opportunity for caregivers to be present which has also been considered an important adaptation in the literature (Whitehouse et al, 2006). Two of the participants opted to have a parent present to support with comprehension and confidence. Two had no one and two had support workers in the house but not in the room of the interview. Interestingly, the presence of support worker hindered their responses. This was even the case when the caregiver was not in the room. The individuals who did not have a caregiver present spoke warmly about them. This suggests that for some individuals with ID the constant presence of a caregiver is overbearing, and they seek more privacy. When support workers do acknowledge boundaries, individuals with ID feel more favourably towards them. This may be because they feel more respected.

Flexibility of the therapist is also important (Banks, 2006) and this was apparent in the current study. Most participants spoke of how their therapists were prepared to flex the usual therapeutic frame to meet their needs. This included the therapist embracing more of an advocacy role and sessions taking place outside of the therapy room, for example, in a park. They also spoke about the use of concrete tools, such as worksheets, to facilitate comprehension. The importance of finding the right fit between the patient, therapist and approach being used has previously been discussed (Frankish, 2013, Schepers and Kerr, 2019). The current research indicates how when this is successfully achieved individuals with ID feel understood by their psychologist, and it strengthens the therapeutic relationship.

There has also been discussion in the literature of power within the therapeutic relationship.

Some researchers have argued that the therapeutic relationship is imbalanced due to power from professionals, but others have found a balance between interactions (Jahoda et al, 2009, O'Malley et al, 2019). So, based on this, it may be that power is determined by how aware the therapist is of it. The disregard of professional titles and attempts made by therapists to make adaptations to ensure therapy best meets the needs of the clients suggests that therapists are aware of the risk of the power imbalance and take steps to moderate this. Using titles was also confusing for some individuals, "Well I get confused with that word. I know, it's a long word, but it's hard for me to remember that." They found the complexity of the word difficult and confused them with other professionals they were working with. The decision of therapists not to use them may have also been in response to this. The current research would suggest that individuals with ID benefit from the absence of titles and this encourages balance within the therapeutic relationship.

#### 6.1.3 'I feel like I know you'

The current study suggests that familiarity was important for individuals with ID and this facilitated a positive therapeutic relationship. This presented itself in two ways. For some participants familiarity with the therapist was the result of having worked with them for a while. This was apparent in the interviews because some of the participants reflected on not being familiar with the interviewer and this making it harder to talk openly. This proposes that

individuals with ID may need an offer of more sessions to ensure there is enough time to establish a relationship they feel comfortable being open in. This supports Skelley et al (2018) who found the average number of sessions was 22 and offering less than this risked participants feeling rejected. Therefore, offering a limited number of sessions to individuals with ID may not be beneficial.

Participants also spoke about familiarity in terms of being reminded of someone else, 'she reminds me of someone'. This was both a specific person and a general personality type and was always positive. It is possible that the participants transferred their feelings from a previous helping relationship to their current therapeutic relationship and this has helped them trust their therapist. The importance of transference is discussed widely in the psychodynamic literature and is an important part of the real relationship (Greenson, 1971). Although the importance of it has not been considered for individuals with ID. This study would suggest that when there are previous experiences of positive relationships, individuals with ID carry these to new therapeutic relationships and trust is built more readily. There were no examples of negative transference in the current study. One participant did reflect on previously being let down and then later stated it took a while for him to trust his therapist, so it may be that it took longer for him to trust than those who had previously had positive helping relationships. Therefore, considering previous helping relationships may help therapists when planning length of treatment for individuals with ID, as some may be able to form relationships more readily based on earlier experiences.

This research found that familiarity was an important part of participants being able to be open with their therapist and in return they felt listened to and validated. For some this was exclusive to the therapeutic relationship, and they reflected on other experiences where they were not listened to. This supports research that has found being listened to and feeling validated are important for individuals with ID (Evans and Randle-Phillips, 2018, Weise et al, 2018 and Mattock, Beard and Baddeley, 2020). It also highlights how reciprocal the therapeutic relationship can be. In exchange for a sense of familiarity, individuals with ID offer the therapist trust that helps them be open within sessions. If the therapist is perceived to be listening, individuals with ID feel

validated and this leads to further openness. Therefore, it feels important that therapists use early sessions to establish a sense of familiarity as this will aid openness that will benefit therapeutic outcomes.

#### 6.1.4 A secure base is offered

Existing literature discusses the attachment history of some individuals with ID and how this can contribute to an insecure attachment style. Therapy has been considered an opportunity to offer individuals with ID a different relational experience from which there can be therapeutic growth (Frankish, 1992, Atkinson et al, 1999, Frankish, 2013). This research would also support this and offers insight into how this is achieved. Participants felt their therapist recognised their needs and respond to these, 'well she does stuff and she actually makes it happen'. They also spoke warmly about their therapist as someone who due to their knowledge was a 'very, very good problem solver'. It could be argued that this more directive approach may contradict PET 1: A person centred experience, but by being led by their needs, which is to have problems solved, the therapist creates a sense of safety within the therapeutic relationship. This mirrors the role an early caregiver may provide for a baby that facilitates a secure attachment style and that some individuals with ID are deprived of (Stern et al, 1998, Potharst et al, 2012, Giltaij et al, 2015 and Hamadi and Fletcher 2019). This can then make experiences of rejection or lack of intimacy more difficult for individuals with ID in adulthood (Banks, 2006). This was reflected in the current study by some participants' descriptions of difficulties they were having such as not understanding why friends let them down. The therapist's warm and responsive approach helped them work through this. Therefore, the current study would suggest that therapy offers an opportunity to experience a type of caring relationship that may have been missing from earlier life, the effects of which persist to adulthood. This learning with therapy, then helps build and strengthen relationships outside of therapy. This is something that the literature suggests is difficult for adults with ID (Cuckle and Wilson, 2002, Bigby and Know, 2009, Friedman and Rizzolo, 2018). Therefore, by being warm and responsive therapists act as stable attachment figures which helps to establish a secure emotional base within therapy from which individuals with ID can experiment and grow.

The working alliance has also been discussed in the literature and considered to be an important part of therapy (Bordin, 1979, Elvins and Green, 2008, Doran, 2016, Cameron, 2020). Recognising a therapist's competencies or skills has been considered a reflection of a strong working alliance (Gelso, 2018). The responses from the current research indicate that participant's do recognise and appreciate the skills and knowledge base they perceive their therapists to possess. This then helps to establish trust because participants felt that their therapist was competent in their role and able to help them. This competence helps the therapist demonstrate that they are attune with the client's needs. This in turn helps establish a secure base (Grossman, 1999, Frankish, 2013). Individuals with ID may also feel validated if working with competent therapists who understand their needs. This is the opposite experience some individuals with ID have when they are young, when parents can feel overwhelmed by their infants' needs and so decrease their engagement (Giltaij et al, 2015). Therefore, the sense of competence achieved through a strong working alliance may be both validating and help establish trust. This then helps to establish a secure base from which a strong therapeutic relationship can be built.

The participant's responses indicated a level of reliance on their therapists to support tasks and meet their needs. It was felt psychologists had an active role in facilitating therapeutic growth for individuals. As evidenced in the literature, individuals with ID may have multiple professional relationships (Lippold and Burns, 2009). Bigby and Know (2009) also highlight how the social relationships of adults with ID tend to be restricted to paid staff. So, it is important to consider whether they develop a lack of independence because they are used to others doing things for them. The responses in the current study do suggest the participants had certain expectations of their therapists but did also reflect progress being made whereby individuals felt more able to do things independently. Therefore, it may be that therapists initially provide support, but this is to establish a secure base that contributes to a positive therapeutic relationship. Individuals with ID then grow in independence and move away from the reliance on their therapist.

## 6.1.5 Change does occur

Across the literature there has been discussion about whether individuals with ID have the emotional capacity or literacy skills needed to engage in talking therapies (Greenhill, 2011, Marwood and Hewitts, 2012, BPS 2015, Lindsay et al, 2015, Langdon et al, 2017, Roberts and Kwan, 2018, Giannaki and Hewitt, 2021). This study supports findings that suggest that success of therapy is not dependent on good emotional literacy skills. Despite not all participants being able to find words to articulate how they experienced the therapeutic relationship; it was apparent from the warmth they used when speaking about their therapists and concrete examples of the difference therapy had made that they had benefited from and enjoyed therapy. This proposes that the experience of change for individuals with ID may be one that is difficult for them to articulate but experienced, nonetheless. This research supports the NICE guidelines (2016) which advocate for a range of psychological therapies being adapted for individuals with ID.

The current research found that for all participants positive change occurred because of therapy. Participants felt they had 'made some progress' and that therapy did help with mental health difficulties. It was apparent that it was not a particular modality or method that was important in eliciting change but having someone they trusted who they could talk to about their problems. This supports existing research in both CBT (Pert et al, 2013, Unwin et al, 2016, Giannaki and Hewitt, 2021) and psychodynamic literature (Merriman and Beail, 2009, Alim, 2010) that has found the relationship and having someone to talk to being more important than the approach used for individuals with ID. It also suggests that teaching prerequisite skills considered important for approaches such as CBT may not be necessary and may not be the best use of limited therapy hours (Robert and Kwan, 2018). Although, the additional benefits of teaching modality specific skills remain to be evaluated.

Individuals with ID are more likely to experience loneliness and have limited friendships (Cuckle and Wilson, 2002, Lipold and Burns, 2009, Bigby and Know, 2009, Friedman and Rizzolo, 2018).

This study would suggest that having someone to talk to, which may potentially reduce the impact of limited friendships, was found to be helpful for individuals with ID. Therefore, an important part of therapy is offering a space within which individuals feel able to talk. In the first instance

this need would best be met through one to one therapy, but this option can be expensive or have long wait lists. So, it may be beneficial to train support staff in basic therapy skills such as active listening to support individuals with ID. Some of the individuals in the current study felt their support staff did not listen to them. Offering training, as suggested by many policy papers (Department of Health, 2011, NDTi, 2012 and NICE, 2016), to develop this skill may enrich the relationship between individuals with ID and those who support them every day and improve their wellbeing. Although, it is important to acknowledge that some individuals with ID appreciate the private space away from their 'regular' lives that therapy offers. For these individuals, it is therapy alone that may prove most useful. Another option could also be groups or community interventions that therapists could facilitate, especially as group interventions have previously found to be effective and this may be due to their social element reducing loneliness (Lindsay et al, 2015 and Marwood and Hewitts, 2013).

For some participants regular support was needed and they acknowledged finding prolonged periods of not talking to their therapists difficult. This supports Skelley et al (2018) who found that participants benefit from prolonged, regular therapy and when this is not offered there is a risk, they feel rejected. Therefore, even though change did occur, some felt 'it doesn't ever last for long' and so sessions needed to be regular for change to be continually experienced. When participants did not have sessions, it was difficult for them to apply positive change from previous sessions. This indicates the importance of regular engagement with the therapeutic relationship. It also suggests that therapists should be mindful about preparing individuals with ID for periods of leave or sickness so that when this happens clients do not feel abandoned. This can be done by therapists taking time at the start of sessions to explain things such as leave and sickness to individuals with ID and reminding them as appropriate. This way individuals with ID are more likely to feel reassured that despite a period of absence, the work will continue.

## 6.1.6 An overlap of subjective experience

The importance of an intersubjective space within therapy has been discussed in the literature (Stolorow and Atwood, 1992, Auerbach and Blatt, 2001, Lyons-Ruth, 2007, Gerson, 2004, Swartz,

2006, Fosshage, 2011) but never with consideration to individuals with ID. The current research would suggest that individuals with ID do experience intersubjectivity within therapy and this is important for therapeutic growth.

Despite some individuals with ID potentially having early experiences that relate to insecure attachment styles, some of the participant's responses made it evident they were able to form attachments as adults to friends and family. Furthermore, all the participants had been able to build a relationship with their therapist. Therefore, regardless of early attachment experiences, individuals with ID can build new relationships. This is important because evidence with the general population suggests that the therapeutic relationship is essential for therapeutic growth and being able to form a relationship is important for intersubjectivity (Freud, 1912, Rogers, 1951, Zetzel, 1956, Stolorow and Atwood, 1992). Privacy was an important part of this as some participants found the presence of others a hindrance to their therapy sessions. This highlights the importance of therapy being exclusive between the client and psychologist (Frankish, 2013). It may be that a third presence interrupts the overlap of the client's and psychologist's subjectivities and limits the opportunity for therapeutic growth.

Some individuals reflected on things they perceived as 'silly' or that they had done wrong. Early supportive caregivers with whom infants can develop a mutual understanding of and experiment with new learnings has been highlighted as important (Stolorow and Atwood, 1992). When this does not occur, there is a risk of unmet developmental needs and reactive feeling states that the individual may hold themselves responsible for. It may also be that maladaptive schemas develop which are triggered in later life (Young et al, 2003). The responses of some of the participants whereby they felt 'bad' or like they'd done something wrong would indicate suggestions of this. The experience of being let down by others was also common across participants and was a problem they found difficult to understand on their own. This may be why, as the third wave literature highlights, learning psychological skills such as non-judgement, self-compassion and willingness to experience difficult emotions has been found to be beneficial (Patterson et al, 2019). Participants spoke about using therapy to help them move away from these beliefs and

problems with the help of their psychologist. No other research has identified how individuals with ID are able to use therapy to discuss previous negative experiences and build new meanings from them because of the therapeutic relationship. The participant's responses in the current study indicate that this is something they find particularly beneficial. This adds further support to the suggestion that therapy has offered individuals with ID a relationship that is unlike one they have experienced previously and so they experience a new way of relating to people. As Fosshage (2011) explains, new principles then arise, and this enriches the individual's flexible and complex understanding. This then leads to psychological healing, because they can think differently about situations that caused them distress and work out other solutions. Furthermore, individuals with ID may be supported by their therapist to understand themselves in a new light as suggested by Buirski, Haglund and Markley (2020). This is aided when the client feels deep acceptance and mutual understanding, as has been evidenced in the current study. It is the presence of these experiences that underlie an intersubjective therapeutic relationship.

Previously, research has only considered this regarding a typically developing population, but the results in the present study would suggest that an intersubjective experience is important for individuals with ID too. Especially as they may be less likely to experience this type of relationship outside the therapy room (Friedman and Rizzolo, 2018, Hamadi and Fletcher, 2019). Although, they may be more likely to experience situations that they perceive as shameful. Therefore, therapy may be important in offering individuals with ID a chance to rework embedded shameful beliefs about themselves so they can move beyond difficult experiences and an intersubjective therapeutic relationship offers the needed environment for this to occur.

The PETs identified in this research relate to and further understanding of key themes highlighted in the literature review. For example, the model of therapy used did not seem important to participants. Rather, their therapists were able to adapt their approach to best meet their needs as represented by PET 2: The importance of adaptions. This strengthened the bond within the therapeutic dyad as it indicated an empathic approach from the therapist. Empathy is important across approaches, and as captured by PET 1: A person-centred experience, participants did feel

their needs were being recognised. Even though, research looking at a person-centred approach for individuals with ID is limited within the literature. Transference with individuals with ID has also not received much research attention, but PET 3: 'I feel like I know you' would suggest it could be an important area to explore. In comparison, attachment has been considered more for individuals with ID (Greenhill, 2011, Frankish, 2013, Bateman, 2020) but with limited applicability to a psychotherapeutic setting. PET 4: 'a secure base is offered', makes initial steps towards understanding this and furthers the work of Frankish (2013) who recognised the importance of providing a secure base for individuals with ID. Despite previous suggestions that individuals with ID don't benefit from psychotherapy (Greenhill, 2011), PET 5: Change does occur, further supports existing research that suggests it is effective (Bender, 1993, Goad, 2022) but indicates the importance of regularity in maintaining this. PET 6 represents the sense that the client used the therapist's subjectivity to guide new learnings, and they felt like the therapist's embraced theirs to demonstrate understanding. This offers a way of understanding Intersubjectivity Theory (Storolow and Atwood, 1992, 1996) from an ID perspective. Based on responses of the participants intersubjectivity felt fluid, unique to each dyad, rather than a rigid construct. Intersubjectivity is an unconcious process and not one participants were expected to comment on explicitly, but it is hoped this theme captured examples of where it could have been happening based on different examples within the literature. For example, feeling understood (Fosshage, 2011), therapy not feeling like other relationships (Gerson, 2004) and being able to learn new things (Buirski et al, 2020).

#### 6.2 Working with individuals with ID in research

The current research sought to capture the voices of individuals with ID and their experiences of therapy. This study achieved this by interviewing six individuals. Whilst growing, the literature is still limited of studies involving participants with ID as a sample group and so it is important to document the processes used and reflections on these to encourage future research with this group.

Participants were recruited from a NHS adult ID team. This was made easier for the researcher due to already working in the NHS in and ID team for young people. It was through this role that the researcher was able to reach out to the adult team. For some of the participants initial contact was with a carer. This made the initial part of the research more time consuming than expected because of working around the carer's working hours. This meant the researcher needed to ensure regular communication and be flexible with their time to not miss an opportunity to speak with a participant. This was manageable and was helped by the researcher already working within the NHS so readily having access to an NHS email address and work phone that they could check regularly. Therefore, for future research involving individuals with ID it would be beneficial to work within or close by to the team from which participants will be recruited from.

The current study gave careful consideration to participant's capacity to consent following the Mental Capacity Act (2005) and previous research (Coons and Watson, 2013, Wills, 2018). All participants had also been assessed as able to consent to therapy by the adult ID team. The researcher was initially concerned the consent process may feel clunky due to the number of steps involved but found it to be effective in ensuring the participants had understood what the study involved. As a result, it felt they more readily answered questions because they knew what to expect. They also seemed to feel quite comfortable around the researcher because they'd previously had the opportunity to meet or speak with them. The researcher remained mindful of consent throughout the process. The researcher paid particular attention throughout the interview to positive and negative body language. If at any point it was felt the participants were confused the interviewer reminded them of the topics being discussed and asked if they were happy to continue. This only happened in one interview, at the end when the participant became confused by the role of the interviewer, mistaking them for a nurse they'd met previously. The interviewer responded to this by reminding the participant of who they were, where they were from and why they were being interviewed. The participant then agreed to continue the interview

and returned to speaking about their psychologist. This highlights the importance of process consenting when working with individuals with ID.

Two of the participants opted to have a carer or parent present with them during the interview. As this research was primarily aimed at hearing the voices of individuals with ID all questions were directed to the individual with ID. Even so, the caregivers did contribute, and this offered unplanned triangulation; all the parents advocated for the benefits of therapy and the positive changes they'd seen in participants. This echoed the experiences of participants. It also offered an opportunity for the researcher to observe a relationship different from the therapeutic one and this contrast added depth to the data. For example, one participant spoke about feeling listened to by his therapist, but had his mother speak over him during the interview. The researcher then redirected the question back to the participant. Despite being able to add some insight to the data, involving parents and carers was not approached in a controlled way in this study as the input of parents or carers was not anticipated. Therefore, future studies would benefit from having clear guidelines for those who accompany individual's to interviews so they are aware of whether to participate.

In addition to being the sample group and asked directly about their experiences, individuals with ID were involved in the design of research materials for this study. Previously research would only ask parents or carers about their experiences on behalf of those with an ID, but fortunately research is moving away from this. Although, to be considered fully 'inclusive' individuals with ID should be included in every part of the research process. This includes design, process and dissemination (Walmsley, Stranadova and Johnson, 2018). Taking a fully inclusive approach to research has been found to increase knowledge and understanding of the experiences and social barriers of individuals with ID (Tilly, 2020). Therefore, more opportunities should be made for this to happen.

### 6.3 Implications for counselling psychology

This study highlights that IPA can successfully be used with individuals with ID and they are able to engage with semi-structured interviews. This study also highlights the importance of a positive therapeutic relationship for individuals with ID and what helps to establish one. Therefore, it is important that professionals working with individuals with ID are aware of these things so that they can facilitate development of a better therapeutic relationship. The current study suggests that empathy, warmth, and security are all important characteristics for individuals with ID being able to form a good therapeutic relationship with their therapist. Having a therapist who can offer these things, is more likely to provide therapeutic outcomes.

This study also indicates the importance of adaptations during therapy and so therapists need to have knowledge about preparing and providing these. The type of adaptation needed varies depending on the individual and so therapists need to be client-led when considering what may be beneficial in sessions. Some examples of potential adaptations that could be considered are visual cue cards, story cards, worksheets printed in an easy read format, fidget toys and being flexible with where the session occurs. For example, some of the participants in the current study spoke about having sessions in the park or going for a walk. Adaptations don't only serve to aid comprehension but are a sign of the therapist's responsivity to client need. Therefore, this may aid experiences of empathy and so are a crucial element to be considered when working with individuals with ID.

Adaptations are also important when working with individuals with ID in research. This study found visual cards displaying emotions and activities and easy read information sheets essential in aiding comprehension and supporting individuals with ID to respond with more depth. It is felt scenario cards may have also been useful, but these were not used in the current study. Therefore, future researchers wishing to work with individuals with ID should think carefully about the adaptations they make to study materials. The most effective way of doing this would be to involve individuals with ID in the entire research process.

The experience of the therapist was also important for individuals with ID. Individuals with ID believed their therapist to be someone who was able to provide advice and help them solve

problems. Individuals with ID appreciated a direct approach by therapists whereby they offered concrete advice or helped them understand situations from another point of view. Therapists that were able to offer this were viewed as knowledgeable by the participants and this was important in building the therapeutic relationship. Therefore, it is important that professionals supporting individuals with ID are aware of this. If they are not experienced working with ID they may not be aware of the need to potentially adapt their style so more concrete advice is given. Furthermore, experience will help professionals understand the common difficulties individuals with ID bring to therapy and so offer insight on how best to support them.

Professionals working with individuals with ID also need to be prepared to be flexible on whether a carer is present or not. This should be guided by the individual with ID. Traditionally, therapy occurs between a client and the therapist, but it was evident in this study that some participants found it beneficial to have another present, although for different reasons. For example, one participant felt more confident with their mother in the room, and another relied on his mother to clarify his speech due to a speech impediment. Whereas others did not appreciate a third individual and spoke about how this limited what they felt they could speak about. Therefore, professionals need to be client-led in decision-making about who is present during therapy sessions to ensure that if a third person is present, they are a help and not a hindrance.

It is perhaps an accumulation of all these things that created a sense of intersubjectivity between individuals with ID and their therapists. Buirski, Haglund and Markley (2020) highlight the importance of the therapist and client being able to make sense together, acceptance and understanding and these were experienced by individuals with ID with their therapist. They also shared guidelines to help therapists achieve this. The current research would suggest that individuals with ID do recognise these and offers insight into how therapists may implement them within their practice. For example, participants felt listened to indicating therapists were open and curious. They also offered useful solutions further demonstrating their understanding. Participants spoke of interventions that they found helpful and willing to do, and that did not appear driven by theory, for example, walking or listening to relaxation music. Participants also

shared experiences they perceived as 'bad' prior to therapy, indicating that they were able to share their subjective experiences within therapy and interpret this differently due to their new relational experience. Therefore, when working with clients with ID it appears that a balance of overt physical gestures such as helping sort a problem out or going for a walk and more subtle relational experiences, such as active listening or interpretation indicating understanding, facilitate an intersubjective relationship and therapeutic change.

Given the focus of this study it seems relevant to consider the current discussion in the literature regarding whether individuals with ID's needs are better met by mainstream services. The responses of the participants in this study highlight the importance of working with a therapist who understands their individual needs and can make adaptations. Individuals with ID present differently and so it is not possible to apply a 'one size fits all approach.' The only way to gain this knowledge is through experience working with this group of people. The results from the current study suggest a person-centred approach may be important but this requires a level of training or experience to best understand need and tailor approach based on this. So, it does feel important that individuals with ID continue to have access to professionals with specialist ID knowledge. Although, it is also important that they can access the same services as those without an ID as this is the only way to ensure equality in healthcare (The Equality Act, 2010). An important part of this is ensuring these services are equipped to meet the specific needs of individuals with ID, the same way as they aim to meet the needs of those without an ID. Therefore, the current study would support the joined-up way of working between services suggested by Hawramy (2020). It is only through the sharing of specialist and service user knowledge that one can ensure consideration is being given to both the mental health needs and other additional needs of individuals with ID. As demonstrated by the current research, individuals with ID can and should be included in research. It is hoped that this study will encourage further researchers to ask individuals with ID

directly about their experience, rather than using parents or carers as a sample. This research can act as a guide for researchers who are considering using participants with ID in their research but are unsure of where to start. By following some of the adjustments made in the current study and

thinking carefully about adapting the methodology to best suit the needs of individuals with ID, researchers should feel encouraged to work with this group of individuals.

### 6.4 Quality

Qualitative studies seek to gain an in-depth understanding of experience from the viewpoint of the participant. Qualitative methods have specific criteria for assessing rigour. The current research will follow the generic guidelines set out by Kitto et al (2008) and reviewed by Hammarberg, Kirkman and de Lacey (2016) to do this. Trustworthiness, credibility, applicability and consistency will all be considered.

Trustworthiness requires the research to include a robust procedural description of the study so that a reviewer can easily follow the progression of events and understand decisions made. The purpose of the study, how it was conducted, decisions about the research and information about data generation and analysis are all documented in this report. The researcher aimed for complete transparency and clear explanations and justifications of the method to establish trustworthiness. It is hoped that due to the level of depth future researchers will feel more able to conduct research with individuals with ID.

Credibility evaluates the internal validity of qualitative research. The aim is for the results to be relatable to other individuals who share the same experience. This research ensured this through reflexivity whereby the researcher considered their own influence on the data. Notes were also made throughout the research process documenting the researcher's thoughts and reasons underlying decisions. This research also involved caregivers in some of the interviews which offered triangulation. Finally, verbatim quotations are provided from the data to support their interpretations.

Applicability evaluates external validity. A study is considered applicable if it can be transferred to contexts outside of the study situation. The researcher aimed to achieve this by providing indepth descriptions of the participants and context used within this study. Furthermore, there is also rich descriptions of the information generated from research interviews. As this research

used a sample from an NHS adult intellectual disability team, it is hoped the results are applicable to this setting. Although, consideration is needed for the level ID and the psychologist's experience, as this study interviewed individuals with mild to moderate ID and all the psychologists were confident working with individuals with ID. Saturation of the sample was also considered. Based on the recommended sample size for this level of research and the convergence of responses it is felt that the sample did provide adequate data to develop a robust and valid understanding of individuals with ID experience of the therapeutic relationship.

Consistency assesses reliability. To ensure consistency the researcher provided a detailed description and justification of the methods and clearly documented the process involved in collecting and analysing data. A clear list of research materials and adaptations made was also supplied. The initial analysis was also shared with another researcher for verification.

#### 6.5 Considerations for future research

Given that both the literature regarding mental health support for individuals with ID and using individuals with ID as a sample is still limited, it is important for future research to use this group of people more. Only by doing this will professionals be able to adapt their practice and best meet the needs of what is currently an under-served group of people. The current research has demonstrated that they have a voice that they are willing to share and so this should be listened to.

There are also some specific considerations that have arisen from the present study that could be interesting to explore further. This study did not assess the participants early attachment history, and this in relation to therapy for individuals with ID remains an under-researched area. Attachment questionnaires for this population are limited in number and psychometric robustness compared to those for individuals without an ID (Bateman, 2020) and so interviewing parents or caregivers about early experiences may provide greater insight. Gaining a better understanding of this and how it may affect individuals with ID may help therapists adapt their practice to best meet these needs. For example, it may be that some individuals with ID benefit

from a more relational approach that helps them consider early attachment experiences. This is important because CBT is currently widely used in mainstream mental health services, but this may not be best meeting individuals with ID needs. If this is the case, then it also highlights future training opportunities for professionals working with this client group.

Transference and countertransference within the therapeutic relationship with individuals with ID has also never been researched. Based on the importance of familiarity for the current participants, this may be an interesting area to explore. This could be accomplished using a method similar to Wills et al (2018) where therapy sessions were recorded and played back to the client and therapist. These could then be played back to identify any possible moments of transference and be discussed with both members of the therapy dyad. Gaining further understanding in this may aid professionals' knowledge of the impact of early experiences and relationships and how these are experienced within the therapy room. It may also help professionals consider what an appropriate number of sessions is to be offered to someone with ID, as already discussed this client group may take longer to build an initial relationship. Finally, the participants in this study all had mainly positive experiences of the therapeutic relationship. This was not a specified criteria but potentially a bias in sample selection. This did allow for a more homogenous sample as all the positive experiences could be compared. Despite this, it would also be interesting to research ruptures within the therapeutic relationship for individuals with ID as this may further professionals' understanding of what to avoid when working with this client group. It may also be useful to explore other relationships, such as those with their support workers as this was something some of the participants referred to during their

#### 5.6 Limitations

interviews.

There are some limitations to this study. Firstly, this discussion has reflected on the potential impact of early attachment experiences on individuals with ID but participants were not assessed for their early attachment experiences. Therefore, it is important to state that all comments on

attachment are speculative and in relation to the existing literature. Despite this, it was apparent the ease with which participants formed relationships differed greatly and so as suggested this may be an interesting future area to explore.

This study recruited participants from an adult intellectual disability service. The lead researcher liaised with a Clinical Psychologist about potential appropriate participants, who acted as a gatekeeper regarding who was and wasn't asked. Therefore, it is not possible to know whether the sample is representative of all who access the service. Due to the requirement of needing to be interviewed, there is a risk that the sample represents more confident individuals who are more at ease with speaking to strangers, and so may also find building relationships easier. This study also did not involve participants who had a more severe ID. This decision was made because the ID service where the sample was recruited from worked more with adults with mild to moderate ID. The researcher does acknowledge the dearth of research involving individuals with a severe ID and feels with the right adaptations, such as use of communication aids, this group of individuals should be involved in more research.

It is also possible that interviewing participants for longer or on more occasions may have produced more in-depth responses. The researcher in the current study was led by the participants in how long to interview for and guided by their responses. On occasion questions were reframed, but this did not always lead to more in-depth responses. The use of video recording sessions and playing this back to participants may have deepened reflections. Although, there was also the risk participants may have got 'stuck' on what was being played back and so would not reflect on the relationship overall.

All the participants in the current study appeared to have a positive experience of therapy. This was beneficial as it allowed the research to focus on what supports a strong therapeutic relationship and the responses were all in convergence. It is possible that participants did experience negative transference towards their therapist but felt unable to talk about this.

Although, participants did speak about negative feelings towards others, and the time it had taken to trust their therapist, suggesting that they were being open about their current therapeutic

relationship. Considering this, it may have been interesting to contrast with more negative experiences of a therapeutic relationship. This comparison may have led to a more in-depth understanding of what causes ruptures and why relationships may not be positive.

#### **6.7 Conclusion**

To the knowledge of the researcher this is the first qualitative study to ask individuals with ID about their experiences of the therapeutic relationship. The results would suggest the therapeutic relationship is important for individuals with ID who are having therapy. Based on the findings of the current study, individuals with ID experience the therapeutic relationship as a trusting, empathetic relationship with an individual who they believe can and will help them. It is not like other professional relationships. This degree of exclusivity highlights the importance of individuals with ID having access to therapy. Being able to establish a trusting relationship with another individual who they feel understood by, enables individuals with ID to process and move away from difficult experiences. It does not appear that individuals with ID are held back by their disability within the therapeutic space, but adaptations and an experienced therapist may strengthen the potential for positive change.

This research also added to the limited literature involving individuals with ID as a sample. It demonstrated how with appropriate adaptations individuals with ID can provide great insight and be involved in shaping the support they receive when it comes to psychotherapy. It is hoped that this research will enable therapists to feel more confident when working with this group of individuals and researchers to feel more able to involve them in research.

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# 8. Appendices

## Appendix A – Interview Schedule

The following points will be used to encourage, expand and deepen the researcher's understanding of the participant's experience of counselling and the therapeutic relationship. This research is focused on getting an in-depth understanding of the participants experience and so questions will be used as guides to prompt further insight. This schedule will be used flexibly, for example, does not need to be asked in order, but in a way that is logical and encourages the participant to talk about their experience of the therapeutic relationship.

All interviews will be conducted by the lead researcher who has experience working with the [Therapist]ple group. Interviews should be around 30 minutes long, but led by the participant. A break should be offered half way through.

#### Interview schedule

#### 1. General experiences of counselling

The aim here is to encourage the client to start thinking about their experience of counselling, not to ask them about why they are having counselling or the specific issues being discussed.

If the client starts to talk about the therapeutic relationship here then the focus will turn to this and prompts from section 3 can be used.

Please could you tell me about your experience of counselling?

- What have you liked / disliked?
- What has been helpful / unhelpful?
- What has been important for you?

#### 2. Therapeutic relationship

This section aims to gain insight into the participant's experience of the therapeutic relationship. It is anticipated this section will take up the most time as it is the focus of the research questions.

What has your relationship with the counsellor been like?

- How would you describe your counsellor?
- Did you feel understood by the counsellor?
- Did you set any goals together?
- Were you able to talk about what you wanted with the counsellor?

Do you feel anything has changed for you since you've had counselling?

- In what way was that good / bad?
- What helped with that change?

# <u>Appendix B – Favourable opinion from the Research Ethics Committee</u>

# <u>Appendix C – Health Research Authority approval</u>

#### REMOVED DUE TO PERSONAL INFORMATOIN

#### Appendix D – Easy read participant information sheet



## **Easy-read Participant Information Sheet**



#### What is this study about?

This study will be finding out what people with learning disabilities think about their counselling sessions and their counsellor



#### Who can take part in the study?

People who:

- Have a learning disability
- Are aged 18 or over
- Are having or have had counselling



#### What will I do if I take part?

- We would meet 2 times
- First, we would talk about the study and I would answer any questions. This will take 30 minutes, and can be in person or on phone
- Second, we would talk about your counselling sessions
  - This would take up to 1 hour
  - It could be at home or with your learning disability team
  - The talk would be tape recorded





#### Do I have to take part?

No. You do not have to do this study.

It is your choice.

Taking part, or not, will not change the support you get from the Learning Disability team or any other services.



#### Can I change my mind?

Yes. You can change your mind at any time when we talk. We will stop talking.

You do not have to tell me why you want to stop.

After we talk you will have one month when you can still change your mind



#### What happens to my information?

Your information will be kept private and safe

What we talk about will be tape recorded

It will then be written down. It will not have your name on it.

If I think you, or someone else if not safe I will have to tell other people about this.



#### Good things about taking part?

You will be helping us make support for people with learning disabilities better.

#### Risks when taking part?

Hopefully there will be no risks but if you feel worried or sad then we can stop and I can support you to talk to someone

2





#### What will you do with the results?

I will write about the results

I will send this to the University of West England

I will send it to a journal so other people can read it. A journal is like a magazine

We can meet again and talk about the results or I can send you a copy



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#### What if there is a problem?

If you are not happy at any time please tell me

You can also speak to Dr Tony Ward or Dr Zoe Thomas

If you want to complain formally you can do this too. I will give you the details of who to talk to.







#### Contact details

#### Researcher

Sarah Parker (Trainee Counselling Psychologist)

Email: sarah8.parker@uwe.live.ac.uk

#### Supervisor

Dr Tony Ward

Health and Social Sciences, UWE

011732 83109



## Consent to contact form

Study title: Individuals with Learning Disabilities and Therapeutic Relationships

This consent form will have been given to you because you have agreed to be contacted by a researcher leading a study looking at your experiences of counselling.

If you are happy to be contacted by the researcher, please tick the boxes below, sign and date the form. You will be given a copy to keep for your records.

	My counsellor has spoken to me about taking part in a research study I agree that my email and phone number can be given to the researcher
	I understand a researcher will contact me with more information
9?	I was able to ask my counsellor questions. I know I can ask the researcher more.
	I understand that by signing this form I am <b>only</b> consenting to being contacted by the researcher
×2	I understand I am not consenting to taking part in the study and I will be asked to sign another form to do this after I have spoken to the researcher
	I agree to be contacted by the researcher

Name (Printed)	
Signature	Date

#### Appendix F - Consent form



## Consent Form

Study title: Individuals with Learning Disabilities and Therapeutic Relationships

Please read the participant information sheet and this form

Please ask any questions before you tick and sign the form.

You do not have to take part in this research

If you are happy to take part in the interview please;

- 1. Read the sentences below
- 2. Tick the boxes
- 3. Sign the form
- 4. Date the form



I have read	and unders	tood the inform	ation in the Pa	rticipant Inform	ation Sheet which	ch I have been given
to read bei	fore asked to	sign this form,				
YES		10				
I have had	time to ask	questions about	the study;			
YES	r	NO ON				
I have had	good answe	rs to my questic	ons by the resea	arch <u>team;</u>		
YES	N	10				
I agree tha	t things I sai	d may be used i	n the final repo	rt of this study	but no one will b	e able to tell I said it
YES	r	NO O				
		ny choice to tak iving a reason;	e part and that	I can stop at an	y time until the	data has been
YES		NO O				
I agree to t	take part in t	he research				
YES [	N	10				
Name (F	Printed)					
Signatur	re			Date		

## <u>Appendix G – Examples of annotated transcripts</u>

Key: Descriptive comments

Linguistic comments

Experiential statements	Original Transcript: Extract from interview with Josh	Exploratory comments
	TCP1.7: OK, so that's not great is it? So is that important to you? Reliability I guess?	
Doesn't see all therapists as useful – does depend on the person	Josh1.7: Yea	
	TCP1.8: Yea. Ok that's amazing. So what makes [Therapist] really good would you say?	
Reliability is important – previously let down	Josh1.8: Well she does stuff and she actually makes it happen, so if she says she's going to do something she actually does it compared to the rest of the therapist I've met.	Sense of trust and reliability with current therapist. Says things and they actually happen. Suggests previous experiences of this not
	TCP1.9: O cool. So can you give me an example of that?	being the case.
	Josh1.9: So urm, just recently, she said any stuff here *gestures around room* she will help out and that and obviously she knows my social worker, she helps with that as well,	Support goes beyond the therapy room. More flexible boundaries/ frame
Flexibility of frame is important	TCP1.10 O cool, so she helps around the house, helps with the social worker –	
Third dimension to the therapeutic relationship – more than 2 people involved	Josh1.10: Well she knows my social worker, they know each other anyway. They work together, it's kind of the [Therapist]e environment	Other professionals involved in the referral route in, and support offered. How does this impact the therapeutic relationship?

	Support to access counselling from another professional

Experiential statements	Original transcript: Extract from interview with Lenny	Exploratory comments
Empathy	Lenny: Who listens and who understands	Independently says listening – reinforces earlier mention of this
	TCP: Aw brilliant. So listening and understanding again are really important. Ok, fantastic. So the next one is, help you do more activities, so they helped you with strictly come dancing, have they helped you with anything else?	being important. <u>Empathy</u>
Therapist as a safety net Support different from than of support worker	Lenny: Urm well back in November 2018 I went to see a band called Basement. Now, this was earlier before the gig, I forgot to tell [therapist] about this so, I urm, urm, urm so on the evening my support worker, [support worker] took me to see Basement, I remember saying to him 'Phone Erin!' 'Phone [therapist]!' because I forgot to mention this to her and I should have	Relies on support from therapist to get through situations Therapist advice offers a safety net Felt support from therapist more
Therapeutic space used as preparation for real life	done and when I knew I hadn't I just felt scared and threatened and urm urm urm about what might happen to me when I went to Dingle with [support worker] – and the forest yea? Felt more threatening than it was	needed than from support worker who was with him Panic recalling the memory
	TCP: OK	
	Lenny: And I think it was cause it was night	
	TCP: aw ok	
Therapist offers reassurance Therapeutic space used as preparation for real life	PM: But Miles helped you then? Your support worker helped you? But what you really mean is you wished you talked to Erin about it so she could give you some ideas to help. Is that what you mean?	Ideas from therapist offer reassurance and <u>prevent anxiety</u> <u>Knowledge is seen as helpful</u>
	Lenny: Yea, yea urm urm	

Experiential statements	Original transcript: Extract from interview with Alex	Exploratory comments
	TCP1.93 OK, so that sounds good. So it sounds like other people help you?	
	Alex: Yea, like my team leader	Other professionals around the individual
	TCP1.94 So do you talk to your team leader about the same stuff you talk to [therapist] about?	
	Alex: Yea	Only tells secrets to therapist.
	TCP1.95 so you tell him your secrets too?	Exclusivity of relationship. Trust. Can't trust team leader.
Exclusivity of therapeutic relationship – only talks to	Alex: NO	Very definitive response Experiences of other people not listening in his life. This may be why
therapist about secrets	TCP1.96 No? just [therapist]?	he only talks to his therapist about certain things.

Isn't listened to	Alex: Just [therapist], but I do sometimes speak to him, [team leader], he doesn't want to listen anyway  TCP1.97 he doesn't want to listen anyway. Ok, but it sounds like Amy is good at listening	Mismatch between what he wants from relationship with team leader and what he gets
Therapist is a good listener	Alex: you bet she is	Therapist is very good at listening, unlike others around him.

Experiential statements	Original transcript: Extract from interview with Amy	Exploratory comments
	TCP: That's ok, you don't need to tell me either. So it sounds like you trust [therapist] with secrets?	
	Amy: Yep	Trust
Trust exclusive to therapeutic relationship	TCP: Brilliant, ok.	Very cautious and quiet. Doesn't want to be overheard by support
Need for private therapeutic	Amy: Whispers quietly – I'm just a bit wary about [supporter worker]	worker. Doesn't have trusting relationships with all professionals.
place	TCP: Ok	Doesn't feel able to speak openly in own home. Concern about being

	Amy: I don't want her to listen	overheard. Importance in the therapeutic place being a private one
Therapist is friendly	TCP: I ok, I understand. I've got you. So when you're with [therapist], how would you describe [therapist]? What's she like. IS she friendly?	Friendly and trustworthy. Opposites to how feels about housemate and support worker.
Therapist is trustworthy	Amy: Yes, definitely friendly. Urm to my mind I'm not too sure, I might be wrong, but trustworthy	
	TCP: Trustworthy. Ok yea, brilliant word. That's great. So friendly and trustworthy. Amazing, and do you feel like you work well with [Therapist]? So you have a good friendship with [therapist]?	<u>Feels likes a friendship but only one</u> <u>sided.</u>
Experience not shared, but good relationship nonetheless	Amy: Well it feels like it to me	
	TCP: Great, great	
	Amy: She might not think that, I think so for me.	

Experiential statements	Original transcript: Extract from interview with Sandy	Exploratory comments

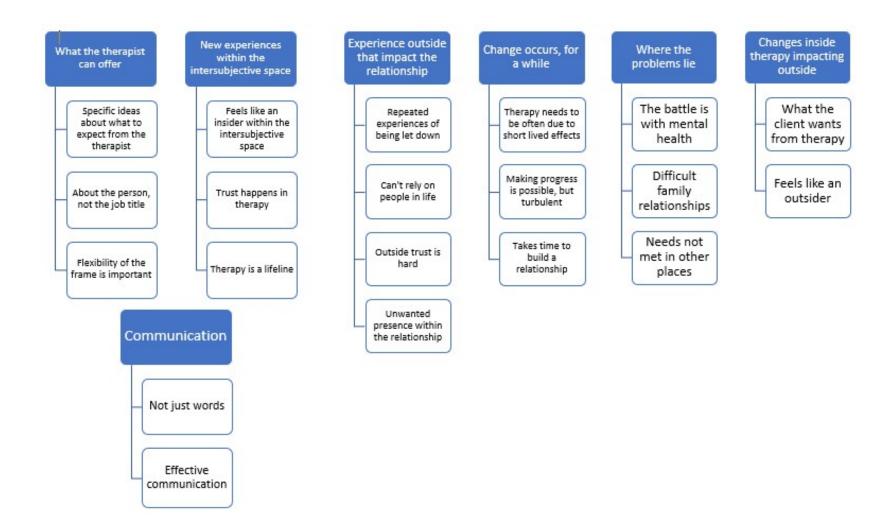
	. Sandy: She always says hello, very bright, she's kind.  TCP: Yea? What makes her kind?	Describes therapist positively. <u>Feels</u> welcomed by the therapist
Feels welcomed by therapist	Sandy: She is always pleased to see me, every week. And she seems like a nice lady.	Feels accepted by therapist. 'seems like' not so definite though, maybe some hesitancy in how well S feels
	TCP: Aw, so she is happy to see you? that's really nice. Urm, and is she good at listening?	like she knows her therapist? or hesitancy in the relationship?
	Sandy: Yea	
	TCP: Yea? What makes a good listener?	Feels listened to and that therapist
Therapist wants to help Therapist is a good listener	Sandy: She listens to what I'm saying and she like help me	likes to help. <u>Doesn't feel like a</u> <u>burden.</u>
	TCP: She helps you	
	Sandy: Yea	
	TCP: Do you feel like she understands you quite well?	
	Sandy: Yea.	

	TCP: Yea? How does she show that she understands you?	
Physical resources help aid understanding	Sandy: Cause, she does like pieces of paper about how I am feeling.	Therapist uses visual aids and this
		shows understand. Adaptations to 'normal' therapy shows understanding

Original transcript: Extract from interview with Tilly	Exploratory comments
TCP: And so [therapist] has helped with that?	
PM: Yes	Parent answering on behalf of participant
TCP: Fantastic, that's really useful. And do you think it was your friendship with [Therapist] that helped or something else?	
Tilly: Urmmm	Interviewer used 'friend' term, but not P. P seems unsure about the use of this term.
PM: well she wouldn't go out or nothing, but she does go for walks now	
TCP: Great	[therapist] has helped her build confidence
	TCP: And so [therapist] has helped with that?  PM: Yes  TCP: Fantastic, that's really useful. And do you think it was your friendship with [Therapist] that helped or something else?  Tilly: Urmmm  PM: well she wouldn't go out or nothing, but she does go for walks now

	PM: and shes got friends she goes out with now don't you?	
Confidence building		Friends are separate to therapist
	Tilly: Yea	Limited responses from participant, suggests nervousness? Mother readily speaks for her. <u>Used to</u>
	TCP: O cool, so working with [therapist] has helped you make friends?	others speaking for her?
Therapeutic relationship is not a friendship	PM: Yea she is elderly, but she takes you out for the day doesn't she?	
Experienced new ways of relating within therapeutic space		Been able to transfer the positives arising out of the relationship with [therapist] to other relationships and is now able to go out with friends.

#### Appendix H - Map of initial PETs for Josh



## Appendix I – Table of initial themes for Josh

	Page No	Key words
PET 1: What the therapist can offer		
Specific ideas about what to expect from the therapist:		
High expectations place on what the therapist should		
produce	3	Knows what she is doing
Physical gestures contribute to helping role of therapist	2	Help out
Therapist should have the answers	5	It's your job, get me help
About the person not the job title:		
Doesn't see all therapists as useful – does depend on the person	1	Have no idea
Not all therapists are the same	5	Get another one, walk
Perceived level of training is important – support of a	6	away
support worker isn't enough		Training wise
Flexibility of the frame is important:		
Therapist is response to needs of client	12	She, idea
Flexibility of approach	14	Different methods
Person-centred – adapts to needs of client	15	That's not gonna work
PET 2: New Experiences within the intersubjective space		
Feels like an insider within the intersubjective space:		
Non-judgemental nature of the therapist is important and	5	Approachable
more common in intersubjective space than real world	_	5 7 1 1 1 11 11
Sense of feeling like an outsider	5	Doesn't judge, not all like
Empathy and acceptance is appreciated, but not commonly experienced apart from in therapy	14	that Actually understands
Trust happens in therapy:		
Therapeutic relationship offers a space to experience trust	3	Private
Able to be honest	8	I will tell her
Some problems are hard to face alone – therapist helps	9	Pushing it away
Exclusivity aids the intersubjective space	12	Me and her
Counselling is a lifeline:	4	Keeps head up
Needs therapist to offload to	13	Builds up
PET 3: Experience outside that impact the relationship		
Repeated experiences of being let down:		
Doesn't want to feel let down	22	Leaving you in the dark
Previous experiences of being let down	1	Just disappeared
Familiarity with rejection	16	Just walk away
Can't rely on people in life:		
Reliability is important	2	Makes it happen
Outside trust is hard:		
	1	Can't truct all 15
Trust is limited to certain people Difficulty trusting	18 18	Can't trust all Part of me

Outside trust is hard:		
Trust is limited to certain people	18	Can't trust all
Difficulty trusting	18	Part of me
Hesitancy with new things	16 17	Didn't last long
Battle with trust	18	Fighting yourself
battle with trust	10	rigitting yoursen
Unwanted presence in the relationship:		
Third dimension to the relationship	11	Wasn't just me and her
Change in the dimension of the relationship	11	Just talk
Exclusivity needs to be earnt	12	Not their session
Unwanted presence	12	Nerve wracking
PET 4: Change occurs for a while		
Counselling needs to be often:		
Importance of regular sessions	13	It sucks
Short lived benefits from therapy	13	Need to, Really bad
Counselling is an outlet, but feelings return	4	Just let it out
Making progress possible but turbulents		
Making progress, possible but turbulent:	2	Made come progress
Progress gets made	3	Made some progress, Shared bond
Shared bond with therapist	20	
Difficult topics, but doesn't avoid them with therapist	20	That's a 'fun' topic
Takes time to build a relationship:		
Taken time to build the relationship because early on trust	8	How long it's been,
had not been established		
Familiarity helps with the strength of the relationship	8	Get to know, trust
Willing to put time into building a good relationship	9	Don't let them in, takes
PET 5: Where the problems lie:		time
The battle is with mental health:		
Mental health causes difficulty	4	Bloody thing
Stigma	10	Doesn't help, runs in
		family
Therapist is an ally	19	Talking, helps,
Needs not met in other places:		
Doctors don't help	10	Say no
Doesn't agree with doctors	11	Hard to get, how is it
DET C. Changes inside the many impact autoids		addictive?
PET 6: Changes inside therapy, impact outside What the client wants	20	Things are changing
Wants more control	20	Things are changing
Therapist helps	22	Not in my control
Understand self-more	23	Someone on my side
Officer staffic Self-Hiore	19	Freaks me out, dunno why
PET 7: Communication		,
Not just words:		
Hard to articulate feelings	7	Urm, bloody hell, a lot of
-		words

words

No idea

9

Difficulty verbalising feelings

## Appendix J – Master table of PETs for participants

Personal Experiential themes (PETs)		Key words from original transcript
1. A person-centred experience		
Unconditional positive regard	Josh	You're weird
Empathy	Amy	Connect with her
Trust underlying congruence	Josh	Me and her
2. The importance of adaptions		
Therapist is prepared to flex the frame	Tilly	We go out
Disregarding professional titles	Amy	Confused with that word
Abstract concepts are difficult but aware of	Alex	Hard to say
good relationship		·
Combating comprehension difficulties with	Sandy	Pieces of paper, feeling
concrete tools		
3. 'I feel like I know you'		
Sense of familiarity	Amy	Reminds me
Being able to talk openly	Alex	I talk about
4. A secure base is offered		
Therapist is responsive to client's needs	Josh	Makes it happen, does stuff
Therapist offers warmth and boundaries	Lenny	Friend to me
Knowledge offers reassurance	Lenny	Knowledge of stuff
Safety and predictability – clients know what	Alex	Out of head
to expect		
5. Change does occur		
Talking to the therapist results in change	Amy	Actually happens
Therapy is support with mental health	Amy	Feel alright
Regularity is important to maintain change	Josh	Doesn't last for long
6. An overlap of subjective experience		
Ability to form attachments	Tilly	Got friend
Third dimension to the therapeutic	Sandy	Supporter worker, my family
relationship		
Positive intersubjectivity, despite previous	Sandy	Never turned up
negativity		
Building new meanings from difficult	Alex	Passed away, did it for her anyway
experiences		
Rethinking the 'bad'	Alex	Not sure whether I'm allowed

#### Appendix K – Description of journal being targeted for submission of article

The article was submitted to 'Advances in Mental Health and Intellectual Disabilities'. This peer-reviewed journal focuses on the mental health needs of individuals with intellectual disabilities. It aims to provide up to date information by integrating research with practice and disseminating a variety of perspectives and international developments within the field. Articles include research papers, policy papers, clinical case studies and resource reviews.

All articles submitted must adhere to stipulated manuscript requirements. All articles must be provided in Microsoft Word format and be between 3000 and 6000 words in length. This is inclusive of all text including tables, figures and appendices. A 250-word abstract should be provided and the title should be concise. References must be formatted using a recognised Harvard style. All articles are submitted through ScholarOne submission, which is an online submission and peer-review system. The article is then checked by the editor. If it is considered suitable for publication, it will be sent to two independent referees for double anonymous peer review. Following feedback but the reviewers the editor may accept the manuscript, request revisions or decline the article.

The British Journal of Learning Disabilities and Journal of Applied Research in Intellectual Disabilities were also considered. These journals cover a wider breadth of topics involving individuals with intellectual disabilities such as carer stress, education and employment. Due to it's focus on mental health and individuals with ID, Advances in Mental Health and Intellectual Disabilities was felt to be the most suitable for the current research

## Appendix L – Article

## Individuals with intellectual disabilities experiences of the therapeutic relationship

#### Sarah Parker, Tony Ward and Amelia Baldwin

#### **Abstract**

Purpose - This research aimed to explore individuals with intellectual disabilities (ID) experiences of the therapeutic relationship.

Design/methodology/approach - Six individuals with ID were recruited who were currently having 1:1 therapy. Semi-structured interviews focused on their experiences of the therapeutic relationship.

Findings - Using interpretative phenomenological analysis, six personal experiential themes were identified. These were labelled as a person-centred experience, the importance of adaptions, "I feel like I know you", a secure base is offered, change does occur and an overlap of subjective experience. The results indicate that participants' accounts of their experiences indicated that the relationship was important to them. This research also demonstrated that the benefits and value of involving individuals with ID in qualitative research.

Originality/value - To the best of the authors' knowledge, exploring the therapeutic relationship from the perspective of individuals with ID has not been previously explored in the literature. This research highlights considerations for therapists working with this population to help them facilitate positive therapeutic outcomes.

**Keywords** Mental health, Intellectual disabilities, Therapeutic relationship, Therapy, Interpretative phenomenological analysis, Qualitative

Paper type Research paper

#### Mental health in individuals with intellectual disabilities

The treatment of people with intellectual disabilities (ID) with mental health and emotional difficulties has been criticised. There is a lack of appropriate services and limited availability to the ones that do exist (Capri, 2014). Individuals with ID have historically not been considered suitable for psychotherapy because they do not have the emotional capacity or ability to form attachments required by such interventions. Therefore, working relationally was not considered to be successful (Greenhill, 2011). This thinking has been challenged and is now considered outdated (Bender, 1993; Goad, 2022), but interventions are still dominated by the behavioural approach (Unwin et al., 2016). This is problematic because they are not considered sufficient to help with individuals with IDs mental health problems (King, 2005). Despite this, there is clearly a need to support individuals with ID because mental health problems are overrepresented in this group compared to the general population (Whittle et al., 2018).

Over the past decade, more people with ID have accessed psychotherapeutic interventions and initial research suggests outcomes are positive and that psychotherapy should be considered a treatment for individuals with ID (Willner, 2005; Taylor, 2010; NICE, 2016). NICE guidelines (2016) highlight the potential need to adapt approaches based on individual needs and consider additional support. A report by Beail (2017) further supports this and aims to provide professionals with information to support them with this. It also highlights despite the increase of research in the last decade, it is still not enough. Other Sarah Parker is based at the University of the West of England, Bristol, UK. Tony Ward is based at the Department of Health and Social Sciences. University of the West of England, Bristol, UK. Amelia Baldwin is based at the University of the West of England, Bristol, UK.

Received 23 September 2022 Revised 6 March 2023 Accepted 14 March 2023

A thank you to the support recieved from my supervisors, Tony Ward and Amelia Baldwin. Also, the psychology team within the ID team. especially Dr Samantha Green. reviews have also supported the usefulness of psychotherapeutic interventions but call for more robust research (Fletcher *et al.*, 2011; Vereenooghe and Langdon, 2013). Individuals with ID have also reported finding psychotherapy beneficial, despite finding it challenging. Lewis *et al.* (2016) found access to therapy, developing skills, enjoying therapy, positive changes and the therapeutic relationship were all themes arising from interviews found to be important to participants with ID. Regarding the therapeutic relationship collaborative working and positive feelings towards the psychologist were highlighted.

#### The therapeutic relationship

The term "therapeutic relationship" is used widely and can be understood in different ways. The concept of the alliance is often used in the literature to discuss issues that relate to the therapeutic relationship. Greenson (1965) suggested two alliances: the "therapeutic alliance" is the bond between the client and the therapist and the "working alliance" is engagement with therapy tasks. Bordin (1979) further conceptualised the "working alliance" to include agreement of goals, assignment of tasks and development of bond. These determine the quality of the alliance between therapist and client. The working alliance is now commonly defined as "as the emotional bond established in the therapeutic dyad, and the agreement between patient and therapist concerning therapy goals and the tasks necessary to achieve them" (Elvins and Green, 2008). It is one of the most robust factors thought to contribute to psychotherapy outcome across contexts (Cameron, 2020).

Intersubjectivity is the mutual influence the therapist's and client's subjectivities have on the therapeutic relationship (Capri, 2014). Within therapy an intersubjective space may be created, this involves the integration of the client and therapist's subjectivities (Fosshage, 2011). This integration creates a relationship space, unique to the therapeutic dyad. It is thought the exploration and testing clients do within this space, leads to therapeutic growth (Swartz, 2006). Intersubjectivity is defined differently depending on the theory, but they all agree that experiences of the world are shaped by subjectivity and that mutual influence and adaption affect the therapeutic relationship. They also recognise influences of transference and countertransference and a focus on the client's rather than the analyst's subjectivity (Swartz, 2006).

An important part of this intersubjective space is that the subjective stance of the therapist is empathic, as how the client interprets things might be shaped by the therapist, and this in turn, may determine how much the client feels understood (Fosshage, 2011). This requires the therapist to be aware of the content and process within therapy and consider what the client brings compared to what they gain.

#### Therapeutic relationship for clients with learning disabilities

There is a limited understanding of the therapeutic relationship between individuals with ID and therapists (Jones and Donati, 2009). Some qualitative studies have tried to gain more insight about this (Wills, 2018; Lewis *et al.*, 2016). Evans and Randle-Phillips (2020) found positive feelings towards the therapist, feeling listened to and valued and feeling it was collaborative were important. "Being heard" has also been identified as being significant, as individuals with an ID often felt like their views were not heard (Mattock *et al.*, 2020). Cameron *et al.* (2020) found that individuals with ID responses to semi-structured interviews validated the alliance dimensions of Bordin's model. Therefore, initial research would suggest, the therapeutic relationship appears to be important to individuals with ID.

The therapeutic relationship may also be the first experience of an individual with ID experiencing a collaborative and equal relationship. Coming to terms with raising an infant with an ID can be an overwhelming experience for parents, who often lack adequate support. This may create a sense of fear, and a potential experience of loss of the child they were expecting to have. This could lead to a disconnect with their child with ID, resulting in different

styles of interaction, such as reduced eye contact (Hamadi and Fletcher, 2019). Decreased parental engagement may also be precipitated by trying to meet the increased demands of raising a child with ID (Giltaij et al., 2015). This disruption in caregiving can be associated with distant, inconsistent or neglectful parenting styles (Mullen, 2018) and it may contribute to the higher rates of disorganised and atypical attachment styles associated with individuals with ID (Schuengel et al., 2013). Social connectedness and warm, intimate relationships with a primary caregiver are known to be important, but these may be missing from early interactions for some individuals with ID (Mullen, 2018). This may be why therapy has been considered an opportunity to offer individuals with ID a different relational experience from which there can be therapeutic growth (Atkinson et al., 1999; Frankish, 2013).

Questions have also been raised about how an ID may impact therapy. By being disabled, a sense of "otherness" may be created with the therapeutic space. Swartz (2012) described this "othering" as emphasizing difference between the self and another, in a discriminative way. It can be problematic and may have negative consequences for the therapeutic relationship. Just as having a disability is seen as a difference, so is being without one. Acknowledging this difference invoked by "otherness" can lead to enriching therapeutic encounters (Capri, 2014). Working intersubjectively contributes to this, as the therapist becomes "open to another conceptual world [...] able to receive new knowledge, new experiences and integrate them with our own, resulting [in] a vastly richer understanding" of living with intellectual impairment (Swartz, 2012). The therapeutic dyad co-create new subjective truths that can be tested outside the therapy room. The therapeutic space supports the individual with ID to potentially reconstruct their past and shift from a linear way of thinking, disabled to abled, to thinking with more possibility and depth (Capri, 2014). To create this space, the client and therapist need to understand each other's experiences and learn from them (Chand, 2017).

#### Aims

The aim of the current research is to explore the research question; how do individuals with ID experience the therapeutic relationship?

#### Methodology

#### Research design

Qualitative methods meet the aims of the current project. They seek depth of understanding from small, homogeneous group of people who are engaged with the research question. Semi-structured qualitative interviews were completed with each participant and analysed using interpretative phenomenological analysis (IPA). This methodology was selected because of its theoretical underpinnings that ensure a focus on the lived experience, a commitment to the particular and it best meets the aim of gaining an "insider's perspective".

#### **Participants**

A purposive sampling method was used. Inclusion criteria included; having mild to moderate ID, over the age of 18, considered by the therapist to have reasonable expression and comprehension skills to consider the therapeutic relationship, having 1:1 individual therapy with a psychologist or counsellor.

Six participants were recruited to the study. They had all been having sessions for between six months and a year and the main approach used was cognitive behavioural therapy (CBT). The researcher did not have access to previous records of therapy, but it was apparent from analysis at least one participant had had therapy before. They were all interviewed once giving a total of six transcripts for analysis. Participants were aged between 23 and 46 years (M = 35, SD = 8.5).

#### **Ethics**

Following a favourable opinion for the NHS Research Ethics Committee and approval from the Heath Research Authority the study commenced.

Careful consideration was given to ascertaining informed consent from participants. It is assumed that adults with ID have the capacity to make decisions, whether wise or unwise, and this includes the ability to consent to research and in cases where this may not be the case it must be assessed on an individual basis (Mental Capacity Act, 2005).

A consent procedure based on Wills (2018) was followed as similar samples and methods were used. All participants went through a two-stage test of capacity (Mental Capacity Act, 2005). This assesses whether the individual understands information, retains and weighs up information for long enough to decide and is able to communicate their decision. This involved the following: therapists gave information to their clients about the study and asked their clients whether they would be happy for a researcher to contact them about participation in a study. The therapists also had an adapted participant information sheet that they shared with the clients and explained the researcher would also go through it. If clients were happy to continue, they completed a "consent to contact" form. The therapist read through the form with the client to ensure they understood what they were initially consenting to. The therapist then passed on contact details to the researcher who arranged a meeting with the client to provide further information about the study. The participant information sheet was read through with the client and they were asked whether they understood what the study was about and whether they had any questions. If the client agreed to participate, they completed a participant consent form.

#### Procedure

Participants were either interviewed in their home or online via Microsoft Teams using a secure NHS account. All interviews were audio recorded. Consent was gained for the recording at the beginning of the interview. Participants were reminded of their right to withdraw throughout the study. An interview schedule acted as a guide to the researcher, but the researcher was led by the participant's answers. Interviews lasted up to 30 min and visual aids were available. Two of the participants opted to have a family member with them during the interview.

The audio recordings were transcribed, and IPA was used to analyse the data. This was achieved in the current research by following Smith *et al.*'s (2021) approach. Each transcript was analysed independently. Initial notes were made and these then contributed to experiential statements that captured the essence of different parts of text. Connected experiential statements were grouped into a table. These became the personal experiential themes (PETs). Any PETs thought not to fit in with the resulting structure were discounted. A final table of PETs was produced by selecting the most relevant based on the richness of the certain passages to support themes and how themes help highlight other aspects of the account.

#### Results

Six PETs and 21 experiential statements were identified from analysis. All names have been changed.

#### Personal experiential theme 1: a person-centred experience

The first theme encapsulates the experience the clients had within psychotherapy with their therapist.

Experiential statement 1a: unconditional positive regard. Participants experienced a non-judgemental nature of their therapists and felt like therapists wanted to listen and help. One participant reported "[...] Like other people, they don't like burdens. They say oh, you're weird. Nah, don't want anything to do with you, why shoulD I help you" (Josh, 1.92)

Experiential statement 1b: empathy. An important feature for all was a sense of being understood without judgement, despite many finding it hard to articulate why in particular. Josie was considered in answering that they found their therapist understanding and that they recognised eye contact to be an important part of this. "Urr. Long pause. I think she is understanding, and I think she keeps eye contact as well" (Josie, 1.11). Shortly after saying this, Josie articulated a connection with the therapist despite finding it hard to explain why. "I don't know why but I just feel like I connect with her" (Josie, 1.16)

Experiential statement 1c: trust underlying congruence. Trust was important for clients. For example, for Josh there was a clear sense of trust with the therapist and that it was unique to the therapeutic relationship. "Sometimes, I ur, the only person I can trust is her, she keeps mine and her conversation private" (Josh, 1.17). This was also recognised by Sandy "Cause if I tell her anything she keeps it to her and me" (Sandy, 1.13)

#### Personal experiential theme 2: the importance of adaptions

This theme reflects how barriers within therapy were overcome by adaptions by the therapist.

Experiential statement 2a: therapist is prepared to flex the frame. This subtheme encapsulates how some therapists were willing to go beyond the standard four walls of a therapy room or adhere strictly to any method. One participant described therapy not being refined to a room "Urm, once she came here but we went to the park" (Josie, 2.02). Josh benefited from the flexibility of the therapist "Well, she tries trying different methods with me" (Josh, 1.94).

Experiential statement 2b: disregarding professional titles. Participants were not familiar with the term "psychologist" suggesting their therapists avoided using their professional titles and this avoided creating misunderstandings. For example, "Well I get confused with that word. I know, it's a long word, but its hard for me to remember that" (Josie, 1.91).

Experiential statement 2c: abstract concepts are difficult but aware of good relationship. Alongside the titles used, it was apparent consideration was given to the language used because many of the clients had difficulty with more abstract concepts. This was apparent through their interview responses often finding articulating in more depth difficult. Alex's inability to use abstract terms results in him being self-deprecating. "Flipping hell, laughs, urrr, can't think right now. My head it's not very good" (Alex, 1.53). Josh also found it difficult to think of the words, "Urm. Bloody hell, anything else. \*laughs\* urm, a lot of nice things, a lot, can't think anything nice about her, but there's a lot of words" (Josh, 1.44).

Experiential statement 2d: combating comprehension difficulties with concrete tools. This subtheme encapsulates the importance of using more concrete tools with the clients, such as worksheets or pictures, "TCP1.38: Yea? How does she show that she understands you? Sandy1.38: Cause, she does like pieces of paper about how I am feeling".

#### Personal experiential theme 3: "I feel like I know you"

There was a sense from the clients of a familiarity towards their psychologist and this contributed to the ease with which they were able to speak with them.

Experiential statement 3a: sense of familiarity. For most of the participants familiarity was an important part of being able to connect with their psychologist. "Josie1.2: Mmm well rather lovely actually, she reminds me of someone. TCP1.3: She reminds you of someone?

Josie1.3: Ya. TCP1.4: who does she remind you of? Josie1.4: She reminds me of a member of staff that I used to have".

Experiential statement 3b: being able to talk openly. Familiarity contributed to the clients being able to speak openly. Alex described being able to talk about anything he wanted to in therapy, "I talk about me. I talk about horses and I talk about things to do at home" (Alex, 1.90). Alex was not able to do this with everyone, "Just [Therapist], but I do sometimes speak to him, Ed, he doesn't want to listen anyway (Alex, 1.96).

#### Personal experiential theme 4: a secure base is offered

There was a sense that therapy offered a safe place to the individuals to explore their needs.

Experiential statement 4a: therapist is responsive to a client's needs. Clients acknowledged when their therapist was responsive to their needs and did something for them. For some this was a physical act, for example, Josh spoke about how his therapist helped with things around the house: "So urm, just recently, she said any stuff here \*gestures around room\* she will help out and that and obviously she knows my social worker, she helps with that as well" (Josh, 1.9). This was clearly something that set the therapist apart from other's they had met because they shared it had not been the same with all therapists: "Well she does stuff and she actually makes it happen, so if she says she's going to do something she actually does it compared to the rest of the therapist I've met" (Josh, 1.8).

Experiential statement 4b: therapist offers warmth and boundaries. Another aspect to the "role" taken on by the therapist was the perceived level of friendship. For Josie, the friendship was one sided, "She might not think that, I think so for me" (Josie, 1.56). Alex also recognised their therapist was not a friend, but also acknowledged the help they received was not dependent on this and did not seem to mind. "She's not a friend but she likes to help me anyway" (Alex, 2.41).

Experiential statement 4c: knowledge offers reassurance. For some of the clients, it also felt important that their therapist felt skilled, and this helped the clients feel reassured by them. "Basically everything, everything around her job. Training wise, she is better than the rest of them" (Josh, 1.34).

Experiential statement 4d: safety and predictability. Clients felt problems could be held by their therapist. Alex was motivated to open up as it got the problems out of their head. TCP1.33: "Yea and what is it about [Therapist] that makes it easy to talk to her?" Alex1.33: "Get things out of my head".

#### Personal experiential theme 5: change does occur

Among the participants there was a clear sense that having counselling sessions did result in change.

Experiential statement 5a: talking to therapist results in change. All clients recognised a positive change because of speaking to their therapist, "Bloody ell, a lot of stuff. We haven't been seeing each other that long but, we've made some progress" (Josh, 1.13).

Experiential statement 5b: therapy is support with mental health. Many of the participants spoke about recognising a change with specific mental health difficulties they had been experiencing "Josie1.62: Muttering [...] I wasn't depressed because of meeting [Therapist], I was depressed because of other things. TCP1.63: Ok, so you were depressed about other things and then you met Sam. So how do you feel now? Josie1.63: Urrr, well I feel alright actually".

Experiential statement 5c: regularity is important to maintain change. Regular sessions were important for clients. Josh reflected: "[...] Cause she was ill for a while and I do ask for her, cause I urm, I need to talk to her really bad sometimes. [Laughter]" (Josh, 1.16).

#### Personal experiential theme 6: an overlap of subjective experience

For all the clients, experiences outside of the therapeutic relationship affected the way they acted within the relationship.

Experiential statement 6a: ability to form attachments. It was apparent from the interviews that clients were able to form relationships with others. Josie reflected, "Urm. Long pause. Yes I do. Urm. MY friends are mostly dotted around the country" (Josie, 1.69).

Experiential statement 6b: third dimension to the therapeutic relationship. Most of the participants also spoke about other professionals involved in their support. For some these were unwanted. Josie found it difficult to answer some questions during the interview because of the support worker being in the next room, "Whispers quietly – I'm just a bit wary about [supporter worker], I don't want her to listen" (Josie, 1.52).

Experiential statement 6c: positive intersubjectivity, despite previous negativity. Most of the clients were accustomed to being let down by others close to them in both professional and personal contexts. Josh reflected "Pfftt, which one now? One bloke I met, he, he I was seeing him for ages and then he just disappeared" (Josh, 1.5).

Experiential statement 6d: building new meanings from difficult experiences. Therapy was used by clients as a space to build new meanings from difficult experiences. A common feature of all the client interviews were them recalling negative experiences that they had shared with their therapist. For example, "Urrrr, feel in the past I've done something silly" (Alex, 1.16) and Josh's previous experience led him to find it hard to build trust, "No, that's yeah, that's the part of me and then I never got rid of" (Josh, 2.18). Josh's negative experience related to a previous therapeutic relationship, which he was using his more positive present therapeutic relationship to move away from.

Experiential statement 6e: rethinking the "bad". There was a sense that anything "bad" should not be spoken about outside of therapy, despite being able to speak about it in therapy. For example, Alex reflected "I'm not sure whether I'm allowed to tell you or not, not sure" (Alex, 1.17) when recalling something he had spoken about in therapy.

#### Discussion

The results of this research suggest that individuals with ID can reflect on their experiences of the therapeutic relationship and that it is important to them to feel like they have a positive bond with their therapist.

It may appear that there are overlaps in terms of the PETs in the analysis. However, the notion of therapeutic relationship is broad and the concepts it encompasses are not discrete. For example, the notion of attachment is linked to the issue of secure base (PET 4), but it was felt important to keep these separate because they are not completely overlapping. Based on responses that indicated individuals related to their therapist, the ability to form attachments, did feel to be an important part of overlapping subjectivities (PET 6).

The use of adaptions and therapists being flexible felt important to participants. It seemed, they felt it was an indication their therapist understood their needs and indicated a sense of collaboration. Adaptions appeared to help participants engage with therapy. It could be suggested that this strengthened the working alliance (Martin *et al.*, 2000; Elvins and Green, 2008) which contributed to the positive psychotherapy outcomes and changes participants also spoke about experiencing.

The current research suggests the experiences of people with ID in therapy seems consistent with the person-centred views of the relationship. Individuals with ID appeared to feel understood and validated by their therapists. This has been found to be important previously for individuals with ID but within the context of using CBT (Pert et al., 2013). No participants referred to the model of therapy, suggesting that the client's perception of interpersonal processes appear to be independent of modality. Empathy did appear to contribute to participant's feeling understood, as has previously been discussed with this population (Fosshage, 2011). Empathy is an important part of intersubjectivity (Buirski et al., 2020) and so it is possible individuals with ID do experience an overlap of subjectivities during therapy and this betters their therapeutic experience. This is supported in the current research as some participants speak about how the feeling of being understood is unique to their therapist rather than other relationships, supporting the speculation that therapy may be the first experience of an individual with ID experiencing a collaborative and equal relationship. It is this experience of being understood that may have aided a sense of connection for some of the participants.

All the participants appeared to have a positive relationship with their current therapist and there was no apparent sense of "otherness" (Swartz, 2012). There was a sense that it was important for the therapeutic relationship to be contained between the participant and therapist, and when there was a third dimension, for example, a support worker, this was considered a hindrance. It may be that a third presence interrupts the overlap of the client's and psychologist's subjectivities and limits the opportunity for therapeutic growth.

Participants seemed able to speak openly with their therapist about negative experiences. This included things they felt they had done wrong and being let down by others. No other research has identified how individuals with ID are able to use therapy to discuss previous negative experiences and build new meanings from them because of the therapeutic relationship. One potential explanation for the benefit participants found from this is that therapy offered them a different relational experience from which they experienced therapeutic growth (Atkinson et al., 1999; Frankish, 2013). Participants felt their therapist recognised and responded to their needs. A sense of safety within the therapeutic relationship may also have been experienced from the problem-solving nature of therapists. This could be likened to the role of an early caregiver who by caring for a baby, facilitates a secure attachment style. This is something some individuals with ID are deprived of Potharst et al. (2012), Giltaij et al. (2015), Hamadi and Fletcher (2019). Therefore, the current study suggests that therapy offers an opportunity to experience a warm and responsive relationship that they have not experienced before.

#### Implications for clinical practice

This study highlights the likely importance of a positive therapeutic relationship for clients with ID. Having a therapist who is empathic, warm and offers security, appears to result in positive therapeutic outcomes. This study also suggests adaptions during therapy are important and so therapists should be aware of how to prepare and provide these. The participants spoke about different adaptions and so therapists should be client-led when considering what may be beneficial in sessions. Some examples of potential adaptions are visual cue cards, story cards, worksheets printed in an easy read format, fidget toys and being flexible with where the session occurs.

It also seemed therapist's competence contributed to them being viewed as knowledgeable by the participants and this was important in building the therapeutic relationship. Therefore, it is important that professionals supporting individuals with ID are confident in meeting their needs or able to access training to help with this.

It is hoped that this study will encourage further researchers to ask individuals with ID directly about their experience, rather than using parents or carers as a sample.

#### Limitations of the study

There are some limitations to this study. Firstly, this discussion has reflected on the potential impact of early attachment experiences on individuals with ID, but participants were not assessed for their early attachment experiences. Therefore, it is important to state that all comments on attachment are speculative and in relation to the existing literature.

This study recruited participants from an adult learning disability service. The lead clinical psychologist determined which clients were asked to participate, therefore, it is not definite the sample is representative of the whole service. Because of the requirement of needing to be interviewed, there is a risk that the sample represents more confident individuals, and so may also find building relationships easier.

All the participants in the current study appeared to have a positive experience of the current therapy they were in. It is possible that participants did experience negative transference towards their therapist but felt unable to talk about this. Although, some participants did speak about negative feelings towards others, including previous therapists and the time it had taken to trust their current therapist. Considering this, it may have been interesting to contrast with more negative experiences of a therapeutic relationship.

This study used individuals with a mild to moderate ID. The researcher acknowledges the dearth of research involving individuals with a severe ID and feels with the right adaptations, such as use of communication aids, this group of individuals should be involved in more research.

#### Future research

Given that the literature regarding mental health support for individuals with ID, using individuals with ID as a sample is still limited, it is important for future research to use this group of people more. Only by doing this will professionals be able to adapt their practice and best meet the needs of what is currently an under-served group of people.

Attachment history in relation to therapy for individuals with ID remains an under-researched area. Gaining a better understanding of this and how it may affect individuals with ID may help therapists adapt their practice to best meet these needs. It would also be interesting to research ruptures within the therapeutic relationship for individuals with ID because this may further professionals understanding of what to avoid when working with this client group.

#### Conclusions

The therapeutic relationship appears to be important for individuals with ID. Based on the findings of the current study, individuals with ID experience the therapeutic relationship as a trusting, empathetic relationship with an individual who they believe can and will help them. The suggested uniqueness of this to the therapeutic dyad highlights the importance of individuals with ID having access to therapy. Being able to establish a trusting relationship with another individual who they feel understood by, may enable individuals with ID to process and move away from difficult experiences. It does not appear that individuals with ID are held back by their disability within the therapeutic space, but adaptions and an experienced therapist may strengthen the potential for positive change.

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#### Further reading

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#### Corresponding author

Sarah Parker can be contacted at: Saraheparker@hotmail.co.uk

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