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**Perceived Barriers and Facilitators to Positive
Therapeutic Change for People with Intellectual
Disabilities: Client, Carer, and Clinical Psychologist
Perspectives**

By

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Thesis Abstract

Over the past 15 years psychological therapy for people with Intellectual Disabilities (ID) has been increasingly advocated (e.g., Linington, 2002) and successful treatment outcomes of psychological therapies for this population have been highlighted in a number of studies (e.g., Beail, 1998). However, the processes underlying these successful treatments are uncertain and some authors argue that success could be attributed to person-centred counselling rather than the specific approach adopted (e.g., Beail, 1998). Current literature highlights a substantial gap and an increasing need for research that identifies conditions under which the effects of therapy are optimised for people with ID through the exploration of barriers and facilitators to positive therapeutic change.

This thesis explored the experiences of Clinical Psychologists (CPs), their clients with an ID and the client's carers, with regards to the perceived barriers and facilitators to positive therapeutic change. Furthermore, this research aimed to develop a cohesive understanding from the multiple perspectives of the topic area. A triadic case design was utilised in which two triads of the CP, clients with ID and carers were nested by one CP. Therefore one 'case' constituted one CP, two of their clients (with ID) and two carers. Three of these cases were recruited and therefore this study had 15 participants and as the CPs were interviewed twice (once regarding each client separately) 18 interviews were completed. Thematic analysis was deemed to be an appropriate methodology to address the gap in qualitative research with people with ID. This methodology allowed the exploration of participant's accounts whilst enabling the flexibility that is required to accommodate the varied abilities of people with ID. From the analysis of the transcripts of the 18 semi-structured interviews, five super-ordinate themes and one central theme were identified based on their frequency and salience from participants across all three participant groups.

The first super-ordinate theme, 'what the client brings' encapsulated a number of factors related to the client that participants perceive to be initial barriers within therapy, namely, the ID itself (e.g., communication skills, memory) and the client's

engagement in therapy. A second super-ordinate theme that the client also brings to therapy is their 'wider system'. This theme encompasses the facilitating role that a wider support network can play and also the barriers that the wider system can bring with regards to the negative influence of others on the client. A third super-ordinate theme related to 'therapy factors' that are generally perceived to be facilitators to overcome the barriers that clients bring to therapy. This included therapy adaptations and the therapeutic relationship. The fourth super-ordinate theme, namely 'the mental health GP' encompasses the concept that psychologists are required to coordinate the often extensive wider system of people with ID and this is because participants felt that in order to benefit from individual therapy, all of the client's needs must be met, including physical health needs and ensuring that the client lives in an appropriate environment. Given the four super-ordinate themes noted above, all of these concepts foster the fifth super-ordinate theme 'systemic dependency'.

The mere presence of an ID means that naturally people are more dependent on others. As a result, therapy factors including the therapeutic relationship and adaptations to therapy (e.g., increased longevity of therapy) can foster strong attachments which can facilitate an unhelpful level of dependency. Additionally, the client's wider system can also become dependent on services to help them facilitate care and coordinate the numerous services involved. All of these super-ordinate themes maintain the concept of the 'revolving door' into services. Additional subthemes noted in the extended paper are examples of barriers and facilitators to therapeutic change that are considered to have an important impact on therapy but were only noted by one group of participants (e.g., clients) and thus did not contribute to cohesive understanding of multiple perspectives aimed for within the journal paper. For example, clients reported confidentiality to be a barrier and CPs reported attachment difficulties of clients to be a barrier.

The results of this study offer the first explorations of conditions under which therapy can be optimised for people with an ID through the awareness of barriers and facilitators to positive therapeutic outcomes. CPs are shown to be skilled at overcoming barriers within therapy; however there appeared to be a process of facilitators creating more barriers within therapy and the phenomenon of the

revolving door needs to be fully considered. Given the potential impact of funding constraints on the role of CPs and access to psychological therapies for people with ID, this has important implications for the way psychologists working within this population market themselves and further evidence their work.

Statement of Contribution

In completion of this project, the majority of the responsibility concerned with reviewing the relevant literature, project design, application for ethical approval, participant recruitment, data collection and transcription, data analysis and write up was held by the trainee clinical psychologist. Advice regarding project design, application for ethical approval, data analysis and write-up was provided by Dr Anna Tickle (Research Supervisor). Dr David Dawson (Research Supervisor) provided further advice on data collection, data analysis, presentation of results and the theoretical underpinnings of the study. Finally, Dr Samantha Harris (Field Supervisor) provided assistance with recruitment of participants as well as advice regarding adapting the participant information sheets, consent forms, and the interview schedules for people with intellectual disabilities.

An Investigation into the Occurrence of Acquiescence in Interviews with People with Intellectual Disabilities: A Systematic Literature Review

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Abstract

Background: People with Intellectual Disabilities are often excluded from research due to their apparent susceptibility to acquiescence and the subsequent perception that they are unable to provide good quality data.

Method: A literature search found 11 eligible peer-reviewed studies published from 1974 to 2000. The studies investigated acquiescence in adults with intellectual disabilities using both quantitative and qualitative methodologies.

Results: The review highlights inconsistent findings as to the relationship between IQ and acquiescence. The phenomenon appears to be mediated by a number of factors including: context, residential living environment, gender and interactions with the interviewer. However the findings are considered with caution due to poor methodological quality and small sample sizes.

Conclusions: The assumption that people with intellectual disabilities respond acquiescently in interviews is not supported by sufficient evidence to justify the exclusion of this population from research.

Keywords: intellectual disabilities, acquiescence, yea-saying, response bias, systematic review

Introduction

Involving people with intellectual disabilities in research is somewhat a recent development. However, recent years have seen a surge of interest in the promotion of inclusion for people within this population in research (Department of health [DoH], 2000, 2001, 2007). Although inclusion has improved, little research has been

completed with people with intellectual disabilities using qualitative techniques. One justification for researchers is that people with intellectual disabilities are likely to acquiesce, and therefore will not provide good quality data for research purposes (e.g. Dagnan & Ruddick, 1995; Flynn, 1986).

One of the most widely accepted definitions of acquiescence is the tendency to answer a question affirmatively regardless of its content (Cronbach, 1946). The most commonly cited literature regarding acquiescence in people with intellectual disabilities is the work by Sigelman and colleagues, which began with the observation that adults with intellectual disabilities tended to answer 'yes' to two questions that contradicted each other (e.g. Are you usually happy? Are you usually sad?). Sigelman et al. (1981a) reported that results showed that the "rate of acquiescence is staggering" (p.56). Further papers (Sigelman et al. 1980; Sigelman, Budd, Spanhel, & Schoenrock, 1981b; Budd, Sigelman, & Sigelman, 1981) arrive at the same conclusion that "because mentally retarded persons asked yes or no questions tend to acquiesce, their answers are likely to be invalid" (Sigelman et al., 1981a, p. 57). There is little doubt that these series of papers have been influential and have resulted in, or at least justified the belief among many researchers that interviewing people with intellectual disabilities is not worthwhile, because they are unable to provide a valid perspective (e.g. Allen 1989; Heal & Chadsey-Rusch, 1985).

There have been several explanations put forward as to why acquiescence might occur when interviewing people with intellectual disabilities. Firstly, Sigelman et al.'s (1980, 1981a, 1981b) body of work identified a correlation between the tendency to acquiesce and IQ, with people of lower IQ being more likely to respond to questions acquiescently. This is further supported by evidence that suggests that acquiescence is more likely to occur when answers are not known (Cronbach, 1942, 1950), when questions are ambiguous (Ray, 1983) and when the individual has spent less time or effort considering the question (Couch & Keniston, 1960; Knowles & Condon, 1999). Another explanation for acquiescence in this population is submissiveness or a greater desire to please (e.g. Perlman, Ericson, Esses & Isaacs, 1994). This response could be seen as a personality trait or a learned response that is adaptive

in a range of situations (Finlay & Lyons, 2002). This tendency is often assumed to be a reflection of people's experience of increased likelihood of failure and greater levels of control exerted on them by others deemed to be in authority (Finlay & Lyons, 2002). Although these explanations seem conceivable, they are usually provided without any evidence to support the claims.

Rationale. Despite the minimal literature regarding this phenomenon, and some research to the contrary, the belief that people with intellectual disabilities are unable to provide a valid perspective to research phenomenon due to the tendency to acquiesce appears to be a relatively entrenched in the minds of researchers. This belief has important implications and stigmatising consequences for people with intellectual disabilities and it is therefore important to consider the evidence and ascertain methods that can support people in this population to participate in research. Service users are arguably the true experts in what works well, what they need and what improvements need to be made and this is a resource that is rarely utilised within the intellectual disability field.

Aims. This review aims to synthesise findings from multiple studies to develop an understanding of the phenomenon of acquiescence in people with intellectual disabilities. The purpose of this review is to assess the extent to which people with intellectual disabilities acquiesce (if at all), if so under what circumstances and is the evidence sufficient to justify the exclusion of this population in qualitative research.

Method

Information sources and search criteria. An overview of the literature selection process is outlined in Figure 1. A systematic search was conducted in June 2013 using the following databases: Medline (1969-2013), EMBASE (1980-2013), PsychINFO (1806-2013) and CINAHL (1982-2013). These databases were selected as they cover large date spans, include a large number of journals and cover topics that are relevant to the review. The Wiley online library was also searched due to it containing over 1500 journals. Finally Google Scholar was searched to ensure that

no relevant papers were missed. The databases EMBASE, PsychINFO and MEDLINE were searched simultaneously using OVID SP, and the remaining three databases were searched individually. Across the databases, groups of terms were combined relating to two specific factors; terms related to intellectual disability (intellectual disability(ies), learning disability(ies), mental retardation and mental handicap); and terms related to acquiescence (acquiescence, suggestibility, acceptance tendency, acceptance bias, yea-saying, response bias and cloak of competence). Where subject headings were not available keyword searches were used. Terms were exploded and used singularly or in conjunction as appropriate for each database.

Inclusion and exclusion criteria. With consideration to the sparseness of the literature in this area, it was important that the searches gave an account of historical and emerging literature. Previously, the definition of intellectual disability incorporated people with an IQ of less than one standard deviation from the mean (IQ lower than 85). In 1971, the definition changed to people who have an IQ of less than two standard deviations below the mean (IQ of less than 70). Therefore searches were restricted to 1971 onwards as any literature prior to that date would include people who wouldn't now be considered to have an intellectual disability. Papers not written in the English language were not included due to the constraints of the study being unable to translate the papers. Additionally, only peer reviewed journals were included as a pragmatic minimum quality threshold. Whilst grey literature could have been a helpful resource as citations tend to be recent and original, they lack the assurance that fundamental quality criteria have been met. No restrictions were placed on research-design as it was felt that this would unnecessarily limit the results of the searches due to the narrow nature of the topic.

All titles were initially checked for relevance. Where there was not enough information in the title, abstracts were checked. Where the abstracts did not contain enough information, or were unavailable, full text versions were obtained. All citations were checked for relevance in this way and were considered eligible for inclusion if they: included adults (over age 18) with intellectual disabilities as participants and explored acquiescence. Additionally, articles were excluded if they recruited from a context in which they would not be consenting to the interview (e.g.

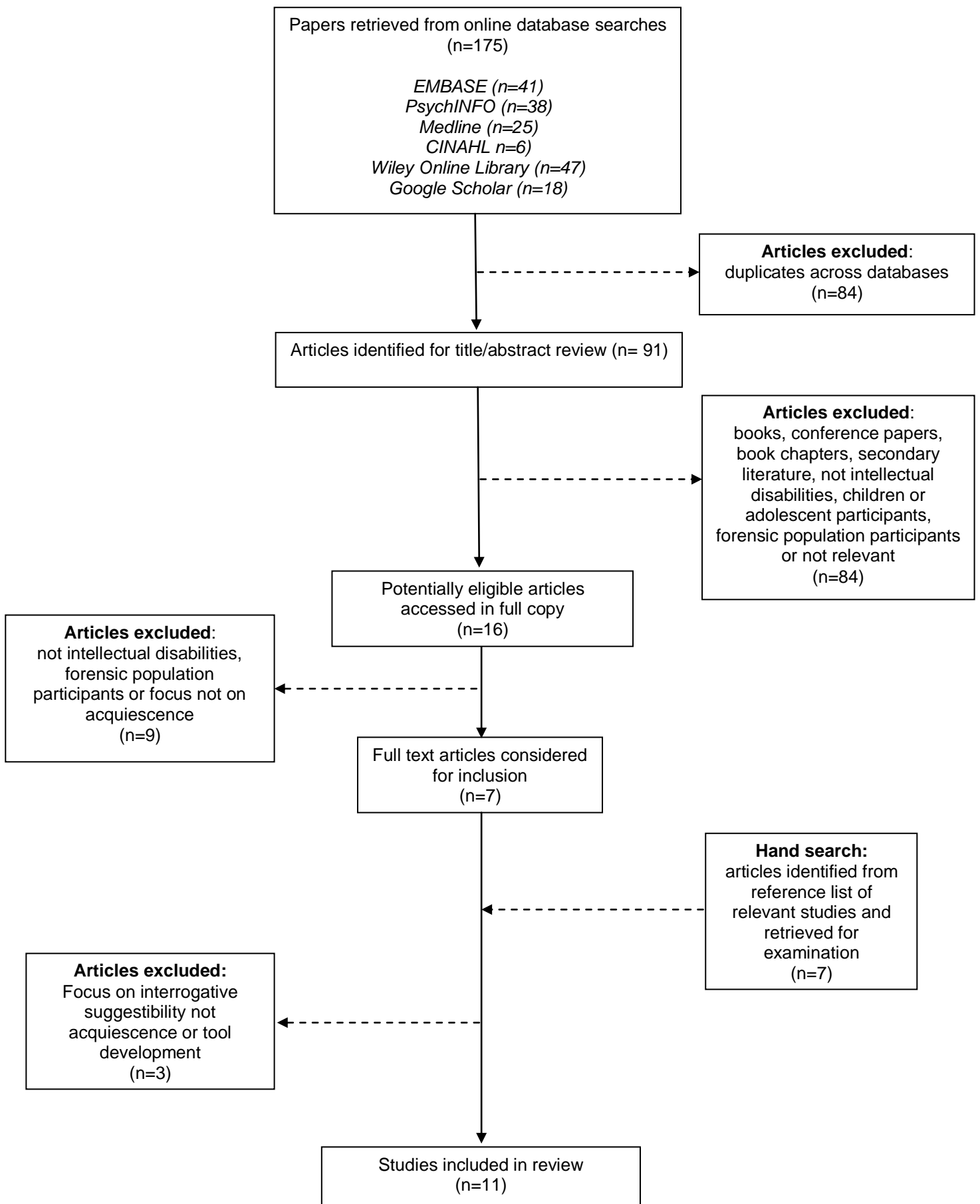


Figure 1. Flow chart identifying study selection process.

prisoners or suspects of crime) due to it being ethically problematic and may illicit alternative motivations to acquiesce. Finally, studies that specifically focused on acquiescence to increase validity and reliability of a specific tool were excluded as they were not considered to be relevant.

Study selection. In Table 1 the reviewed studies have been numbered 1-11 and for ease of reporting will be referred to by this number throughout the review. Initial database searches identified 175 articles that were potentially relevant for review. Due to separate searches within databases as well as across the different databases, there were 82 duplicates removed by scanning the titles of all search results. Through re-examination of the remaining 93 articles in more detail, 66 articles were excluded based on the titles, a further 13 articles were excluded based on abstract review and nine based on the full text version. A large majority of the articles (35%) were excluded based on titles due to them being completely irrelevant to the topic of acquiescence, for example 'Aerobic fitness, functional exercise capacity and muscle strength of adults with intellectual disability'. Seven studies were selected as relevant for review and four relevant studies were identified from manually reviewing the reference lists of the selected studies. Therefore 11 studies were included in the final review. It was clear that four articles reported findings from the same study (1, 2, 3 & 4). This was evident from the authors, sample groups and sample size being the same. All articles were included in the review due to the data being analysed in light of different aims and objectives and their many citations within the literature.

Data abstraction. The general characteristics including: location, study design and analysis used were abstracted. Additionally general characteristics of the sample were recorded including: population, sample size, level of intellectual disability of participants, age range of participants and gender of participants were recorded. Lastly, summary points and key findings were gathered for all selected studies. If data is not reported in table 1 (e.g. standard deviations) this is a reflection of it not being stated in the article. All abstracted data are tabulated in table 1.

Table 1:
General Characteristics and key findings of Selected Studies

Author(s), year and location	Methodology	Sample Characteristics	Summary points and key findings
1. Sigelman, et al. (1980) USA	Quantitative Item-reversal Analysis Inferential statistics	Population Institutionalised adults Total sample of adults (n=42) Level of Intellectual Disability Mild, moderate, severe; Mean IQ=39.76, (SD=13.12) Age Mean age=23.49 years (SD=4.42) Gender Not stated	<ul style="list-style-type: none"> • No relationship between IQ and ability to respond to questions. • Acquiescence occurred in 44.7% of respondents. • Higher IQ was associated with answering a higher number of questions appropriately*. • Higher IQ participants were significantly less likely to acquiesce*.
2. Sigelman, Budd, Spanhel & Schoenrock (1981a) USA	Quantitative Item-reversal Analysis Inferential statistics	Population Institutionalised adults Total sample of adults (n=42) Level of Intellectual Disability Mild, moderate, severe; Mean IQ=39.76 (SD=13.12) Age Mean age=23.49 years (SD=4.42) Gender Not stated	<ul style="list-style-type: none"> • Acquiescence occurred in 41.7% respondents. • For first question pair (Are you usually happy? Are you usually sad?), low IQ respondents were more likely to acquiesce than high IQ respondents*. • No significant correlation for the second question pair (Are you usually by yourself? Are you usually with other people?).
3. Sigelman, Budd, Spanhel & Schoenrock (1981b) USA	Quantitative Item-reversal Analysis Inferential statistics	Population Institutionalised adults Total sample of adults (n=42) Level of Intellectual Disability Mild (n=2); Moderate (n=20); Severe (n=20); Profound (n=16; excluded from analysis); Mean IQ = 39.76 (SD=13.12) Age Mean age=23.3 years (SD=4.1) Gender Female (n=29); Male (n=29)	<ul style="list-style-type: none"> • 46.9% of participants responded acquiescently. • Yes-no questions elicited more contradicting responses than the either-or questions**. • Respondents were more likely to respond acquiescently than in a nay-saying manner***. • No significant difference was found between the tendency to favour the first option over the second option. • On three out of four responses, people were likely to reliably respond to the same question when asked again.

Table 1 (continued)

4. Budd, Sigelman & Sigelman (1981) USA	Quantitative Item-reversal Analysis Inferential statistics	Population Institutionalised adults Total sample of adults (n=42) Level of Intellectual Disability Mild (IQ=55-69), moderate (IQ=40-54), severe (IQ=25-39); Mean IQ=39.8 (SD=13.1) Age Mean age=23.5 years (SD=4.4) Gender Not stated	<ul style="list-style-type: none"> • Acquiescent responses occurred 41.7% of the time in two question pairs and 50% to the third pair. • The least stigmatised behaviour (staying up late) was the only question pair to elicit more acquiescent responses (38.2%) than nay-saying responses (23.5%). • There was no relationship between contradicting responses (both nay-saying and acquiescence) and IQ.
5. Shaw & Budd (1983) UK	Quantitative Item-reversal Analysis Inferential statistics	Population Sheltered workshop Total sample (n=24) Level of Intellectual Disability Mild (IQ=52-77; n=8), Moderate (IQ=45-51; n=8), Severe (IQ=40-41; n=8); Mean IQ=49.3 (SD=13.2) Age Mean age=30.2 years (SD=8.2) Gender Female (n=9); Male (n=15)	<ul style="list-style-type: none"> • Lower IQ subjects were more likely than higher IQ respondents to contradict themselves*. • The questions regarding prohibited behaviours (e.g. is hitting people allowed? Is hitting people against the rules?) were more likely to elicit contradicting responses than behaviours rated to have high social desirability (e.g. smiling at people)**.
6. Gudjonsson (1990) UK	Quantitative Item reversal Analysis Inferential statistics	Population Referred for court reports Total sample (n=60) Level of Intellectual Disability Not stated Age Mean age=31 years (SD=12; Range =16-62) Gender Female (n=5); Male (n= 55)	<ul style="list-style-type: none"> • There was a relationship between acquiescence and IQ***. • There was a relationship between acquiescence and all individual subtest and indexes within the Wechsler Adult Intelligence Scale – Revised (WAIS-R; Wechsler, 1981)*** (digit span subtest**). • There was no relationship between acquiescence and either suggestibility or compliance.

Table 1 (continued)

7. Rosen, Floor & Zisfein (1974) USA	Quantitative Experiment Analysis Inferential statistics	Population Students living in residential home or attend day centre Total sample (n=50) Level of Intellectual Disability Mean IQ of residential group = 77.1 (SD = 10.5); Mean IQ of day group = 77.6 (SD = 8.8) Age Mean age of residential group = 28.1 years (SD=11); Mean age of day group = 23.2 (SD = 4.9) Gender Female (n=9); Male (n= 16)	<ul style="list-style-type: none"> • Significant differences between day group, residential group and mental age control group on yea-saying**, contradictions***, conformity in drawing replication*, taking a pill when instructed to*, pressing a button that they were told would give them an electric shock* and total score **. • Both adolescent mental age controls and day centre students were significantly less compliant than institutional residents*. • The mental age control group were significantly less acquiescent than both adult groups*. • Those with high IQ were less likely to acquiesce*.
8. Clare & Gudjonsson (1993) UK	Quantitative GSS 2 Item reversal Analysis Inferential statistics	Population Day centres and supported residential living and staff in a mental health facility Total sample (n=40) Level of Intellectual Disability Mild (n=20; Mean IQ = 65; SD=5.3; IQ range = 57-75); Average intelligence (n=20; Mean IQ = 99; SD=7.2; IQ range = 83-111) Age Mean age of Mild LD group = 27 years (SD=7.3; Range = 20-48); Mean age of average intelligence group = 30 years (SD=9.4; Range = 18-50) Gender Female (n=5); Male (n=15)	<ul style="list-style-type: none"> • People with mild intellectual disabilities were more suggestible than people with average intelligence as shown by: immediate recall***, delayed recall***; yield 1*** (number of leading questions given into before negative feedback), yield 2*** (number of leading questions given into after negative feedback), total suggestibility (yield 1 and shift added together)**; confabulation* and acquiescence**. • No significant difference between people with mild intellectual disabilities and people with average intelligence on tendency to shift (extent to which a person alters previous answers after been given negative feedback).

Table 1 (continued)

9. Gudjonsson, Murphy & Clarke (2000) UK	<p>Quantitative</p> <p>WAIS-R</p> <p>GSS 2</p> <p>Item reversal</p> <p>Analysis</p> <p>Inferential statistics</p>	<p>Population Residential homes</p> <p>Total sample (n=37)</p> <p>Level of Intellectual Disability</p> <p>Mean IQ=53.8; Range=45-82</p> <p>Age Mean age=37 years (SD=12.6; Range=24-70)</p> <p>Gender Female (n=18); Male (n=31)</p>	<ul style="list-style-type: none"> • There was no relationship between acquiescence and IQ or suggestibility measures.
10. Rapely & Antaki (1996) UK	<p>Qualitative</p> <p>Semi-structured interview</p> <p>Analysis</p> <p>Conversation analysis</p>	<p>Population Former residents of a long stay institution</p> <p>Total sample (n=8)</p> <p>Level of Intellectual Disability Mild and Moderate</p> <p>Age Not stated</p> <p>Gender Not stated</p>	<ul style="list-style-type: none"> • The participants reported that they perceived the interview as a test that had potentially serious consequences for them. • The participants reformulated their responses because the interviewer repeated the questions (relevance of the first answer not comprehended by interviewer). • The interviewer was 'shepherding' to a 'correct answer' (the researcher's guessed at what their informant believes) • The interviewer was 'shepherding' to a 'competent answer' (interviewer fails to comprehend the relevance of answer and has the power to deem it as 'irrelevant', 'unintelligible' or 'inadequate'). • The interviewee is echoing or back-channelling responses (e.g. answering yes to options to indicate that they understood and the interviewer should continue to the next item). For the actual answer the participant used a rising intonation and repetition. • The interviewee's resisted pressure to change answers.

Table 1 (continued)

11. Matikka & Vesala (1997) Finland	Quantitative Item-reversal Analysis Inferential statistics	Population Nationwide survey of mentally retarded persons living: with parents (n=255); independently (n=107); in group home (n=288); in institutions (n=107); with foster family (n=41). Remaining 24 not stated. Total sample (n=616) Level of Intellectual Disability Borderline-average IQ (n=37); Mild (n=271); Moderate (n=240); Severe (n=37). Not stated (n=31) Age Mean age = 36.9 years (SD=10.9; Range = 18-69) Gender Female (n=302); Male (n=314)	<ul style="list-style-type: none">• Participants were more likely to answer 'yes' than 'no' to questions***.• There was a relationship between the two measures of acquiescence*** (total number of yes answers and number of contradictions on paired questions)• No relationship between acquiescence and all variables of intelligence.• People who lived in group homes were more likely to acquiesce than participants living in other types of residence***.• Females were more acquiescent than males to word pairs**.• There was an interaction between the direction of the difference in acquiescence between men and women which depended on the gender of the interviewer*.• Female participants were significantly more likely to acquiesce with a female interviewer***.• Acquiescent responses were more likely to occur when respondent and interviewee were the same gender***.
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Note. For quantitative studies the following significance indicators are used: *p<.05; **p<.01; ***p<.001. Where percentages are recorded, no statistical analysis was reported.

Methodological quality. It is imperative to assess the quality of the research that has been included in the review, particularly when the research for the topic is sparse, because there may be a history of over-reliance on certain studies to fully explain the phenomenon. When assessing the methodological quality of the published research, many standardised assessments are available. Many of these tools were developed for the purpose of assessing quality in randomised control trials (RCTs), and although these measures have attempted to standardise a valid tool for the review process, evidence questions the reliability of these assessments (Juni, Witschi, Bloch & Egger, 1999), particularly when applied to reviews that focus on non-RCT research. For the purpose of this review, the Newcastle-Ottawa Scale (NOS; Wells et al., 2009) was adapted to assess the quality of quantitative studies (see table 2) as recommended by the Centre for Reviews and Dissemination (Tacconelli, 2010). In order to assess the quality of the qualitative research, the Critical Appraisal Skills Programme (CASP) tool was utilised as advocated by the National Health Service and adapted to ensure its relevance to this review (see table 3). These criteria are coherent with other tools that assess quality of qualitative research.

Results

Methodological Characteristics and Quality.

Quantitative studies (Table 2). The quality of the studies was generally varied; in half of the studies the participant demographics were reported adequately (3, 5, 8, 9 & 11), whereas several others failed to report basic characteristics such as age range, gender or level of intellectual disability (1, 2, 4, 6 & 7) which may have implications of the generalisability of the findings. Only two studies (4 & 5) reported how level of intellectual disability was defined (e.g. mild intellectual disability is someone with an IQ of 55-69), but the justification for these cut off points was not clear. For those studies that didn't report how many people had mild, moderate, severe and profound intellectual disabilities (1, 2, 4, 6, 7 & 9) it was difficult to ascertain if the sample was a fair representation of the population.

Table 2:
Methodological Characteristics and quality of quantitative studies

Study	Participant demographics	Sample representativeness (n)	Adequate conceptualisation of Intellectual Disability	Adequate conceptualisation of acquiescence	Inclusion and exclusion criteria	Standardised measures	Statistical analysis	Other sources of potential bias
1.	Moderate	No (n=42)	No	Yes	No	No	Moderate	<ul style="list-style-type: none"> • Consent gained via telephone. • Diverse intelligence tests from client files. • Institutionalised adults only.
2.	Moderate	No (n=42)	No	Yes	No	No	Yes	<ul style="list-style-type: none"> • Institutionalised adults only. • Some questions that could be confusing.
3.	Yes	No (n=42)	No	No	No	No	Yes	<ul style="list-style-type: none"> • Research emphasis shifted during project. • Small and variable sample • Institutionalised adults only.
4.	Moderate	No (n=42)	No	Yes	No	No	No	<ul style="list-style-type: none"> • Institutionalised adults only. • Missing results. Only significant results reported.
5.	Yes	No (n=24)	Yes	Yes	No	No	Yes	<ul style="list-style-type: none"> • Recruitment from one sheltered workshop. • Small sample size

Table 2 (continued)

6.	Moderate	Moderate (n=60)	No	No	No	Yes	Yes	<ul style="list-style-type: none"> • Participants referred by solicitor for court report.
7.	Moderate	Moderate (n=50)	No	No	No	No	Yes	<ul style="list-style-type: none"> • Students only • Lack of normative data
8.	Yes	Moderate (n=40)	Yes	Yes	No	Yes	Yes	<ul style="list-style-type: none"> • Community sample only • Some participants had IQ of above 70.
9.	Yes	Moderate (n=49)	No	No	No	No	Yes	<ul style="list-style-type: none"> • Recruitment from two private residential homes. • Stress of their home being under police investigation.
11.	Yes	Yes (n=616)	No	Yes	No	No	Yes	<ul style="list-style-type: none"> • 21% participants excluded

Note. (1) Participant demographics: yes, participant demographics are reported clearly; moderate, participant demographics are reported partially; no, participant demographics are not reported adequately. (2) Sample representativeness: yes, sample represents a range of appropriate levels of intellectual disability of different genders, varied age range and recruited from varied settings; moderate, sample represents a limited range of levels of intellectual disability, such as only mild intellectual disabilities; no, sample has poor representation, such as only institutionalised participants. (3) Adequate conceptualisation of Intellectual Disability: yes, a recognised definition of intellectual disability reported and criteria for level of intellectual disability was recorded; moderate, definition of intellectual disability and level of intellectual disability assessed by IQ only; poor, no definition of intellectual disability reported. (4) Adequate conceptualisation of acquiescence: yes, recognised definition reported; no, no definition reported. (5) Inclusion and exclusion criteria: yes, inclusion and exclusion criteria are reported clearly; moderate, inclusion and exclusion criteria are reported partially or indirectly; no, inclusion and exclusion criteria are not reported. (6) Standardised measure: yes, appropriate and standardised measures were utilised; moderate, appropriate but adapted measures were utilised; no, no standardised measures are utilised. (7) Statistical analysis: yes, appropriate statistical analysis reported for all measures; moderate, some statistical analysis reported for some measures; no, no statistical analysis, only percentages reported.

Sample sizes of participants included in the analysis ranged from 24 to 616, with 957 participants in total across all studies. Seven of the ten studies recruited participants from one particular setting; four focused on participants who lived in institutions (1, 2, 3 & 4); one from a sheltered workshop (5); one only recruited students (7) and one from residential homes only (9). Not only might this impact on the generalisability of findings, it may be that different settings may prime acquiescent responses more readily. Only one study (11) had reported enough information to determine that they had adequate sample representativeness.

A mere two studies operationally defined intellectual disability (5 & 8). Additionally, no study reported any inclusion or exclusion criteria, either directly or indirectly. It is therefore unclear as to whether the participants included in the study were recruited based on their IQ, whether they had a deficit in social adaptive functioning or whether they relied on self or carer reports that an intellectual disability was present. Six of the ten studies (1, 2, 4, 5, 8 & 11) reported an operational definition of acquiescence. This is important because some literature uses a broader definition of acquiescence to include other types of response bias, not just yea-saying. All studies adequately described the measures used, although only two (6 & 8) used standardised measures (e.g. Gudjonsson suggestibility scale, Gudjonsson, 1987; Weschler Adult Intelligence Scale, Weschler, 1983). Furthermore, whilst most studies used appropriate statistical measures to analyse the data, one study only reported the results that were statistically significant and that were in-line with their hypothesis (1) and one study only reported percentages and completed no statistical analysis (4). Therefore the possibility that type I and type II errors occurred cannot be ruled out.

Other sources of potential methodological bias were also considered; the discussion section of one paper (3) noted that the 'research emphasis shifted during the study'. No further details of how the emphasis changed or why were noted. Ethical issues were barely discussed in any of the articles. Considering that these studies measured the tendency for individuals to say "yes" despite the content of the question, no study commented on the impact of this on their informed consent procedure. Furthermore, one study (9) interviewed participants whose residential

homes were being investigated for malpractice, and it can't be ruled out that stress has an impact on the tendency to acquiesce.

Qualitative studies (Table 3). Only one study used a qualitative methodology (10), but it was decided that this appeared to be a reflection of researcher's attitudes towards interviewing people with intellectual disabilities and it would still be important to incorporate this study into the review. The methodological quality of this study is moderate but there was an overall absence of methodological description. The study did not demonstrate that they had considered their own subjective biases and how this might impact on the data. The findings are extensively discussed but the credibility of the findings, methodological limitations and the evidence for and against the findings are not adequately reported. The research appears to add value to an under researched area and they offer suggestions as to the other ways that the findings can be used.

Key findings.

Relationship between IQ and acquiescence. The majority of the selected studies focused on the effect of IQ on the tendency to acquiesce. Although some studies reported a significant relationship between IQ and acquiescence (1, 2, 5, 6, 7 & 8), this finding was not consistent across all studies; and two studies appear to be based on the same sample (1 & 2). In fact within one study (2), high IQ participants were significantly less likely to acquiesce on one question pair, but not in the second question pair. This suggests that the content of the question may play a part in acquiescence.

The role of social desirability in acquiescence. Two studies (4 & 5) found that prohibited behaviours (e.g. hitting someone) were more likely to elicit a nay-saying response (contradicting by answering

Table 3:
Methodological Characteristics and quality of qualitative studies

Quality Question	10. Rapely & Antaki (1996)	
Was there a clear statement of the aims of the research?	Moderate	Aims are reported in discussion section.
Is a qualitative methodology appropriate?	Yes	They seek to interpret the actions of research participants.
Was the research design appropriate to address the aims of the research?	Yes	The research design was reported and justified appropriately.
Was the recruitment strategy appropriate to the aims of the research?	No	Selection of participants is unclear.
Were the data collected in a way that addressed the research issue?	Yes	How data was collected is clear, the method is reported and justified (tape-recorded).
Has the relationship between researcher and participants been adequately considered?	No	The researcher's own role, potential bias and influence on aspects of the study procedure were not acknowledged.
Have ethical issues been taken into consideration?	No	Only one ethical issue reported (consent).
Was the data analysis sufficiently rigorous?	Moderate	Some description of the analysis process was reported. Sufficient data are presented to support the findings but contradictory data not taken into account.
Is there a clear statement of findings?	Moderate	The findings are discussed in relation to the research question. No discussion of the credibility of findings nor is there adequate discussion of the evidence for and against the arguments.
How valuable is the research?	Moderate	Contribution to existing knowledge and other ways that the findings can be used is discussed. No identified areas for future research.

“no” to both questions) than socially desirable behaviour (e.g. smiling at someone). Conversely, socially desirable behaviour was more likely to elicit an acquiescent response. Studies that found that acquiescence was more likely to occur than nay-saying (3 & 11) did not use questions that contained socially undesirable behaviour. Therefore findings suggest that participants are likely to contradict themselves, and social desirability determines the direction of the contradiction.

The impact of question structure on acquiescence. One study reported that the structure of the question impacts on the tendency to acquiesce (3). It appears that yes-no questions elicit more contradicting responses than either-or questions. This therefore suggests that although more difficult to answer, either-or questions may yield more valid responses. Additionally, either-or questions were more likely to encourage reliable and consistent answers.

The impact of context on acquiescence. One study (7) found that mental age equivalent children were significantly less acquiescent than the residential group and the day centre group of adults who had intellectual disabilities; therefore suggesting that the effect is not necessarily related to IQ and may be primed by specific settings and experiences. Additionally the mental age control group and the day centre group were significantly less compliant than the residential group. To further support this another study (11) found that people who lived in residential group homes were more likely to respond acquiescently than people living in any other type of residence. The qualitative study (10) found that participants perceived the interview to be a test, which could have potentially serious consequences for them. This suggests that the context has an impact on their tendency to respond in such ways.

The impact of gender on acquiescence. One study (11) reported gender differences in acquiescent responses, with more women responding this way than men. However, the direction of the difference between men and women was dependent on the gender of the interviewer. Acquiescent responses were more frequent when the interviewer and interviewee were of the same gender. No other study within this review analysed the impact of gender on responses.

Alternative explanations for acquiescence. One study (10) used conversation analysis to investigate whether the interactions between the interviewer and the respondents who had learning disabilities encouraged acquiescence to occur. It was claimed that due to the interaction between the interviewer and the interviewee, and the overall context of the situation, the interviewers had a tendency to reformulate the interviewee's responses. This was done in two ways: firstly, when the interviewer perceived the response to be incomplete they attempt to 'shepherd' the person to a perceived adequate and relevant answer; secondly, the interviewers pre-conceptions of the 'correct answer' led them down a line of questioning that drives the interviewee to the stereotypical response. Repeating questions was also used to encourage respondents to change their answer. In these circumstances the perceived contradicting statements may be a reflection on the interactions between the interviewer and respondent.

The same authors also found several instances where the person was answering "yes" to every question because they were merely indicating that they had comprehended the question and the interviewer should move on. For the actual answer the respondent used a rising intonation in their speech and utilised repetition to indicate this. Furthermore it was found (11) that respondents with intellectual disabilities demonstrated anti-acquiescence in which they resisted pressure to change their answers as encouraged by the strategies noted above. This was noted even though there was a perceived power imbalance and despite the perception that the interview was a test.

Discussion

This review explored the phenomenon of acquiescence in people with intellectual disabilities. Eleven papers were included in this review to assess the evidence base and the extent that it justifies the exclusion of people within this population from research. The fact that none of the selected articles were published within the last 13 years has a number of implications. Firstly, the phenomenon of acquiescence is not a new one, with research on the general population starting in the 1940's and a

surge of interest in intellectual disabilities in the 1980's. Secondly, this phenomenon is perceived by the research community to have been resolved. Finally, the questionable methodological quality of many of the identified studies is likely to be reflective of the quality standards of the time as the quality standard required for publication has dramatically improved in the last 20 years.

Overview of findings. The tendency for people with intellectual disabilities to respond acquiescently ranged from 25.2% (11) to 46.9% (3). Inconsistencies regarding the relationship between IQ and acquiescence across the literature could be a reflection on the differing sample characteristics, methodological design, methodological quality and the context of the research. Many of the studies that found a relationship between acquiescence and IQ recruited participants from institutions and residential settings (1, 2, 5, 7 & 8). Therefore these differences may be explained by the context of their living environment rather than IQ specifically. It is hypothesised that people in residential settings and institutions may be more likely to acquiesce due to an increased power imbalance between individuals and their carers, particularly if they were unable to choose their residence or are detained against their will. Considering Perlman et al.'s (1994) theory, it may be that certain residential settings encourage individuals to adapt to the environment by being more submissive than their peers, thus encouraging acquiescence. It may benefit people in residential settings to be submissive due to having complex needs that warrant more reliance on carers than people who live in supported living for example. This would be made clearer if future research incorporated measures of social adaptive functioning as well as IQ. Although significant findings may be a reflection of limited cognitive ability, they may alternatively be explained by a lack of motivation on the part of the respondent. Further research may highlight a correlation between people with lower IQ feeling less listened to and less empowered and therefore lack motivation to answer questions.

The findings also suggest that the content of the questions, particularly related to social desirability, impacts on acquiescence. Potentially people in institutions and residential settings may exhibit more challenging behaviour or witness more challenging behaviour than their peers in other residences, which may make them

more sensitive to socially undesirable behaviour and therefore lead to contradictions in their answers. Considering that one study identified that participants perceived the interview to be a test, this may explain why people in residential settings may acquiesce when asked about socially undesirable behaviour. However, there is currently no evidence to support such a hypothesis.

If future research continues to highlight a relationship between IQ and acquiescence, it should be further investigated to assess the aspects of IQ that impact on this response style as to find strategies to reduce this. If the effects are related to poor memory abilities, this may be improved by utilising visual material and repetition of questions. Alternatively, lower IQ may be related to the expectation that they get answers wrong and therefore change their answers more readily.

Without further investigation, it is difficult to hypothesise why there appears to be differences in gender combinations. No current theories regarding IQ, submissiveness, greater desire to please or complexity of questions sufficiently explain why these differences may occur.

Measuring acquiescence. The most common methodology utilised within the selected studies is item-reversal. This technique has been subject to several criticisms. Firstly, contradicting answers may be a result of difficulties with memory or attention or other cognitive abilities that are related to their intellectual disability and is not necessarily a reflection of motivated acquiescence (10). Secondly, reversing the content of some questions is a difficult task, and answering “yes” to both questions does not always represent a psychological inconsistency (Heath, 1986). For example, one study (11) used the question pair "Are you treated fairly/unfairly" (p. 77), yet people might be treated fairly by some people and not others, thus they did not contradict themselves.

Another method used (4) to indicate acquiescence was if a person said 'yes' to participating in an activity, but then failed to report participating in that activity in an answer to an open ended question. However, given the low levels of responsiveness of people with intellectual disabilities, this may not be valid evidence that the

responses were acquiescent. The measurement of acquiescence in people with intellectual disabilities is seen as a straightforward issue. However, as discussed, these methods have different problems when interpreting and can often be explained in different ways. It is therefore pertinent future research pay special attention to the methods used, and the specific questions asked. Due to findings that highlight pseudo-acquiescence in which the interviewers behaviour impacts on the perception that acquiescence occurred, this should also be robustly monitored in future research to maintain the validity of findings.

Limitations. There are a number of limitations within this review and the broader literature which could limit the conclusions that can be made.

Limitations of the review. Excluding papers published before 1971 seemed important due to the previously noted change in the definition of an intellectual disability. However, there may have been older research that could have added extra value to this review. Additionally, only peer reviewed literature was included in this review, therefore excluding any papers that were unpublished or published in non-peer reviewed means. Although this criteria was put in place to ensure a minimum quality threshold, with consideration to the limited evidence base, and the possibility of publication bias, it would have been beneficial to source 'grey literature' and it would be a recommendation that any future reviews incorporate such literature. The decision to included both qualitative and quantitative methodologies, even though only one qualitative article was eligible for inclusion made it difficult to synthesise findings as it compounded the heterogeneity within the reviewed studies. However, it was felt that by disregarding literature based on methodology alone may have led to this review overlooking key information.

Finally, the amount of studies that were considered to be eligible for this review was a small percentage of the total studies identified from the searches. This therefore questions the suitability of the search terms which may have identified studies that were irrelevant. For example the term 'suggestibility' is fundamentally different from the specific response bias of acquiescence. However, the literature shows that these response biases are not mutually exclusive. It was therefore crucial to identify

studies that investigated suggestibility to ensure that no relevant studies were missed.

Limitations of the studies in the review. Overall the methodological quality of the selected studies was poor. The lack of methodological clarity and transparency was apparent across all studies within this review, which limited the ability to synthesise findings into a coherent narrative. Therefore the generalisability of the findings is questionable. This is particularly the case when research only presented percentages and no statistical analysis; and when one article (4) only reported the significant findings. The consideration of ethical considerations within the selected studies is cause for concern, particularly when considering the nature of these articles. The suggestion that people with intellectual disabilities will say yes regardless of the question content, the issue of informed consent is particularly crucial for consideration when interviewing people within this population.

Four of the 11 papers appear to be based on the same sample of 42 participants. Considering that these four papers are widely cited as key evidence that this phenomenon occurs, this calls into question the generalisability of the findings from such a small sample to justify this phenomenon being a significant concern when interviewing people with intellectual disabilities. Additionally, due to the small sample size and numerous papers being based on the same sample, the possibility that a type 1 error occurred should be considered.

Future research. Future research should be more transparent and explicit in their methods and the impact that their findings on ethical issues (e.g. informed consent). The measures used in future research should be more robust to assess acquiescence and ensure that when using item reversal techniques, questions are appropriate and clear contradictions are used. More research is required to further explore the effect of living accommodation on tendency to acquiesce and the function this might have. Furthermore, gender differences and interactions between interviews of varying genders should be further assessed.

Conclusions. There is an assumption that the issue of acquiescence when interviewing people with intellectual disabilities has been resolved. The results of this review have found that a large proportion of the already limited evidence-base is presented as four separate papers, but are actually based on the same sample of 42 participants. Additionally the methodological quality of many of the studies in this review is generally poor. Therefore it cannot be assumed that all people with intellectual disabilities are likely to provide invalid responses to interview questions; rather this phenomenon is likely to be mediated by a number of factors including the interactions between the interviewer and respondent, gender differences, residential settings and IQ. Further, more rigorous research is required to understand this phenomenon so that people with intellectual disabilities can participate in research. Currently the evidence is not sufficient to justify the exclusion of this population from qualitative or quantitative research.

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Appendix A: Summary of Search Terms and Strategies Used]

Database	Terms
Ovid SP: MEDLINE PsychINFO EMBASE	<ol style="list-style-type: none"> 1. Intellectual Disability 2. Intellectual Disabilities 3. Intellectual Disability 4. Intellectual Disabilities 5. Mental Retardation 6. Mental Handicap 7. 1 or 2 or 3 or 4 or 5 or 6 8. Acquiescence 9. Suggestibility 10. Response Bias 11. Acceptance Tendency 12. Acceptance Bias 13. Yea-saying 14. Cloak of Competence 15. 8 or 9 or 10 or 11 or 12 or 13 or 14 16. 7 and 15 17. Remove Limits from 16
CINAHL	<ol style="list-style-type: none"> 1. Intellectual Disabilit* and Acquiescence 2. and Suggestibility 3. and Response Bias 4. and Acceptance Tendency 5. and Acceptance Bias 6. and Yea-saying 7. and Cloak of Competence 8. Intellectual Disabilit* and Acquiescence 9. and Suggestibility 10. and Response Bias 11. and Acceptance Tendency 12. and Acceptance Bias 13. and Yea-saying 14. and Cloak of Competence 15. Mental Retardation and Acquiescence 16. and Suggestibility 17. and Response Bias 18. and Acceptance Tendency 19. and Acceptance Bias 20. and Yea-saying 21. and Cloak of Competence 22. Mental Handicap and Acquiescence 23. and Suggestibility 24. and Response Bias 25. and Acceptance Tendency

	<p>26. and Acceptance Bias</p> <p>27. and Yea-saying</p> <p>28. and Cloak of Competence</p>
Wiley Online Library	<p>Intellectual Disabilit* or Intellectual Disabilit* or Mental Retardation or Mental Handicap</p> <ol style="list-style-type: none"> 1. and Acquiescence 2. and Suggestibility 3. and Response Bias 4. and Acceptance Tendency 5. and Acceptance Bias 6. and Yea-saying 7. and Cloak of Competence
Google Scholar	<p>“Intellectual Disability” OR “Intellectual Disabilities” OR “Intellectual Disability” OR “Intellectual Disabilities” OR “Mental Retardation” OR “Mental Handicap”</p> <ol style="list-style-type: none"> 1. and Acquiescence 2. and Suggestibility 3. and Response Bias 4. and Acceptance Tendency 5. and Acceptance Bias 6. and Yea-saying 7. and Cloak of Competence

Appendix B – Reference List of Reviewed Studies

Assigned Number	Authors	Title	Journal
1	Sigelman, Schoenrock, Spanhel, Hromas, Winer, Budd & Martin (1980)	Surveying mentally retarded persons: Responsiveness and response validity in three samples.	American Journal of Mental Deficiency, 84(5), 479-486.
2	Sigelman, Budd, Spanhel & Schoenrock (1981a)	When in doubt, say yes: Acquiescence in interviews with mentally retarded persons.	Mental Retardation, 19(2), 53-58.
3	Sigelman, Budd, Spanhel & Schoenrock (1981b)	Asking questions of retarded persons: A comparison of yes-no and either-or formats.	Applied Research in Mental Retardation, 2(4), 347-357.
4	Budd, Sigelman & Sigelman (1981)	Exploring the outer limits of response bias.	Sociological Focus, 14(4), 297-307.
5	Shaw & Budd (1983)	Determinants of acquiescence and naysaying of mentally retarded persons.	American Journal of Mental Deficiency, 87(1), 108-110.
6	Gudjonsson (1990)	The relationship of intellectual skills to suggestibility, compliance and acquiescence.	Personality and Individual Differences, 11(3), 227-231.
7	Rosen, Floor & Zisfein (1974)	Investigating the phenomenon of acquiescence in the mentally handicapped: I. Theoretical model,	British Journal of Mental Subnormality, 20(39, Pt 2), 58-68.

		test development and normative data.	
8	Clare & Gudjonsson (1993)	Interrogative suggestibility, confabulation, and acquiescence in people with mild intellectual disabilities (mental handicap): Implications for reliability during police interrogations.	British Journal of Clinical Psychology, 32, 295-301.
9	Gudjonsson, Murphy & Clarke (2000)	Assessing the capacity of people with intellectual disabilities to be witnesses in court.	Psychological Medicine, 30, 307-314.
10	Rapely & Antaki (1996)	A conversation analysis of the "acquiescence" of people with intellectual disabilities.	Journal of Community & Applied Social Psychology, 6, 207-227.
11	Matikka & Vesala (1997)	Acquiescence in quality-of-life interviews with adults who have mental retardation.	Mental Retardation, 35(2), 75-82.

Appendix C – Reasons for exclusion

Reason for Exclusion	Number of studies excluded
Title indicates not relevant	33
Secondary literature	5
Children as participants	9
Forensic populations	9
Testing validity of survey	7
Not Intellectual Disabilities	8
Non peer-reviewed	10
Memory	7
Not measuring acquiescence	9

Appendix D – Original Non-adapted Version of Newcastle-Ottawa Scale (NOS)

Case Controlled Studies

Note: A study can be awarded a maximum of one star for each numbered item within the Selection and Exposure categories. A maximum of two stars can be given for Comparability.

Selection

- 1) Is the case definition adequate?
 - a) yes, with independent validation
 - b) yes, eg record linkage or based on self reports
 - c) no description
- 2) Representativeness of the cases
 - a) consecutive or obviously representative series of cases
 - b) potential for selection biases or not stated
- 3) Selection of Controls
 - a) community controls
 - b) hospital controls
 - c) no description
- 4) Definition of Controls
 - a) no history of disease (endpoint)
 - b) no description of source

Comparability

- 1) Comparability of cases and controls on the basis of the design or analysis
 - a) study controls for _____ (Select the most important factor.)
 - b) study controls for any additional factor (This criteria could be modified to indicate specific control for a second important factor.)

Exposure

- 1) Ascertainment of exposure

- a) secure record (e.g. surgical records)
- b) structured interview where blind to case/control status
- c) interview not blinded to case/control status
- d) written self report or medical record only
- e) no description

2) Same method of ascertainment for cases and controls

- a) yes
- b) no

3) Non-Response rate

- a) same rate for both groups
- b) non respondents described
- c) rate different and no designation

Appendix E – Original Non-adapted Version of Critical Appraisal Skills Programme (CASP)

Screening Questions

1. Was there a clear statement of the aims of the research?

Consider:

- What the goal of the research was
- Why is it important
- Its relevance

2. Is a qualitative methodology appropriate?

Consider:

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

3. Was the research design appropriate to address the aims of the research?

Consider:

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

Consider:

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Were the data collected in a way that addressed the research issue?

Consider:

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)

- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?

Consider:

- If the researcher critically examined their own role, potential bias and influence during:
 - o Formulation of the research questions
 - o Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

Consider:

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

Consider:

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?

- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

Consider:

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

Consider:

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Journal Paper

Perceived Barriers and Facilitators to Positive Therapeutic Change for People with Intellectual Disabilities: Client, Carer, and Clinical Psychologist Perspectives

Running Title:

'Barriers and positive facilitators to therapy for people with intellectual disabilities'

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Keywords:

Intellectual disabilities; Learning disabilities; therapy; barriers; facilitators; therapeutic change

The following article is prepared for submission to the Journal of Applied Research in Intellectual Disabilities (JARID). For submission guidelines, see: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-3148/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3148/homepage/ForAuthors.html)

Journal word limit:

Abstract: 150 words

Main text: 7000 words

Abstract

Background: Studies have highlighted successful outcomes of psychological therapies for people with intellectual disabilities (ID). However, processes underlying these outcomes are uncertain.

Method: Thematic analysis was used to explore the perceptions of three Clinical Psychologists, six clients and six carers of barriers and facilitators to therapeutic change for people with ID.

Results: Six themes were identified relating to: what the client brings as an individual and with regards to their wider system; therapy factors, including the therapeutic relationship and adaptations; psychologists acting as a 'mental health GP' to coordinate care; systemic dependency; and the concept of the revolving door in ID services.

Conclusion: The influence of barriers and facilitators to change is complex; with facilitators overcoming barriers and yet simultaneously creating more barriers. Given their potential impact on the psychologists' roles and access to therapy for people with ID, results suggest these factors should be formulated as part of the therapeutic process.

Introduction

Current literature highlights a substantial need for research that identifies conditions under which the effects of therapy are optimised for people with intellectual disabilities (ID)¹. Several assumptions have been made regarding barriers (factors that negatively impact or obstruct therapeutic progress) and facilitators (factors that positively impact or enable therapeutic progress) to positive therapeutic change for people with ID (Willner, 2005). For example, a positive therapeutic relationship, motivation to engage in therapy, and the extent to which carers support the transition of skills into the client's life. However, such assumptions are drawn exclusively from professional perspectives, and such studies are even sparser than research related to the effectiveness of psychological interventions (Willner, 2005).

Successful treatment outcomes of psychological therapies for people with ID have been highlighted in a number of studies² (e.g., Beail, 1998). However, the processes underlying successful treatments are uncertain. Success could be attributed to person-centred counselling rather than the specific approach adopted (e.g., Beail, 1998) based on the concept that the therapeutic relationship is the most important facilitator for successful outcomes across all therapeutic approaches³ (Martin, Garske & Davies, 2000). The therapeutic relationship could arguably be even more important for clients with ID as they are more likely to experience relationships based on practical support rather than their emotions being the focus. Additionally, people with an ID may be in the less powerful position in relationships due to difficulties in communication and understanding. Therefore developing a therapeutic relationship in which the client's emotional life is the focus, empowering people to make changes themselves and ensuring that people understand the content of the therapy may be problematic and time consuming within therapy for people with ID. There is also a lack of reported studies in which a collaborative relationship exists between clients with ID and their therapists (Stenfert-Kroese & Dagnan, 1997),

¹ See extended paper 1.1.1 for definitions of intellectual disability and section 1.1.2 discusses terminology

² Section 1.2.1 considers the evidence base for psychological therapies for people with ID

³ Section 1.2.2 discusses attachment theory and the importance of the therapeutic relationship

which might make the therapeutic process more demanding and achievement of quick treatment gains more challenging. Furthermore, it is often the case that the person is brought to services by someone who perceives them to have a problem rather than referring themselves. This might be important because the therapeutic alliance will depend on the client's perception of the 'problem', their motivation to change, and their engagement in therapy⁴ (Emerson, Hatton, Bromley & Caine, 2001). In addition to the therapeutic relationship, there are other considerations of barriers and facilitators to positive therapeutic change for people with ID. For example, the impact of cognitive abilities on a person's capability to benefit from therapy has been debated⁵ (e.g., Taylor, Lindsay & Willner, 2008); and whether lessons learned in therapy are integrated into the client's life through the support of their carers may be worth considering⁶ (Willner, Jones, Tams & Green, 2002).

Working to optimise therapy for people with ID through the consideration of barriers and facilitators to successful outcomes is important because of higher prevalence rates of psychiatric disorders in people with ID (Hatton & Taylor, 2005) than in the general population⁷ (Meltzer, Gill, Petticrew & Hinds, 1995). Developing a mental-health problem is associated with a number of life events that people with ID are likely to experience (Brown, 2000) including: poverty, abuse and lack of support networks⁸ (Hastings, Hatton, Taylor & Maddison, 2004). Additionally, people with ID may find it more difficult to cope with stressful life events due to cognitive difficulties (van den Hout, Arntz & Merckelbach, 2000). Clinical Psychologists (CPs) are arguably better equipped than other professionals to work with people with an ID as a result of their knowledge, specialist skills and training that means they are well placed to understand the broad and specific needs of this population. However, the CPs working with people with ID do not have the advantage of referring to as extensive an evidence base as those who work with the general population (Beail, 2010; Sturmey, 2005).

⁴ See section 1.2.3 for discussion on engagement in therapy and psychological models of change

⁵ See section 1.2.4 for full discussion on the impact of cognitive function on therapy

⁶ See section 1.2.5 for discussion on involving carers in therapy

⁷ See section 1.3.1 for further discussion of prevalence rates of mental-health problems in people with ID

⁸ See section 1.3.2 for further discussion on vulnerability of people with ID to mental health problems

Some studies have cited ethical concerns regarding the vulnerability of people with an ID and the potential harm of their inclusion in research as an exclusion criterion (Northway, 2014). Key aspects of people's lives may thus remain unexamined, potentially allowing unhelpful cultures and practices to go unquestioned. More recently research approaches have enabled the safeguarding of people with ID whilst also supporting their right to participate (Northway, 2014). CPs and carers may also offer valuable insight into barriers and facilitators to positive therapeutic change. Amering, Hofer and Rath (2002) suggested that working in triads with clients, mental-health professionals and carers, is helpful to understand and share the complex and subjective experiences of people with mental-health difficulties. This can then lead to forming a common language, and establishing a culture of discussion, which professionals perceive to be necessary for working together effectively. Although this approach has not yet been utilised in research within ID settings, it is thought that by accepting each other as 'experts by experience' and 'experts by training', triads can provide an opportunity to gain new insights and knowledge and interact beyond role stereotypes. This study recruited based on the triad format by considering the perspective of clients, carers and CPs to develop a cohesive and robust understanding of the research question. Furthermore it sought the perspective of those who benefitted and those who did not significantly benefit from therapy in order to encourage diverse accounts and develop a broader understanding⁹.

This study sought to inform clinical practice by aiding understanding of how therapy can be optimised for people with ID, with a specific focus on individual talking therapy. For this purpose, therapeutic change was not operationally defined within this project. Rather, whether therapeutic change occurred or not depended on participant's perspectives of whether any positive changes happened as a result of therapy. This was therefore based on each client's individual needs, reasons for referral and goals within therapy and as a result, therapeutic change was not bound to only psychological symptoms, but also allowed the inclusion of therapeutic change with regards to wider health and

⁹ Extended paper section 1.3.3 considers the inclusion movement and current government policy

social care needs. With consideration of the small sample size of this study, it aimed to take a tentative step towards improving the experience of accessing mental-health services for people with ID. This study therefore aimed to explore three different perspectives (client, carer and CP) regarding barriers and facilitators to positive therapeutic change for people with ID. The main aims of this research were: to explore what are facilitators of positive therapeutic change; to explore what are barriers to positive therapeutic change; and to integrate the perceptions of clients, carers and CPs to move towards a cohesive understanding of barriers and facilitators to positive therapeutic change.

Method

Study design. A qualitative, inductive-deductive research design was used, utilising thematic analysis (Braun & Clarke, 2006) to identify and interpret themes within the data from triadic cases. Critical realism with a constructionist influence (Willig, 1999) was the framework that grounded the research; this position assumes that a 'reality' exists, even though we cannot fully capture it¹⁰. However, you can gain a helpful understanding of a 'reality' through intense examination (Guba & Lincoln, 1994). Within thematic analysis, this epistemology assumes that you can acquire knowledge and insight into people's experiences through their narratives, whilst recognising that there is an element of the researcher constructing knowledge (Madill, Jordan & Shirley, 2000)¹¹.

Population and sampling. Participants were recruited from a specialist ID Psychology service. Three cases (see Figure 1) of two dyads of a client with ID that was deemed to have benefited from therapy and their carer, and a client that was deemed to have not significantly benefited from therapy and their carer were nested by one CP.

¹⁰ Section 2.1 of extended paper further discusses the epistemological position taken in this study

¹¹ See section 2.2 of extended paper for further discussion on thematic analysis, the rationale for this methodology and consideration of alternative approaches

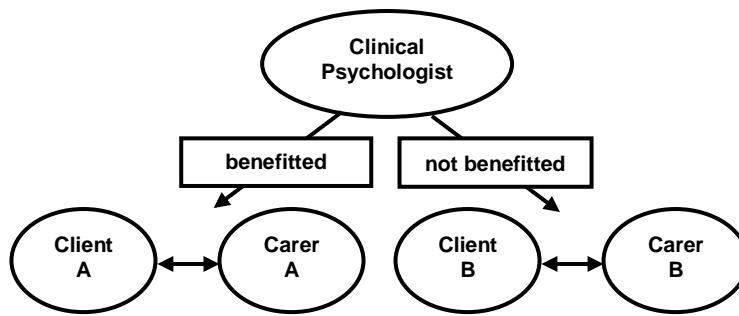


Figure 2. Diagrammatic representation of a single case

Recruitment procedure.¹²

Recruitment of Clinical Psychologists. Qualified CPs were invited to participate via email¹³. Those individuals that were interested were provided with an information sheet¹⁴ and were asked to provide signed informed consent¹⁵.

Recruitment of clients with intellectual disabilities. The CPs were asked to identify their most recently discharged clients (within the last three months) that met all of the inclusion and exclusion criteria. They then separated potential participants into two groups: those who they deemed to have benefited and those they thought did not significantly benefit from therapy. They could use both their clinical judgement and any outcome measures to determine the groups. The rationale for this was to encourage a more diverse sample and reduce ‘cherry-picking’. The investigator remained blind to which participants were in which group until after data collection and analysis. The CP then made initial contact with people they identified (most recently discharged first) invited them to participate¹⁶ and provided them with an information sheet¹⁷ and optional audio version. If permission was given, contact details were passed to the researcher and clients were then asked to provide informed consent¹⁸ both to participate in the study and for us to talk to their CP and a carer about them.

¹² See extended paper section 2.3 for further information on the recruitment procedure and rationale

¹³ See Appendix A for invitation to participate for Clinical Psychologists

¹⁴ See Appendix B for participant information sheet for Clinical Psychologists

¹⁵ See Appendix C for consent form for Clinical Psychologists

¹⁶ See Appendix D for invitation to participate for Clients

¹⁷ See Appendix E for participant information sheet for Clients

¹⁸ See Appendix F for consent form for Clients

Recruitment of carers. The client's carer that supported them during therapy was invited to participate¹⁹. They were provided with a participant information sheet²⁰ and asked to provide informed consent²¹.

Inclusion and exclusion criteria. CPs were eligible to participate if they were registered with the Health Care Professions Council. Clients were eligible if they met the criteria for a global ID and had completed individual therapy within the last 3 months. Clients were to have completed one-to-one therapy sessions with the CP, even if carers were also involved at some stages, thus excluding any potential participants who had undergone purely indirect therapy. Potential participants were excluded if they were deemed not to have capacity to consent to participate. Carer participants were eligible to participate if they cared for the client whilst they were working with the CP. Furthermore, any participants who did not provide informed consent and had an inability to speak and articulate in English language were excluded²².

Participants. A total of 15 participants took part in this study²³. The three CP participants (see Table 1 for demographic information) were female, ranging from age 37 to 59 (mean age = 46.6).

**Table 4:
Demographic Information for Clinical Psychologist participants**

Pseudonym	Age	Gender	Ethnicity	Number of years Qualified as a CP	Number of years in ID services
Jacqueline	53	Female	White British	4	19
Anne	38	Female	White British	3 ½	4
Caroline	37	Female	White British	2 ½	10

Six clients took part in the study, all of whom were male aged 19 to 43 (mean age = 30.8). This sample included clients with a range of characteristics related to their reason for referral and the level of support they received (see Table 2).

¹⁹ See Appendix G for invitation to participate for Carers

²⁰ See Appendix H for participant information sheet for Carers

²¹ See Appendix I for consent form for Carers

²² See extended paper 2.4 for further discussion of inclusion and exclusion criteria

²³ See Extended paper section 2.5 for the triadic cases (how each participant relates to each other)

Table 5:
Demographic information for client participants

Pseudonym	Age	Gender	Ethnicity	Level of ID	Reason for referral	Therapeutic approach	Length of therapy	Accommodation status
Andrew	40	Male	White British	Mild	Depression	Integrative	3 years	With parents
Ryan	32	Male	White British	Mild	Depression	Integrative	1½ years	Supported Living
Tyler	23	Male	White British	Mild	Forensic - Fire setting	Systemic approach	3 years	Inpatient (Under Mental-Health Act)
Keith	43	Male	White British	Mild	Forensic - Assault	Behavioural	2 years	Inpatient (Under Mental-Health Act)
Liam	19	Male	White British	Mild	Forensic - Sex offence	Schema Therapy	3 years	Supported Living
Phillip	28	Male	White British	Mild	Anger and Capacity	Systemic approach	1 year	Residential Home

The six carer participants (four female and two male) ranged from age 43 to 67 (mean age = 52.7). The sample included different carer types within different types of support settings (see Table 3).

Table 6:
Demographic Information for carer participants

Pseudonym	Age	Gender	Ethnicity	Carer type	Length of time known the client	Length of time working with people with ID
Mary	67	Female	White British	Mother	Lifelong	-
Andrea	50	Female	White British	Paid carer - Supported Living	6 months	4 ½ years
Helen	47	Female	White British	Nursing Assistant - Inpatient service	3 ½ years	26 years
Alistair	53	Male	White British	Nursing Assistant - Inpatient service	2 years	6 years
Sue	43	Female	White British	Senior paid carer - Supported Living	6 months	15 years
Paul	56	Male	White British	Paid carer - Residential Home	6 years	6 years

Study procedure. Ethical approval was received from the Leicester NHS Research Ethics Committee, the University of Lincoln and NHS Trust Research and Development department²⁴. Data was collected one case at a time (interview order: client-A, carer-A, client-B, carer-B, CP). Clients were

²⁴ See Appendix J for Ethical Approval Letters and extended paper section 2.6 discusses ethical considerations

interviewed first due to potential difficulties with retrospective accounts; and the CPs were interviewed last to reduce the likelihood that the interviewer could guess who was the 'benefitted' and was the 'non-benefitted' client. CPs were interviewed regarding each client separately²⁵.

Measures. Data were collected through face-to-face semi-structured interviews. Demographic information was collected during the interviews. Interview schedules were developed with the cognitive ability in mind and were intended to be used flexibly to facilitate open ended discussion. The schedules covered six topic areas including: decision to see a psychologist, expectations of seeing a psychologist, experience of therapy, most helpful experiences including facilitators, least helpful experiences and barriers and future plans²⁶. Care was taken in the phrasing of questions to ensure that participants understood (Booth & Booth, 1996). Interviews were digitally recorded and transcribed verbatim.

Data analysis. The thematic analysis procedure was carried out at semantic-level as outlined by Braun and Clarke (2006). Therefore codes and themes were identified within the explicit meaning of the data without making interpretations beyond what the participant said. Through familiarisation with data set via transcription and repeated reading, the first author developed initial codes using a combination of inductive and deductive processes of analysis (Fereday & Muir-Cochrane, 2006). This allowed the data analysis to be based around the pre-existing theory and assumptions outlined by Wilner (2005) including: the impact of the therapeutic relationship, engagement in therapy and the extent that carers support the clients; whilst also offering participants the opportunity to offer new insight. These codes were noted manually next to the relevant data²⁷ and occurrences of the same code were physically collated together²⁸. Codes were then organised into potential super-ordinate and sub-themes, which were continually reviewed for internal homogeneity and external

²⁵ See extended paper section 2.7 for further discussion on the study procedure and rationale

²⁶ See Appendix K for the client's interview schedule; Appendix L for Carer interview schedule and Appendix M for the interview schedule for Clinical Psychologists

²⁷ See Appendix N for a coding extract from a client transcript; Appendix O for a coding extract from a carer transcript; and Appendix P for a coding extract from a Clinical Psychologist transcript

²⁸ See Appendix Q for an example some data extracts for a single code

heterogeneity to ensure that there were clear distinctions between the themes and that each theme was coherent. Themes were then named, defined apropos to their content and organised into a thematic map. The second author reviewed two transcripts to establish reliability of codes²⁹. Inconsistencies between the authors were discussed and resolved (Fereday & Muir-Cochrane, 2006).

Results

The results are presented visually in Figure 2, outlining the main themes and subthemes identified in the analysis, and their inter-relationship. Five super-ordinate themes were identified, each with several subthemes³⁰.

Super-ordinate theme 1: What the client brings. This theme encompasses factors that the clients bring to the therapy as an individual that are out of the therapist's control. There seemed to be a general discourse around the client bringing barriers to therapy that must be overcome in order for therapy to progress.

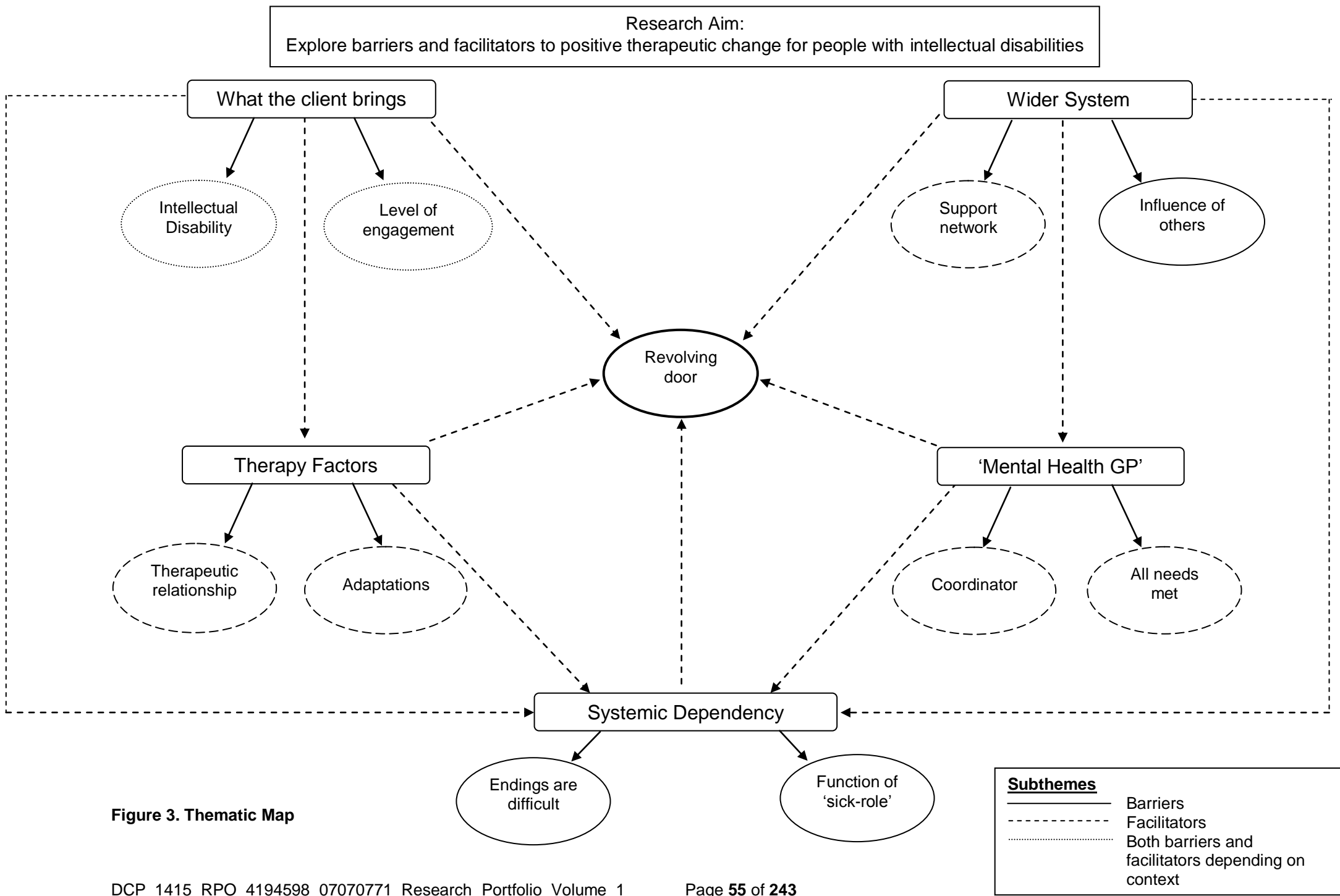
Subtheme 1.1: Intellectual disability. This theme encapsulates the impact that having an ID has on therapy³¹. Interestingly, all participants consistently felt that although cognitive deficits are generally a barrier within therapy, they were not considered to be problematic. For example one psychologist stated:

The thing is we know that people are coming in with a cognitive deficit. So if we couldn't overcome that barrier we wouldn't really get very far. I think we are so used to adapting the work that we don't even realise we are doing it anymore. (Caroline)

²⁹ See section 2.8 of extended paper for discussion on reliability and validity of qualitative research

³⁰ See section 3.1 for an overview of extended thematic map with extended subthemes.

³¹ See extended paper 3.2.1 for further discussion on the subtheme 'intellectual disability'



However, participants across all three groups did consider the impact of memory deficits specifically as being challenging. For example one client reflected: “I do struggle with my memory. It’s really hard to remember in the situation what to do” (Phillip)

Within all of the ‘non-benefitted’ cases, participants reflected on an inability to communicate effectively being a barrier within therapy and also a significant factor in maintaining psychological distress for clients. For example one carer states:

That’s why he gets frustrated because it is difficult to communicate. And I mean I get frustrated when I can’t understand what he’s saying because I want to know what he’s saying, you know. I want to help. (Alistair)

Communication was not a barrier for all participants. Within all ‘benefitted’ cases at least one person in each triad reflected on the client’s ability to communicate being a facilitator for change. For example a carer stated: “He’s pretty good at communicating with us, and letting us know if there’s anything bothering him... if they can’t make you aware of what the problem is, then you can’t help them” (Andrea).

Subtheme 1.2: Level of engagement. It was noted that all clients included in this study were referred to services by someone other than themselves, and furthermore they all needed some level of ‘convincing’ to engage with psychological therapy. Three clients were reported to respond well to this and begin to engage with therapy relatively quickly. For example one client stated: “I soon realised that I needed support. I needed help basically.... I was ready to do the things that I needed to do” (Liam).

Two clients took a little more ‘convincing’. One carer said:

I think he did the ‘if I bury my head in the sand, and it would all go away’ thing really... he’s sort of grown to work with her and realise how he needs to change I suppose. He took some convincing. (Helen)

One client did not engage with therapy as a result of his belief that there was no need for individual change. A psychologist gave an example of this: “he doesn’t want to change; he wants the world to change around him” (Caroline).

Super-ordinate theme 2: Wider system. This theme captures what the client brings in terms of their wider system, which is also out of the therapists control. The clients support network is generally perceived to be a positive influence whereas the subtheme ‘influence of others’ is predominantly the negative impact that other people have on clients.

Subtheme 2.1: Support network. Having a wider support network was mentioned by participants across all three groups as being a positive facilitator for change, as socialising was noted to have a positive impact on general well-being³². For example, one carer said: “there are friends that have started to get him out and involved with things now. And he goes out socialising which helps lift his mood” (Mary)

Conversely, having no friends or family support other than paid staff was seen as a barrier for one particular client with regards to this causing significant psychological distress. One carer was particularly concerned about this:

It’s very hard for [Keith] because he’s the only person here that doesn’t have anybody come and visit ... [Keith’s] got no one, which is difficult because, effectively the guy’s on his own. (Alistair)

Subtheme 2.2: Influence of others. Influence from others was mentioned by all participants³³. Two clients and their respective carers and CPs showed concern regarding the impact of other people on offending behaviour, which for both clients was their reason for referral. One example of this is from a carer:

As much as he tries to keep himself out of trouble, other people haven’t been quite so helpful with him and his family member and family friends

³² See extended paper section 3.2.2 for further discussion of the subtheme ‘support network’

³³ See extended paper section 3.2.3 for further discussion of subtheme ‘Influence from others’

haven't taken into consideration his real feelings. He's tried to keep away from situations and it's been pushed in his face. (Sue)

A further two clients were actively discouraged by their family from engaging in therapy. For example, Anne reported:

He was being told by his family not to talk about it [abuse]. He was getting a lot of mixed messages from his family, who found it very hard to understand why he needed to talk about something that was in the past.

(Anne)

Carer negativity was also reported by clients and CPs as a barrier in therapy. For example: "his mum's downtrodden attitude sometimes, that 'oh nothing's going to work, you know'. So her negativity impacts on his belief that change can happen" (Jacqueline).

Super-ordinate theme 3: Therapy Factors. Therapists implemented a number of therapy factors to overcome barriers in relation to what the client brings. A positive therapeutic relationship and several examples of therapy adaptations were deemed to be facilitating factors to enable positive therapeutic outcomes.

Subtheme 3.1: Therapeutic relationship. All participants reflected on the importance of having a positive therapeutic relationship with the CP with regards to talking openly, feeling listened to, respected and able to trust³⁴. Although all participants discussed this, clients in particular emphasised this as a dominant facilitator to help them engage with therapy. For example: "she got to know me really well and she was kind and listened to me which made me want to keep coming" (Tyler).

³⁴ See extended paper section 3.2.4 for further discussion of the subtheme 'therapeutic relationship'

For one client, the therapeutic rapport was reported to be lacking by all members of the triad, and this was deemed to be a barrier for this person. For example his carer said: “He struggles to trust people... it impacted on the relationship definitely” (Paul).

Subtheme 3.2: Adaptations. Participants felt that many adaptations are required within therapy, including slower pace and increased longevity of therapy to help with time to build trust and repeat skills. Furthermore visual tools and involving carers were thought to be facilitators. For example one client commented:

I told staff what I'd got to do and they helped... There were pictures of faces and I had to tick which one I was feeling and that was ok. She helped me understand what emotions were. (Keith)

For two clients, their carers were offered training by the CPs to help them adapt their way of working for the individuals. This was thought to be a facilitator by all participants involved. For example one carer states:

We had two training sessions with all the staff and [Caroline] gave us information about what we needed to know and the best ways to deal with [Liam's] behaviours, and she updated us on how he will present and triggers and all of that was really helpful. (Sue)

Super-ordinate theme 4: 'Mental-Health GP'. This theme encompasses the concept that for individual therapy to facilitate positive therapeutic outcomes, coordinating the usually extensive wider system of people with ID and ensuring that all the clients' health and social care needs are met is crucial. This requires the psychologist to become a 'mental-health GP' in that they formulate wider needs and signpost people to appropriate services.

Subtheme 4.1: All needs met. Ensuring that the clients have all of their wider health and social needs met was thought to be a crucial facilitator within therapy, as they felt that clients come to services with multiple and complex needs. For example one psychologist said:

So much of the problems that people come with, is because they have so many needs. And unless you address those needs, you're never going to get anywhere ... without addressing those I don't see how you can work effectively or make those changes happen. (Anne)

Common examples of wider needs were physical health problems and inappropriate living environments. One client gave an example of this:

[Caroline] helped sort me somewhere better to live. They [other residents] just make me angry all the time. I want to act like a grown up but when they are nasty I can't be a grown up. (Phillip)

Subtheme 4.2: Coordinator. The CPs and carers reflected on the need for them to step outside of their role and coordinate the wider system. For example:

I see it as more coordinating and taking more of a bird's-eye-view. Whereas everyone's thinking of their remit and that's what they're doing, I'll just step outside my role and go, OK, what's going on here and what do we need? Otherwise you'd end up with a ton of referrals that aren't appropriate. (Anne)

All six clients reflected that they felt that the role of the psychologist was to help them get the right support for any problems or difficulties. For example:

If I had a problem with anything I would just ring her and she would get back to me and help me get in touch with the right people to sort it. (Liam)

Super-ordinate theme 5: Systemic dependency. All four themes that have been discussed have factors that foster a dependency on the system. Firstly, the fact that people have an ID means that naturally people are more dependent on others. As a result, therapy factors including the therapeutic relationship and adaptations to therapy (e.g., increased longevity of therapy) can foster strong attachments which can facilitate an unhelpful level of dependency. Additionally, the client's wider system can also become dependent

on services to help them facilitate care and coordinate the numerous services involved. For example one psychologist said:

If you're not careful you can quite easily foster dependency, we do have an issue with that ... people are more dependent. They feel less able to cope with life and like they need more help, and you can become that help but they will attach to you very strongly. And then to end sessions when somebody has attached to you has to be really thought through or you are going to have problems. (Caroline)

Subtheme 5.1: Endings are difficult. As a result of becoming more dependent on the system, the attachments made through the therapeutic relationship, and reliance on the psychologist as a care coordinator can make endings difficult for all involved. One psychologist reflects on this:

I've actually had people say it to me 'I'm not going to get better because then you'll stop seeing me'. But then I just tell them, because I work in LD that's fine, they can call me and they can come back whenever they need to. And then, funnily, they get better. (Caroline)

Endings being difficult was also one of the most frequent and salient themes for clients. For example, Andrew stated: "I didn't want her to stop coming. I'm not well enough for her to stop coming and I will prove I'm not".

Subtheme 5.2: Function of 'sick role'. The idea of systemic dependency was also reflected by participants through there being a function to the 'sick role' to prevent them from being discharged from services, as-well-as other inter-relational functions. For example one carer reports:

He wanted there to be something wrong with him ... and doctors never consulted anyone or realised that there's nothing wrong with him why does he keep coming back. He just wanted some attention from somewhere. (Mary)

Central theme: The revolving door. The revolving door was mentioned by everyone and it seems that all themes contribute to this. The revolving door is the concept that people continue to be re-referred to psychology services.

However, participants did not always see this as problematic. For example one psychologist states:

This criticism of the high re-referral in intellectual disabilities, this idea of the revolving door, it's not actually a problem, I actively encourage it, if input is needed again. I think its called life. You just have to accept that people with intellectual disabilities have less of resources than people in the typical population. (Caroline)

Although dependency on the system is expected, it can be reduced and at times it is avoidable. For example, another psychologist states:

I don't think it is our clients that are the revolving door; I think it's our services. I think what we actually see are failings in staff groups where you go in, you do the work, and then the staff group changes ... then you get exactly the same referral again. You end-up telling the staff groups the same thing. (Jacqueline).

This idea of the revolving door not only relates to client's continuing to come in and out of services, but several participants across the three groups mentioned there being a revolving door within therapy. For example:

We just seem to be going round in circles, I don't know if we'll ever be there. I'm wondering whether on one hand I'm maintaining it at a controllable level, on the other hand I'm probably keeping it going as well. And we need to go back to the very beginning and start all over again. (Jacqueline)³⁵

Discussion

Results suggest that carers, CPs and to an extent clients are aware of factors that the client brings to therapy that can be considered barriers and facilitators to therapeutic change³⁶. As a result, factors such as having an ID are perceived as minimally problematic as people actively seek to overcome such barriers.

³⁵ See section 3.3 of extended paper for results of the service data collected and section 3.4 discusses client data.

³⁶ See extended paper section 4.1 for discussion of extended subthemes

The process of barriers and facilitators to positive therapeutic change is a complex one, with concepts that begin as facilitators becoming barriers themselves, or at least creating further barriers; thus maintaining a sequence of barriers and facilitators throughout therapy (see figure 3).

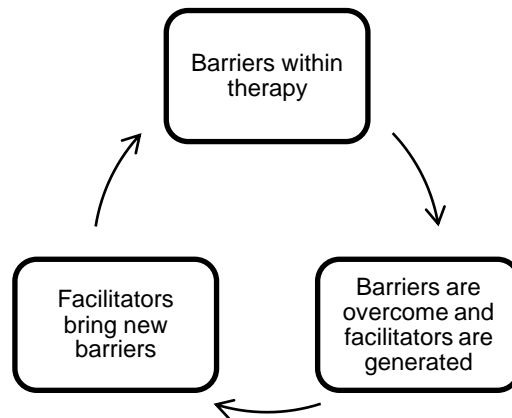


Figure 4. Cycle of barriers and facilitators

Subsequently, psychologists report feeling as though they are going around-in-circles within therapy, and participants across all three groups talk about maintaining the concept of the ‘revolving door’ into services. One example of this process from the data is as follows: the client comes to therapy with cognitive deficits. As a result, the CPs implement a number of adaptations including more flexible therapy structure and longevity of therapy is increased to allow time to build trust and repeat skills. Fewer boundaries are therefore enforced meaning that people are unaware of when therapy will end; and strong attachments are formed between the psychologist, the client and their carer. Subsequently, endings become a barrier; clients are reluctant to progress because they do not wish to be discharged, and carers become increasingly anxious about coping without input from the CP. This was reported to leave psychologists feeling anxious about discharging clients and people are often left on their caseloads for extensive periods of time, or alternatively people are discharged with the reassurance that they will be able to be re-referred, which they often are. This is evident in that three of the clients had been re-referred at the point of data collection.

What the client brings. The literature regarding whether cognitive deficits impact on a person's capability to benefit from psychological therapies has shown equivocal findings (e.g., Taylor, Lindsay & Willner, 2008) but seems to focus on IQ specifically. Rather than considering cognitive deficits as a whole, participants specifically reflected on memory and communication difficulties as being problematic within therapy. They also thought that the impact of these difficulties could be minimal if appropriate adaptations were made.

The findings support prior research regarding the importance of engagement in the effectiveness of therapy. Participants articulated similar factors that affect engagement to those identified by Willner (2006), including: client's motivation; confidence in completing emotionally and intellectually challenging psychological work; the extent to which the referral was voluntary or coerced; and 'readiness' for therapy. Although such factors can impede any client's ability to benefit from therapy, they are likely to be of heightened importance for people with ID due to the increased probability that people have not referred themselves and cognitive impairments³⁷. Therefore the results of this study reflect the available literature that the client's cognitive functioning and skills deficits need to be assessed in detail, along with their willingness to engage, so that the psychologist can understand what therapy adaptations are required to ensure it is reflective of the individual needs of each client (Lynch, 2004).

The wider system. The importance of a support network emphasised in the findings is in-keeping with theories regarding the role of social support in mental-health. Some authors (e.g., Kaplan, Cassel & Gore, 1977) argued that support acts as a resilience factor to the psychological impact of negative life-events. Studies have opposed this resilience only view, suggesting that a lack of social support can be a stressor in itself and will impact on psychological symptomology (e.g., Thoits, 1983, 1985), which was reported to be the case for at least one participant. Surprisingly, there appears to be a substantial gap in literature regarding the impact of only having paid support on psychological

³⁷ Section 4.2 of extended paper discusses the trans-theoretical model of change and its relevance to people with ID

distress. It could be that only having relationships with paid carers may impact on the person's psychological well-being and self-esteem.

With regards to the influence of others; carers and family members were described by several participants as intentionally obstructive, generally negative and impacting on the client's attitude towards whether change is possible or necessary. Azjen's (1985) theory of planned behaviour could help explain why members of the wider system did not actively support clients to facilitate therapeutic change. This theory postulates that several factors would affect whether this behaviour occurred including: intention to do so; attitude towards the behaviour; social norms; and perception of control. Therefore, for those individuals that either actively opposed supportive behaviour, or agreed to and then did not comply, it may be that they believed that they were unlikely to generate effective outcomes from support behaviour, thus affecting their engagement towards this. Although in some cases social norms can impact on such intentions through criticism of socially undesirable behaviour, stigma for people with ID is still such that this may not occur. With the addition of carers often feeling under-trained, under-equipped, and too burnt-out to support people with ID (Langdon, Yaguez & Kuiper, 2007) it is unsurprising that some carers do not support clients in the most effective way.

Therapy factors. Therapy factors were perceived to be facilitators by all participants. This is unsurprising considering the growing body of evidence regarding how to adapt psychological therapy for people with ID. Hurley, Tomasulo and Pfadt (1998) emphasise that all therapists should adapt their approach to every client; therefore making adaptations for people with ID should not be problematic. They also identified several adaptations for adults with ID including: simplification of techniques, language and activities, integration of developmental level, directive and flexible methods and involving carers. All of these were evident within this study, suggesting that psychologists are aware of, and actively utilise this literature. The one adaptation that was not evident within the data was the consideration of stronger boundaries, which may have proven to be an important factor to facilitate ending therapy. Many studies of adaptations of therapy for people with ID, including Hurley et al. (1998) are

determined by professional perspectives. The current study offers clients perspective of this which was supported by all members of the triad to reinforce such adaptations. It is also unsurprising that the therapeutic relationship was one of the most frequent and salient themes in the analysis, considering the vast body of evidence suggesting that this is of fundamental importance and efficacy to all psychological therapies (e.g., Shapiro & Shapiro, 1982).

Mental-health ‘GP’. The concept that for therapeutic change to occur, more basic needs must be met is in-line with Maslow’s (1943) hierarchy of needs. This five stage theory includes: 1) biological and physical needs (food, water); 2) safety needs (protection, security); 3) love and belongingness (friendship, affection); 4) esteem needs (independence, respect); and 5) self-actualisation (self-fulfilment, personal growth). The theory postulates that basic lower needs must be met before progressing on to meet higher level needs towards self-actualisation. Maslow (1943; 1954) posits that every person is capable of moving up the hierarchy. However, current literature does not consider what self-actualisation might look like for people with an ID. Further research into this concept may prove beneficial to help outline therapy goals. With reference to this theory it would make sense that participants expressed that lower level needs such as an appropriate living environment and physical health needs would need to be met before therapeutic change towards self-actualisation takes place. It seems sensible that psychologists are in a well-equipped position to act as a coordinator for the person to move up this hierarchy as a result of their specialist knowledge and skills. However, although this appears to be an accepted role of psychologists within services, the literature is yet to explore and evidence the need for this role.

Systemic dependency. Many participants in this study referred to endings as being one of the biggest barriers for therapeutic change as it affects the client’s willingness to progress towards discharge. This is in-line with literature regarding ending therapy which suggests that for clients with a history of substantial loss, endings can be particularly difficult (Hill, 2005). However, even people without substantial loss often respond to endings with a number of reactions including: loss, regression and avoidance (Siebold, 2007). Roe,

Dekel, Harel, Fennig and Fennig (2006) found that ending therapy is more likely to be experienced as a loss or rejection when clients feel they cannot return. Subsequently, this produces more symptoms in the client including anger, anxiety and abandonment. Furthermore, individuals with attachment difficulties and loss may not have capacity to work through issues of separation as such clients often have difficulties with emotional and behavioural regulation (Schoore, 1997). Such considerations would need to be made for people with ID, and ending therapy may need to be formulated differently. More recent research suggests that therapists should consider the management of endings in relation to the client's attachment to the therapist, other attachments in the client's life and previous experiences of loss (Zilberstein, 2008).

The function of the 'sick-role' for clients was also deemed to contribute to systemic dependency. This is in-keeping with literature suggesting that the 'sick-role' has specific learning components that can impede therapy outcomes (Moss, 1986). People who frequently display 'sick-role' behaviour possess a distinct learning history including: 1) positive reinforcement of illness behaviour; 2) parental modelling of maladaptive responses to illness or disability; and 3) unassertive or socially unskilled models from parents (Turkat, 1982; Turkat & Guise, 1983). Furthermore, several studies (e.g., Turkat & Pettegrew, 1983) have postulated that individuals who exhibit high rates of 'sick-role' behaviours are likely to be positively reinforced by gaining attention and nurturing behaviour directed towards them; and negatively reinforced by being allowed to refrain from disagreeable activities. Therefore participants were reluctant to make changes as to maintain the attention and nurturance gained from CPs.

The Revolving Door. Four of the clients in this study had received previous psychological support from the service. Historically, returning to therapy has been seen as a sign of unsuccessful or incomplete therapeutic work (Zilberstein, 2008). However, Wachtel (2002) states that "the very 'reality' that termination is something final that the patient must come to terms with is an artefact" (p. 375). In therapy, both remediation of symptoms and ability to function independently are goals before therapy ceases (Zilberstein, 2008). This constitutes a tall order as few therapies end in such graceful conclusions

(Golland, 1997) partly because the definition of ending implies that psychological issues will resolve in therapy, and that endings are permanent and feelings regarding ending should be mastered.

Although there is currently no literature regarding the 'revolving door' phenomenon in ID services, there is generally a discourse within services that the high re-referral rates in ID services was an issue that needs to be resolved. Conversely, the findings of this study suggest that re-referral to the service is both acceptable and necessary for people with ID. However the findings also suggest that some measures can be taken to reduce the re-referral rate and minimise inappropriate referrals through the role of CPs as the 'mental-health GP'. Furthermore, it would be important to assess this role further to determine whether this is a role that is required of CPs specifically as a result of their specialist skills in formulating wider needs. Or alternatively, are other professionals able and best-suited to complete this role?

Clinical Implications. Overall, the results of this study suggest that having an ID does not necessarily impair someone's ability to benefit from psychological therapy. The finding that the psychologist and client become locked in a cycle of barriers and facilitators offers more avenues for change and there is no strict rule as to what constitutes a facilitator or a barrier. Barriers and facilitators should be assessed and formulated in detail and psychologists should utilise clinical supervision to reflect on barriers to therapeutic change and facilitators that may offer avenues to change. The findings from this study also indicate that the supposition that the 'revolving door' phenomenon is a problem that needs to be fixed is not necessarily the case. Conversely, service planning and commissioning should consider the need of this client group to re-visit therapy throughout the life-span, either as a result of new issues that arise or simply a 'refresher'. Thus re-referrals as a preventative measure could actually be more cost-effective for services in the long run. Despite this, practitioners should reflect on clear justifications for re-referrals as there seems to be a fine line between promoting independence³⁸ versus creating a dependency³⁸.

³⁸ Extended paper section 4.3 discusses further clinical implications

Critique of Study Methodology. Employing qualitative methods with people with ID was simultaneously this study's strength and weakness. Literature has commented on acquiescence (Rapley & Antaki, 1996) and inconsistent responses (McIver & Meredith, 1998) during interviews as evidence that people with ID are inarticulate participants and therefore are unable to provide good quality data (Booth & Booth, 1996). There were few examples of contradictions within this study, however through a structured process of analysis it was possible to incorporate contradictions within the codes, which allowed the exploration of explanations of these contradictions. A strength of this study was the use of multiple groups to broaden the perspectives, reduce biases from one group and to develop a more comprehensive understanding of the research question.

Qualitative research can have the potential to generate themes purely based on the questions asked, and present findings based on the pre-conceptions of the researcher (Cohen, Manion & Morrison, 2007). These potential threats to reliability were minimised by: acknowledging the researcher's views through the development of a reflective concept map³⁹; keeping an audit of decisions; and keeping a reflective diary. In a further attempt to minimise potential biases the researchers were blind to which clients were deemed to have benefitted or not significantly benefitted from therapy. Although some interpretation of the data was required, analysis of the interviews remained faithful to the participant's narratives and the results were relatively concrete. This was thought to reflect the ID participants own concrete representations of themselves and therapy. With regards to assuming transferability of findings, care should be taken considering the small sample size and homogeneity of the client participants, particularly apropos gender as all client participants were male. From reviewing the available data from the service, referral rates were fairly equal across genders (42% female; 58% male). However the discharges rate was much higher for males each month (73%) than females (27%). Therefore further research might consider whether this is a common pattern and if so why might females be kept on psychologists caseloads for longer periods of time than

³⁹ See Appendix R for concept map of potential researcher bias'

males⁴⁰. Furthermore with regards to transferability of findings, it should be noted that the CPs recruited for this study were relatively newly qualified with less than five years post-qualified experience. It may be that more experienced CPs might offer alternative perspectives based on many years of experience and extended knowledge on how services and the evidence-base for psychological therapy in ID settings have developed over time.

Future Directions. Given that participants in this study highlight the importance of a prosperous support network for both therapeutic effectiveness and general psychological well-being, it would be interesting for future research to consider the impact of diminishing day services and social groups on the well-being of people with ID. Furthermore, accounts from participants in this study highlight that a necessary and familiar role for CPs in ID services is to utilise their specialist skills as a ‘mental-health GP’ to coordinate multiple services. Without further exploring and evidencing the need for this, the implementation of commissioning criteria and outcome based funding for individual therapy within services may prove disastrous for client’s quality of care. It would also be worth considering what the benefits of utilising CPs for this role, whether it is cost-effective or whether other professionals are able to complete this role effectively. Finally, detailed consideration should be given to the repeated use of services by individuals with ID and how commissioning and service frameworks can strike the balance between supporting this and creating a sense of dependence.

Conclusions. In summary, this research provides an initial foundation for research investigating how therapy can be optimised and made more accessible for people with ID. CPs are shown to be skilled at overcoming barriers within therapy; however the process of facilitators creating more barriers and the phenomenon of the revolving door needs to be fully considered within therapy. The findings of this study indicate that the role of CPs within ID services should be multifaceted and take into account wider health and social care needs of clients with ID. Therefore the implications of the findings of this

⁴⁰ Extended paper section 4.4 further discusses critique of study methodology

study are that work should take on a systemic perspective beyond purely individual therapy. Given the potential impact of funding constraints on the role of psychologists and access to psychological therapies for people with ID, this has important implications for the way CPs and carers work people with ID⁴¹.

Journal Article Word Count: 6997 (excluding footnotes, tables and abstract)

⁴¹ Extended paper section 5 offers critical reflections of the research process

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Extended Paper

1. Extended Introduction

1.1 Background information.

1.1.1 Definition of intellectual disability. The definition of ID has not been included in the journal paper due to the chosen journal for publication (Journal of Applied Research in Intellectual Disability) being a specialist ID journal and the editors therefore request that authors assume some degree of expert knowledge for its readership. ID is a social construct with regards to what it means and how it is measured and therefore who is deemed to have an ID has varied over time. Early accounts until the nineteenth century conceptualized ID with regards to deficits in what would now be considered 'adaptive functioning'. Recent years have seen a shift to a professionally driven conceptualisation that emphasises deficits in intellectual functioning (Wright & Digby, 1996). Definitions of ID also vary across countries (Fernald, 1995) in light of a variety of ideological, political, economic and cultural factors (Fryers, 1993). It is therefore crucial to acknowledge the definition of ID that was utilised within this research.

Although there are some variations in terminology or wording of definitions, diagnosis and classification of ID is generally accepted within America and the UK as having three core criteria (e.g., Department of Health [DoH], 2001a):

- 1) A significant impairment in intellectual functioning
- 2) A significant impairment in social and/or adaptive functioning
- 3) The age of onset before adulthood

All three of these criteria must be met for a person to be considered to have an ID. A deficit in cognitive functioning is defined as a score of less than two standard deviations from the mean on a standard IQ test (Emerson & Einfield, 2011). Therefore anyone with an IQ score of 70 or less is considered to have significant intellectual impairment. However, it should also be noted that conceptualisations have changed over time, as prior to 1971 the definition of ID

incorporated people with an IQ of less than one standard deviation from the mean (IQ lower than 85). Therefore it should be noted that any research completed prior to 1971 might include people who would not now be considered to have an ID. Furthermore, to recognise that the term ID is not a description of a homogeneous group, there are three categories that are utilised. These are: mild (IQ: 55-70), moderate (IQ: 40-55) or severe (IQ: below 40) ID (Carr & O'Reilly, 2007). Carr and O'Reilly (2007) estimated that 80% of the ID population in the UK have a mild ID, 12% moderate and 7% have a severe ID.

Not all definitions have previously incorporated the deficit in social adaptive functioning. There appears to have been an overall tendency for clinicians to concentrate on assessment of intellectual functioning only, often due to difficulties in assessing adaptive and social functioning. It seems that the assumption has been that provided a significant impairment in intellectual functioning has been evidenced, similar deficits in adaptive and/or social functioning are likely. However this is not always the case (British Psychological Society [BPS], 2000). The concept of social adaptive functioning relates broadly to an individual's ability to cope on a day-to-day basis with demands of their environment (BPS, 2000). Therefore this should be assessed in the context of a person's age and socio-cultural expectations associated with their environment at any given time. Both the American Association on Mental Retardation (Luckasson et al., 1992) and the diagnostic and statistical manual of mental disorders (American Psychiatric Association, 2000) utilise a criterion of impairments in at least two of the following areas: communication, self-care, home-living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, and health and safety. There has been some criticism that the use of 'at least two' may lack face validity as it may produce some anomalies. For example, where only work and leisure are impaired the extent of the overall impairment of adaptive skills may be questionable. There is also no guidance provided regarding the severity and nature of impairments required in these areas. It is generally accepted and stated by the BPS (2000) that an impairment in social adaptive functioning means that the person requires significant assistance to provide for their own survival skills (e.g., eating and drinking, keeping themselves clean, warm and

clothed) and with social and community adaptation (e.g., social problem solving and social reasoning).

The definition's emphasis on such deficits emerging during the developmental period, therefore before the age of 18 is to purposely exclude people who acquire cognitive deficits later life, for example due to a dementia or brain injury. However, there is some contention with regards to this as some individuals may develop an ID as a result of cerebral trauma before aged 18. This may not be a significant issue if assessments are individualised and are intended to identify a person's support needs. However, if assessments are simply for the purpose of 'gate-keeping', a person may be disadvantaged if this results in the exclusion of a more appropriate service, for example neuropsychology.

As the definition of ID has evolved over time, so have the criteria for inclusion of people with ID in research. Studies investigating people with ID have utilised a number of criteria to limit inclusion in research. For example, early research might favour previous institutionalisation as a sampling criterion (e.g., Floor, Baxter, Rosen, & Zisfein, 1975). Recent years has seen two predominant methods to define samples. More commonly, studies have utilised a definition based on IQ scores alone (e.g., Willner, Jones, Tams, & Green, 2002). However the cut-off scores seem to vary with some studies using a cut-off of 69 plus or minus five (e.g., McGaw, Scully, & Pritchard, 2010) and others including those with an IQ as high as 85 (e.g., Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005). This clearly causes difficulties when reviewing the literature as participants have such varied abilities that they may not be representative of the ID population. Alternatively, some studies have utilised a 'social-systems' definition of ID (Mercer, 1973) in which a person meets the inclusion criteria if they are identified as having an ID by service providers (e.g., Macdonald, Sinason, & Hollins, 2003). Although this method eradicates the difficulty of unavailable intellectual functioning data (i.e. IQ scores) it may ignore a population of people who are unknown to services. Furthermore, it should be noted that there are a number of studies which fail to report any inclusion criteria or demographic information for selected participants (e.g., Sigelman,

Budd, Spanhel, & Schoenrock, 1981), thus again making it difficult to determine whether they have selected a representative sample of the ID population.

Within the current study a more socially constructed definition of ID was utilised in that inclusion is dependent on whether the person has accessed a specialist psychology ID service. However, where results from previous cognitive functioning assessments are available, they will be accessed in order to consider whether the sample is likely to be representative of the ID population. Although it has been explicitly stated within the inclusion criteria that participants should meet the criteria for an ID, it is important to consider that the specialist ID services may accept those with a borderline level of intellectual functioning (IQ: 70-85). This may be a result of a lack of a cognitive assessment, an inability to complete a cognitive assessment initially due to risk or high levels of distress from the client, or because it is felt that the need is best served by a specialist ID service despite not meeting the IQ cut-off of 70. It is therefore possible that the current study may recruit individuals with a borderline ID. Furthermore participants must have capacity to consent to participate in this research. It is therefore likely that the sample may not have representatives from the moderate or severe ranges of ID. Such considerations will be further discussed in relation to the recruited participants in the extended discussion section.

1.1.2 Terminology. The current study will utilise the term 'intellectual disability' (ID) within the report. This is the term that is preferred by the selected journal for publication and is often utilised within American and Australian research. There are a number of other terms that have been used for this population including: learning disabilities, mental handicap, developmental disabilities and mental retardation. The term 'learning disability' is in common use in the UK, particularly within services, therefore there may be instances where participants have utilised the term 'learning disability'. As a result there may be some occasions where the term is used interchangeably. Within the current study where other terms occur in the literature are used they will be replaced by the term 'intellectual disability' with the exception of direct quotes from participants. Furthermore the ethical approval procedure was undertaken

before the journal for publication was chosen and therefore the majority of supporting documents including consent forms, information sheets and ethical approval letters utilise the term 'learning disability'.

The term 'learning difficulty' has been expressed by some advocates for people with ID as the preferred term as a result of the stigma associated with the term 'intellectual disability' (Walmsley, 2001). However, it is thought that this term can cause confusion with specific learning disorders such as dyslexia and dyspraxia therefore this recommendation was not adopted in the current study. With this in mind, this recommendation raises an important issue with regards to the lingering stigma that the label 'intellectual disabilities' carries with it, which can have a number of consequences for people including psychological distress, isolation within the community, bullying and inequality within society, services and schools (Ho, 2004).

1.2 Psychological therapy for people with intellectual disabilities.

1.2.1 The evidence base for psychological therapies for people with intellectual disabilities. Over the past 15 years psychological therapy for people with ID has been increasingly advocated (e.g., Lington, 2002). Nagel and Leiper (1999) completed a survey of the interventions used by CPs in ID settings which suggested that psychological therapy is now in widespread use in this population. This study showed that behavioural interventions through carers were the most common intervention (utilised by 81% of the sample). Other common approaches included organisational interventions (42%), direct behavioural work with clients (34%), cognitive behavioural therapy (CBT; 35%), humanistic and person centred (31%) and psychodynamic (17%). It would be interesting to see how this might have changed over the last 15 years however there is no more current research available regarding this.

Past discourses regarding psychological therapy for people with ID have moved from "is it relevant?" in the 1980s, to "is it equitable?" to the most recent discourse within the literature of "is it effective?" (Beail & Warden, 1996). The increased availability of therapy for people within this population is welcomed by

professionals with regards to the rights to treatment for a disadvantaged and often excluded group (Bender, 1993). However whether this shift is based on evidence that these approaches are useful and effective for people with ID will now be considered.

Beail (1995) completed a review of reports concerned with the use of psychodynamic psychotherapy for people with ID. Out of 23 patients within these reports, only nine of the cases provided outcome data and although these reported outcomes appeared encouraging in almost all cases, the evaluation was descriptive and anecdotal. Since this time Beail has published two studies utilising more objective measures. Beail and Warden (1996) found that ten patients with a range of presenting problems (aggression, sexually inappropriate behaviour and psychotic symptoms) showed significant decreases in psychological symptoms and increases in self-esteem at the end of therapy and at three month follow-up. The second publication (Beail, 1998) reported the elimination of problem behaviours in all 12 referred patients and complete eradication of all offending behaviour in eight sex-offenders. Furthermore these gains were maintained at 6 month follow-up. The latter study included no control group, however problem behaviour maintained stable for four participants who did not complete the therapy. This supports previous findings postulating that spontaneous remission of problem behaviours is uncommon in people with ID (Eyman, Borthwick, & Miller, 1981). Although Beail (1998) recognised that such positive outcomes could be attributed to person-centred counselling, rather than the specific approach adopted and that the processes underlying the successful treatment outcomes are uncertain, such findings demonstrate the potential value of this approach and the requirement for more research in this area.

CBT emphasises empiricism and utilises rigorous scientific investigation of its clinical efficacy through randomised control trials (RCTs). Through this, CBT has provided evidence to support its use for most psychological presentations (National Institute for Clinical Excellence [NICE], 2004; 2005; 2009; 2010; Roth & Fonagy, 2005). The Royal College of Psychiatrists (2004) concluded from a review that the lack of good quality research evidence to support the use of psychological therapies with people with ID is partly a result of ID routinely

being used as an exclusion criterion for research. The so called 'therapeutic disdain' (Bender, 1993) has historically limited the availability of these techniques for people with ID. However, they also surmised that albeit limited, evidence for the effectiveness of approaches for individuals with ID including CBT is promising, particularly for anger difficulties (e.g., Taylor, Lindsay, & Willner, 2008). Flynn (2012) argues that CBT continues to dominate psychotherapeutic research for people with an ID; however, research supporting its effectiveness is aging with few recent additions.

Randomised control trials (RCTs) are often considered to be the 'gold standard' of research and are encouraged when building an evidence base for treatment effectiveness. A report by Oliver et al. (2002) identified some obstacles for conducting RCTs with people with ID. Firstly, some ethical dilemmas have been noted, particularly regarding randomisation. These seem to be a reflection of the need for the offered interventions within the RCTs to be evidence based. However, whether this concern is typical of ID services is questionable as there have been several RCTs of non-evidence based drug trials with people with ID (e.g., Brylewski & Duggan, 2004). Secondly, methodological barriers were encountered including involving carers in decision-making, and the relatively limited client base of many ID services meaning that group comparisons are likely to be small and thus generalisation and statistical power is often problematic (Oliver et al., 2002). Finally, RCTs can be problematic to measure therapeutic approaches. This is because if different therapists are used, the competence and personal characteristics of the therapist as well as the differences in the therapeutic relationships of participants and their therapist are likely to have an impact on the research outcome. Even if the same therapist was to be used for all participants, the differences in the therapeutic alliance are still likely to vary between participants. Furthermore, if the same therapist was used, the preferences and expectations of the therapist with regards to the different therapeutic approaches being measured in the RCT are likely to impact on the outcome. As a result, although RCTs have their place within the evidence base, they are not without their limitations and as such, other research methodologies including qualitative methods and single case designs can offer value to the increasing evidence base.

1.2.2 Attachment theory and the importance of the therapeutic relationship when working with people with intellectual disabilities.

Attachment theory is based on the concept that our experiences of relationships in childhood have a significant influence on how we develop and maintain interpersonal relationships in later life (Bowlby, 1973). Within the first two years of a child's life the child and care-givers form a marked pattern of 'secure' or 'insecure' attachment behaviour (Ainsworth, Blehar, Waters, & Wall, 1978; Main, Kaplan, & Cassidy, 1985). Ainsworth et al. (1978) postulated that an individual is likely to develop a 'secure attachment style' if caregivers within their early life are responsive and sensitive to distress. This 'secure attachment' is characterised by active seeking of the child to maintain proximity to the caregiver, who is said to be a 'secure base'. This is associated with the development of self-esteem, positive affect, autonomy, better capacity to manage distress and better ability to form and maintain relationships (Berry, Wearden, Barrowclough, Oakland, & Bradley, 2012; Carr, 2003).

Ainsworth et. al. (1978) postulated three types of 'insecure' attachment style, namely, avoidant, ambivalent and disorganised. Primary caregivers who have not learnt to manage their own negative emotions may find it difficult to cope with such emotions expressed by their children (Gerhardt, 2006). In such cases, these children learn to avoid the expression of emotions in order to maintain proximity to their caregiver. To further support this theory, research has found that these children can externally appear calm but internally their arousal levels indicate high levels of anxiety (Gerhardt, 2006). In cases such as these, children are said to develop an 'avoidant attachment style' (Ainsworth et. al., 1978). This attachment style is linked to consistent neglect or criticism from early caregivers and is further characterised by negative beliefs about others, inhibition of affect and avoidance of relationships (Crowell & Treboux, 1995; Shaver & Mikulincer, 2002).

Conversely, some caregivers may be more inconsistent in their responses to the child's emotions, whereby they sometimes show concern but on other occasions ignore the expression of feelings (Gerhardt, 2006). Therefore the children of these caregivers tend to keep their feelings close to the surface until

the optimum moment when they believe they are more likely to get the response they seek. As a result, their strategy is to exaggerate emotions and to be excessively aware of their needs and fears. Such characteristics are termed as an 'ambivalent' attachment style (Ainsworth et. al., 1978). Finally, when caregivers have been incapable of providing the most basic parental functions of protection and providing a secure base, and the children have not been able to develop a consistent or coherent defensive strategy they are said to develop a 'disorganised' attachment style (Gerhardt, 2006).

With regards to people with ID, Champion (2010) postulates that often these individuals are born prematurely and spend significant periods of time in intensive care, which can lead to disrupted early attachments. It is thought that when the child is incubated, it can disrupt bonding between the infant and parent because the caregiver has limited physical contact with the child and because the child is often not able to be held or fed in the usual way due to physical health and fear of infection. Rejection of children with ID by early caregivers (either consciously or sub-consciously) is said to be very common and can lead to a disruption in attachments or the lack of any attachment being formed (Murphy, 2014). Furthermore, when people with ID live within a care system or residential environments in which there is a high number of staff providing care, there can be disruptions in attachments. This is because often in such cases there is inconsistent care provided and therefore a reduction in opportunities to form meaningful and consistent attachments to another person (Murphy, 2014). Finally, research has shown that people with an ID are more likely to experience abuse and trauma than people within the general population (Deb, Thomas, & Bright, 2001). If a person has experienced abuse or been raised within an abusive environment, this is also likely to disrupt the formation of attachments (Murphy, 2014). On the basis of early attachment relationships, a person develops expectations about the role of themselves and of other people within relationships. For example, they may expect that all relationships will result in rejection or abuse. As such, this will undoubtedly affect how they relate to others in all kind of relationships, including the therapeutic relationship with their CP.

The therapeutic relationship is characterised by many features (e.g., warmth, empathy, attunement) which can activate a client's attachment experiences and expectations of relationships. Similarly to care-giving relationships, the CP is emotionally available, offers a comforting environment and affect regulation and potentially a sense of a secure base from which the client can explore emotions and internal experiences (Holmes, 1999). Thus, attachment theory can offer some insight into the relational process impacting on therapeutic change (Bender et al., 2003; Jordan, 2007; Woodhouse, Schlosser, Crook, Ligiéro, & Gelso, 2003). For example, Mallinckrodt, Gantt and Coble (1995) found that individuals with an avoidant attachment style tend to mistrust their therapist and be afraid of rejection. Furthermore these clients showed a strong need for emotional closeness but simultaneously felt uncertain apropos their capacity to establish a supportive and fulfilling relationship as a result of their previous negative experiences, their negative expectations of others and the need for approval from others. Within therapy, the client's patterns of relating to others can manifest and the client can attempt to 'pull' the therapist into responses that are familiar and predictable to the client. For example, clients with an avoidant attachment style may attempt to avoid developing an attachment with the therapist and increase interpersonal distance, thus eliciting a disengaged or distancing response from the therapist in which the therapist may feel hopeless and disconnected from the client. Conversely, for those clients with an ambivalent attachment style, strategies to increase interpersonal closeness may be utilised such as communicating their sense of helplessness and dependency, thus potentially eliciting a rescuing response from the therapist (Mallinckrodt, 2000; Shilkret, 2005). Therefore, from an attachment perspective, clients behaviour is meaningful within the therapeutic relationship and the therapists awareness of the strategies adopted by the client to maximise emotional safety can be used to facilitate empathy and offer insight into new and helpful ways of relating to others through the therapeutic relationship (Skourteli & Lennie, 2010).

1.2.3 Engagement in therapy and psychological models of change.

Howells and Day (2003) argued that 'readiness' for therapy is an important issue for effectiveness of therapy. Several factors that can affect willingness to

engage have been suggested by Willner (2006) including: the clients motivation to engage which could be influenced by their confidence to complete emotionally and intellectually challenging therapy; their level of self-efficacy and self-determination; whether the referral was voluntary or coerced; the skill of the therapist to adapt therapy; and the level of support or obstruction from carers. Three widely cited psychological theories of change will now be considered in relation to engagement in change within therapy, namely, the theory of planned behaviour (TPB), the trans-theoretical model of change and Maslow's hierarchy of needs.

Theory of planned behaviour. One widely cited theory to explain behaviour is the theory of planned behaviour (Ajzen, 1985, 1991; Ajzen & Madden, 1986) which could aid understanding as to what would encourage engagement in therapeutic change for people with ID. TPB evolved from the theory of reasoned action (Fishbein & Ajzen, 1975) which postulates that intention to act is the biggest predictor of behaviour. Further to this, TPB posits that intention is an outcome of the combination of attitudes towards the behaviour (see Figure 4). As such, evaluation of the behaviour (both positives and negatives), expected outcomes and subjective norms which are social pressures placed on the individual from their perceptions of what other people think they should do, as well as their proclivity to comply with these, impacts on behaviour. TPB further postulated that perceived behavioural control further influences both intention and the behaviour. Therefore, considering that often people with ID are referred to therapy by someone else, they should be supported to consider their beliefs about behaviour outcomes, evaluate expected outcomes from behaviour change, consider normative beliefs from others and the benefit and therefore their motivation to comply with these and their perceived level of control over change. The latter consideration may be particularly important as people with ID may be used to being in relationships where things are done for them, therefore their perceived level of control over their life and behaviour may be minimal and thus impact on their intention to change behaviour. It is thought that if such aspects are not considered, and the person does not have any intention to make changes, then any changes that do occur within therapy due to acquiescence or to please the CP may not be

maintained post therapy. Furthermore, this theory may be helpful when involving carers within therapy to assess their intention to support the person based on their beliefs that the client with ID is able to make changes.

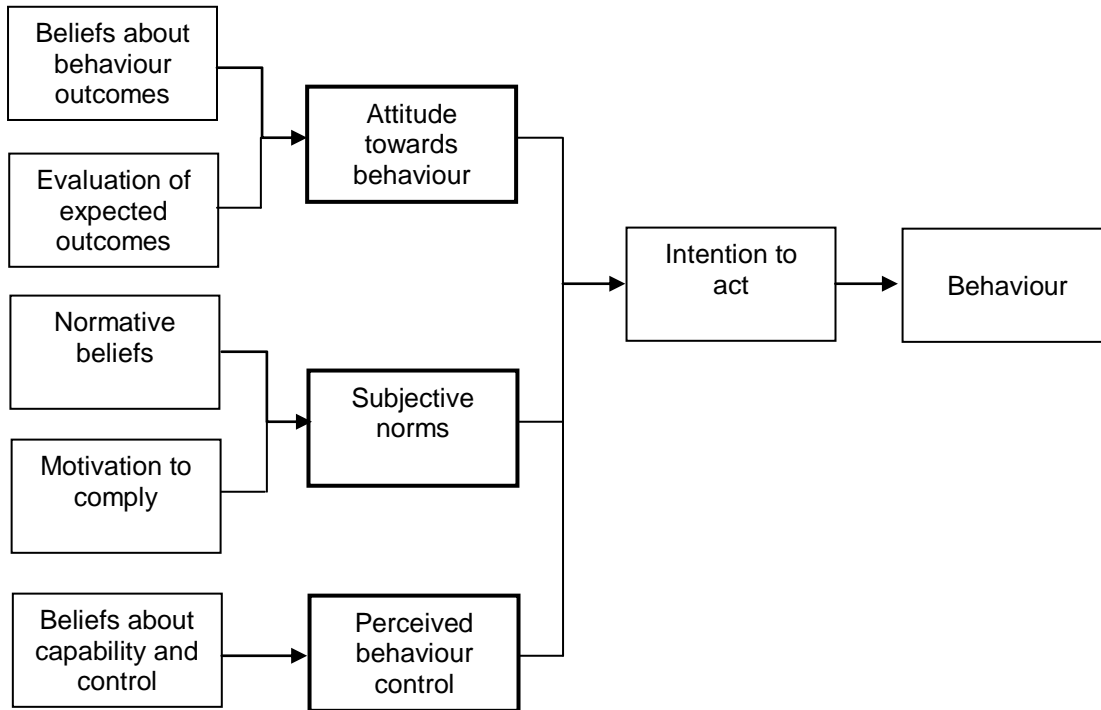


Figure 5. Theory of planned behaviour (adapted from Munro, Lewin, Swart, & Volmink, 2007)

Munro et al. (2007) report strong correlations between both attitudes towards the behaviour and perceived behavioural control with the actual behaviour. However, only weak correlations have been found between subjective norms and behaviour. Although Armitage and Conner (2001) postulate that this is more likely a result of methodological issues apropos how the studies measured subjective norms. The studies that were deemed by Armitage and Conner (2001) to measure subjective norms more appropriately found stronger associations with behaviour. It has been argued that TPB is not useful or effective for planning and devising treatments to encourage engagement in behaviour change (Hardeman et al., 2002; Taylor et al., 2006; Webb, Joseph, Yardley, & Michie, 2010). However TPB could help explain and predict probable behaviour and as such could be a useful contribution to help identify particular

behavioural influences that can be targeted in order to encourage engagement in change and therefore for positive change to occur (Morris, Marzano, Dandy, & O'Brien, 2012).

Trans-theoretical model of change. The trans-theoretical model of change (Prochaska, 1979; Prochaska & DiClemente, 1983; Prochaska, DiClemente, & Norcross, 1992) is a widely cited cognitive model which divides behaviour change into five categories that represent different milestones within the change process. These are: (1) pre-contemplation, (2) contemplation, (3) preparation, (4) action, and (5) maintenance (see Table 4 for a summary). It is posited that progression through the stages is powered by self-efficacy and the outcome of a pros and cons assessment of the behaviour (Armitage, Sheeran, Conner, & Arden, 2004; Heimlich & Ardoin, 2008). This theory appears to be more commonly used by clinicians rather than researchers because the model has been criticised for its lack of clarity in the definition of the concepts (Morris et al., 2012). Furthermore, it is often noted that the rigidity of stages is unclear and whether an individual must move through each stage and not skip stages is a common criticism for this model (Morris et al., 2012). Additionally, it is not clear how individuals change from this model nor does it encapsulate why some people change more effectively or more quickly than others. Considering that people with ID often have a wide system of people around them to support them to make changes, the fact that this model is egoistic and misses the social and environmental influences on behaviour change is problematic. There is no available research with regards to the use of this model, or many other widely cited models of behavioural change (e.g., TPB) for people with ID. It therefore should be queried whether such models are transferable to this population, whether such models can be adapted to be relevant for people with ID or whether new theories of change should be developed for people with ID. Possible adaptations based on the findings from this research will be considered within the extended discussion section.

Table 7:

The stages of change model (adapted from Prochaska et al., 1992)

Stage	Stage Definition	Process	Process Definition	Psychotherapy Interventions
1. Pre-contemplation	Individual is unaware of problems. No intention to change behaviour	Consciousness raising	Increasing information about self and problem	Observations, confrontations, interpretations
		Dramatic relief	Experiencing and expressing feelings about one's problems and solutions	Psychodrama, grieving losses, role playing
		Environmental re-evaluation	Assessing how one's problem affects physical environment	Empathy training, documentaries
2. Contemplation	Individual is aware of problem. Serious consideration of change in behaviour	Self re-evaluation	Assessing how one feels and thinks about oneself with respect to a problem	Value clarification, imagery, corrective emotional experience
3. Preparation	Individual is intending to take action	Self-liberation	Choosing and commitment to act or belief in ability to change	Decision-making therapy, commitment enhancing techniques
4. Action	Individuals modify their behaviour, experiences and/or environment in order to overcome problem	Counter-conditioning	Substituting alternatives for problem behaviours	Relaxation, desensitisation, assertion, positive self-statements
		Stimulus control	Avoiding stimuli that elicit problem behaviours	Restructuring environment, avoiding high risk triggers
		Helping relationships	Being open and trusting about problems with someone who cares	Therapeutic alliance, social support, self-help groups
		Reinforcement management	Rewarding one's self or being rewarded by others for making changes	Contingency contracts, overt and covert reinforcement, self-reward
5. Maintenance	Individual works to prevent relapse and consolidate gains	Social liberation	Increasing alternatives for non-problem behaviour	Advocating rights for the oppressed, empowering, policy interventions

Maslow hierarchy of needs. Maslow's hierarchy of needs (Maslow, 1943; 1970) is a five stage model of motivation for change (see figure 5). These stages include: 1) physiological needs (oxygen, food, water); 2) safety needs (security and protection); 3) social needs for love, belongingness and affection (overcome loneliness and alienation); 4) need for self-esteem and esteem from others (respect, social stability, confidence and sense of value) to prevent feelings of inferiority weakness, helplessness and worthlessness; and 5) self-actualisation. Self-actualisation is a person's need to be and do what they were 'born to do'. This is about realising personal potential, self-fulfilment, seeking personal growth and peak experiences. Basic needs are thought to motivate people when such needs are not met.

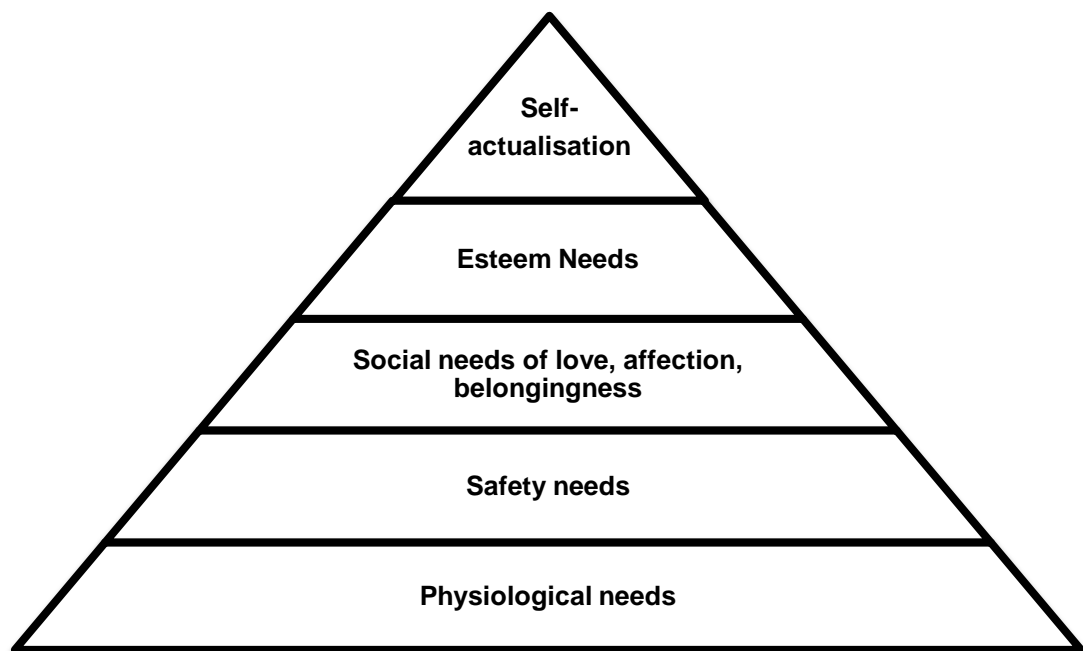


Figure 6. Maslow (1943) hierarchy of needs

The theory postulates that basic lower needs must be met before progressing on to meet higher level needs towards self-actualisation. Furthermore Maslow (1970) posits that every person is capable of moving up the hierarchy. However, current literature does not consider what self-actualisation might look like for people with an ID. This should be considered within therapy to assess what the person wants from life, what their personal potential is, and how they can feel

fulfilled as each person will have different perspectives of this. By definition, many people with ID may have difficulties with social-adaptive functioning and therefore difficulty in getting even the most basic of needs met independently. They therefore rely on others to help them meet such needs and therefore before self-actualisation can be considered within therapy, it must be ensured that more basic lower needs are met and that the person is receiving the appropriate support for this.

1.2.4 The impact of cognitive function on therapy. Cognitive ability can also impact on a person's ability to engage in therapy (Taylor et al., 2008). Much of the research on the impact of cognitive function on therapy has been completed with CBT specifically due to its overall dominance within the literature as a therapeutic approach. The suitability of therapy (specifically CBT) for people with ID has been questioned in the literature and therefore authors have outlined the importance of pre-therapy assessments to examine a client's ability to link activating events with beliefs and consequences (Dagnan, Chadwick, & Proudlove, 2000; Dagnan & Chadwick, 1997). Furthermore the authors report that that some adults with ID will need introductory training to help them grasp CBT concepts, and some people will not be able to benefit from CBT. Thus, CBT may only be accessible to people with mild ID. However, considering that up to 80% of people with ID are said to have a mild ID (Carr & O'Reilly, 2007) it is thought that the majority of people with ID should be able to benefit from therapies such as CBT. Lindsay (1999) reported that essential aspects of Beckian CBT including agenda setting, testing cognitions and setting homework (e.g., Beck, Rush, Shaw, & Emery, 1979) can be retained, whilst adapting and simplifying specific techniques for this client group. Hurley, Tomasulo and Pfadt, (1998) emphasise that all therapists, no matter what approach is adopted, should adapt their approach to every individual client, therefore making adaptations for people with ID who have a deficit in cognitive function should not be problematic. They identified nine ways in which all psychological therapies can be adapted for adults with ID so that they are able to understand and benefit from therapy (see Table 5).

Table 8:**Adaptations of psychotherapy for individuals with intellectual disabilities (Hurley et al., 1998)**

Adaptation	Definition/Example
Simplification	Reduce complexity of technique; breakdown interventions into smaller chunks, shorter session length.
Language	Use short sentences and simple words.
Activities	Augment typical techniques with activities to deepen change and learning. Add drawings, homework assignments.
Developmental Level	Integrate developmental level into presentation of techniques and material. Use games; assess development into relevant social issues.
Directive Methods	Outline treatment goals, progress, give extra 'visual' guides.
Flexible Methods	Adjust usual techniques to suit cognitive level and lack of progress.
Involve Carers	Use family, support staff to help with change. Assign homework or rehearsals at home with the help of staff or family.
Transference/Counter-transference	Attachments are stronger and quicker. Therapists urged to be stronger in boundaries and to utilise supervision.
Disability/Rehabilitation Approaches	Issue of disability must be addressed within treatment; therapist must raise issues and support positive self-view

1.2.5 Involving carers in therapy. Psychological services have been slow to respond to the emotional and mental-health needs of people with ID (Bender, 1993; Gardner & Smyly, 1997; Sinason, 1992; Wright & Digby, 1996). It is therefore unsurprising that services have also been slow to respond to the emotional needs of families and carers of people with ID (Baum, 2006). The service's philosophies of individualisation have tended to pathologise the person with ID by seeing the problem as inherent to the person and therefore ignoring the wider resources of the person (Baum, 2006). Conversely, systemic approaches can be a helpful approach to understanding the benefit of involving carers through its emphasis on the contextual and relational aspects of people's difficulties. Historical and political contexts have impacted on the way systemic approaches have evolved over time (Fredman, 2006). The mid 1950s to 1970s saw the first phase which began the consideration of problems having stemmed from interpersonal factors, rather than intrapersonal, thus providing a rationale for involving people's wider system within therapy. Concepts such as context, connections in relationships, communication and circularity were considered

within this phase. Developments such as collaborative practice and curiosity of multiple perspectives were generated within the second phase (mid 1970's to 1980's). Finally, concepts including power dynamics, co-creating meanings, choice and competence developed in the third phase (mid 1980's to 2000's).

Within ID services systemic approaches are a well-established practice and they may offer several advantages over interventions which focus on the individual. One benefit of this approach is that it emphasises the importance of context of the problem. Therefore, not only families, but all member of the wider system including carers, GP and other professionals are all included and are considered to have a role within the maintenance of problems or to help overcome problems. For many individuals with ID, life-cycle transitions bring increased emotional distress and their wider system, which can be exacerbated by discrimination and blame (Fidell, 2000; Turnbull, Summers, & Brotherson, 1986). As systemic approaches actively consider the life-cycle and issues of power, such difficulties may be better addressed through a systemic approach (Baum, 2006). Additionally, the boundaries of professional agencies and carer responsibilities can often become blurred when many services are involved (Vetere, 1993). In order to negotiate the complexity of relationships and communications between sub-systems which can be confusing for carers (Mitchell & Sloper, 2000) systemic approaches can be a helpful approach. Finally, from a systemic perspective problems and difficulties are understood within the context in which they emerge and within the context of inter-personal relationships.

We know that families and carers are important in the lives of people with ID (Felce, 1988). For people with ID, staff can provide the main source of social interaction (Felce, de Kock, & Repp, 1986; Hastings & Remington, 1994). Carers are usually the people that individuals with ID communicate their distress too, and they are usually the people that attempt to meet their needs as well as enable access to specialist services. Therefore any model of intervention, systemic or individualised, needs to acknowledge this role of carers and help support them to care for the client (Varela, 2014). Attitudes and emotions of staff are crucial predictors of the type of care they provide. When a

client is labelled as challenging and perceived to be in control of their behaviour, staff are thought to be less sympathetic (Markham & Trower, 2003) and are more likely to utilise seclusion and medication (Duxbury, 2002; Duxbury & Whittington, 2005) and a reduction in helping behaviour is often displayed (Sharrock, Day, Qazi, & Brewin, 1990). Harper and Wadsworth (1993) found that whilst clients with ID may describe their experiences in emotional words (e.g., I feel angry), paid carers are more likely to focus on observable behaviour (e.g., they hit someone) rather than personal experiences or meaning of behaviour. It is also noted that carer's behaviours and emotions can be intrinsically linked to the maintenance of challenging behaviour of clients, thus socially reinforcing the behaviour (Duxbury, 2002; Hastings & Remington, 1994). For example, aggressive behaviour that increases social attention may be reinforced. Therefore involving carers can both be helpful in the generation of therapy goals and formulations as well as including them in interventions to reduce unhelpful behaviours in clients and reinforce more adaptive behaviours. Furthermore as therapists tend to see clients once per week, carers are able to more frequently and consistently reinforce behaviours in the client's everyday life.

1.3 Mental-health and people with ID.

1.3.1 Prevalence rates of psychiatric disorders in people with intellectual disabilities. While studies of psychiatric disorders within people in the general population report a prevalence rate ranging between 16% to 25% (Goldberg & Huxley, 2001; Meltzer, Gill, Petticrew, & Hinds, 1995) prevalence rates of psychiatric disorders for people with ID are reported to range between 20% to 39% (Hatton & Taylor, 2005). Prior to this study, prevalence rates for people with ID were reported to range between 10% to 80% depending on the definitions of the disorders, methods of participant identification and the population studied (Borthwick-Duffy, 1994; Campbell & Malone, 1991). Within these studies, higher prevalence rates of 40% upwards were usually due to behavioural problems being included as a psychiatric disorder (e.g., Gillberg, Persson, Grufman, & Themnér, 1986) or if the sample were individuals who had

been referred for a psychiatric evaluation (e.g., Bouras & Drummond, 1992; Pary, 1993). Lower prevalence rates of 15% and below tend to use case notes in order to identify whether a psychiatric diagnosis is present, thus potentially missing out on data that has not already been collected and reported within the persons clinical notes (Borthwick-Duffy & Eyman, 1990; Reiss, 1990). For those studies whose prevalence rates fell within the middle of the two extremes (ranging between 25% and 40%) they often utilised a sample of the general population of people with ID and assessed psychiatric disorders with a psychiatric evaluation tool (Hatton & Taylor, 2005; Iverson & Fox, 1989; Lund, 1985; Reiss, 1990). Thus, those studies which report prevalence rates of between 25% and 40% appear to utilise better methodological approaches within their research and this is therefore likely to be a more representative range of prevalence of psychiatric disorders in people with ID. Further differences in prevalence rates across studies are also likely to be a result of the variety of definitions of ID utilised within the research (as discussed in section 1.1.1). There have also been differences between the levels of ID noted with regards to prevalence of psychiatric disorders. People with mild ID are more likely to have a psychiatric disorder than those with a severe ID (Borthwick-Duffy & Eyman, 1990; Bouras & Drummond, 1992; Jacobson, 1990). Although there is no current evidence to support this, this may be a result of people with mild ID being more aware and therefore more distressed or frustrated apropos their deficits. Conversely, this difference may be a reflection of the caution of clinicians to diagnose people with a severe ID and limited communication skills; or the increased likelihood of a person with a psychiatric diagnosis and borderline ID being included within the research and labelled as mild ID (Emerson, Hatton, Dickson, Gone, & Caine, 2012). It should also be noted that prevalence studies referenced within this section are ten years old or more. There were no available studies that were more recent than this. As more people with ID are now living to an older age, more current research into prevalence rates is required to provide a more representative account of prevalence of psychiatric disorders for this population. Particularly because dementia is becoming an increasingly important issue for ID services (Patel, Goldberg, & Moss, 1993).

1.3.2 Vulnerability of people with intellectual disabilities to mental-health problems. It has been reported that people with ID are more likely to experience a number of negative life events that are associated with mental-health problems than people in the general population (Brown, 2000). For example: unemployment, poverty, a lack of friendships, other meaningful relationships and support networks, stressful family circumstances, birth trauma, institutionalisation, stigmatisation and traumatising abuse (Deb et al., 2001; Emerson, Hatton, Dickson, Gone, & Caine, 2012; Emerson, Hatton, Felce, & Murphy, 2001; Hastings, Hatton, Taylor, & Maddison, 2004). Not only are people with ID more likely to experience stressful life events, they are also reported to have a reduced capacity to cope with stressful life events as a result of fewer psychological and cognitive resources, including memory and problem solving skills (Reiss & Benson, 1984; Szymanski, 1994; Van den Hout, Arntz, & Merckelbach, 2000).

One of these factors that people within the general population are not likely to experience, whereas people with ID are, is stigma. Stigma can be detrimental to psychological wellbeing (Emerson et al., 2012) and therefore the impact of this will be further considered. Werner, Corrigan, Ditchman, and Sokol (2012) define stigma as encapsulating cognitions, emotions and behaviour which relate to stereotypes, prejudice and discrimination. As a result of the negative evaluation produced by stigmatisation, attitudes and stereotypes about a population of people, prejudice and discrimination apropos the group is generated (Corrigan, 2004). Research shows that people with ID are one of the most highly stigmatised groups within society (Thomas, 2000) and people with ID experience stigmatisation related to their disability as emotionally distressing (Beart, Hardy, & Buchan, 2005; Jahoda, Wilson, Stalker, & Cairney, 2010).

Labelling theory (Scheff, 1974) postulated that when given a label, for example 'mentally ill' or 'intellectually disabled', expectations are put onto the individual which they ultimately start to meet. As such 'self-stigma' is created and the expectations become somewhat a self-fulfilling prophecy. Corrigan, Larson and Ruesch (2009) posit the 'why try' model of self-stigma in which the person is aware of the attitudes encapsulating them (e.g., people with ID cannot cope

independently), agree with these attitudes (e.g., it is true that people with ID cannot cope independently) and finally apply these attitudes to themselves (e.g., I have an ID therefore I am unable to cope independently). It is also noted that people can respond differently to self-stigma. Some people may experience decreased self-esteem and self-efficacy as a result of self-stigma and therefore present a behavioural response of 'giving in' to the belief and behaviour begins to reflect the stereotypes (Markowitz, 2001). Conversely, some people may feel somewhat empowered by stigma and as a result of anger of the label people feel motivated to disprove stereotypes (Corrigan, Faber, Rashid, & Leary, 1999). When considering differences in reaction to stigma Corrigan and Watson (2002) report that the extent to which the person agrees with the initial attitudes and stereotypes and the extent to which they associate themselves with the labelled group mediates their response. For some people with ID, they may attempt to avoid the distress associated with the stigma of their label they may utilise a 'cloak of competence' (Edgerton & Bercovici, 1976). This means that people may utilise strategies to mask their deficits in order to appear more competent than they actually are. This may further reinforce stereotypes for some people if they refuse to engage with therapy and may therefore be perceived as lacking insight, being un-cooperative and unable to change (Aunos & Feldman, 2002). Therefore stigma continues and people with ID continue to be isolated and marginalised within society which continues to contribute to their vulnerability to mental-health problems.

1.3.3 The inclusion movement and current government policy. In the 1970s and 1980s, ideals of normalisation were a key influence for changing the discourses regarding people with ID. Nirje (1980) posits that these principles advocate that patterns of life and conditions of everyday living should be made available for people with an ID which are as close as possible to the regular circumstances and ways of life in society. Furthermore growing evidence indicated that people with ID were able to learn and change their behaviour (Rice, 1968). Concurrently, UK government policy began to advocate moving people with ID into community based care and out of institutions (Department of Health and Social Security, 1971). Therefore most people with ID now live in the community but nevertheless remain among the most disadvantaged in society

(Emerson, Davies, Spencer, & Malam, 2005; Emerson & Hatton, 2008). Furthermore, the Joint Committee on Human Rights (JCHR; 2008) postulates that for people with ID, a violation of human rights is 'a normal part of their everyday lives' (p. 16).

In recent years there has been a surge of interest in promoting rights, choice and inclusion for people with ID (DoH, 2007). The introduction of the Valuing People white paper (DoH, 2001a) saw a decisive change to thinking about provision for people with ID in England, in that 'inclusion' was placed firmly on the policy agenda. Policy imperatives that promote service user involvement have resulted in a variety of service-users with mild and moderate ID being included in health and social care planning and furthermore within research (Boxall, Carson, & Docherty, 2004; Boxall, Warren, & Chau, 2007).

Furthermore, recent years have seen a shift from research 'on' service-users with ID towards research 'with' service users with ID and as such people with ID have been included throughout the research process (Stalker, 1998). The NHS Plan (DoH, 2000) and the research governance framework for health and social care (DoH, 2001b) further reinforced the importance of user participation in research to give people a 'voice' regarding services devised for them. Therefore including people with an ID was important within the current study to encourage service-user engagement in research.

2. Extended Method

2.1 Epistemological position. It is important to acknowledge the epistemological position within research as this can guide and shape the sort of knowledge created and the methodological frameworks utilised (Braun & Clarke, 2013). This study is grounded within the ontological perspective (how we understand the nature of reality) that there is a true reality, but it can only be apprehended and measured imperfectly, and our understandings are tentative (Ponterotto, 2005). Bhaskar (1998) postulates that this ontological perspective suggests that there exists a reality external to what can be observed and it has three premises. Firstly, the premise of empiricism, which encompasses aspects that are able to be observed within our direct experience. Secondly, the actual premise is concerned with all that transpires, despite whether it is observed or not. Finally, the real premise encapsulates all that is existent including the processes that underlie a phenomena (Sayer, 2000). As a result, the undertaking of research should be to “investigate and identify relationships and non-relationships, respectively, between what we experience, what actually happens and the underlying mechanisms that produce the events of the world” (Danermark, Ekström, Jakobsen, & Karlsson, 2002, p. 21). Therefore, from this epistemological and ontological perspective, thematic analysis seeks to scrutinize the experiences of people with ID, their carers and the CPs, exploring how they connect their observable experience with events outside of their observations, as well as the processes which potentially underlie these events.

The epistemological position (the nature of knowledge) taken within this study is a critical realist position which postulates that “truth” is the prevailing consensus, at any time, regarding multiple perspectives of a phenomenon (Barker, Pistrang, & Elliott, 2002). By taking this epistemological stance, it is accepted that ‘multiple valid descriptions and explanations of the same phenomenon are always available’ (Hammersley, 2004, p. 243). Realists such as Pawson and Tilley (1997) argue that to promote the validity of studies regarding therapy, they must acknowledge that the clinicians, clients and carers will have different viewpoints on what promotes or inhibits effectiveness. Therefore the perspectives of individual participants within this study can be

explored to develop a tentative, consensual understanding about barriers and facilitators to positive therapeutic change for people with ID.

The fact that qualitative research from a critical realist perspective may examine phenomena based on people's accounts of events and experiences rather than exploring an observable entity may be seen as a disadvantage; however this is not necessarily the case. For example, Madill, Jordan, and Shirley (2000) report that all individual's accounts are subjective and consequently not invalidated by perspectives that contradict them. Within this study, it is probable that clients with ID will offer conflicting narratives to those of CPs and both clients and CPs narratives may further conflict with carer's accounts. A critical realist perspective recognises that any narrative is influenced by a person's past experiences, beliefs and history (Bunge, 1993) and that composed knowledge is therefore essentially subjective. Therefore the current research does not aim to generate an objective account of participant's experiences, but rather a contextual account of their viewpoints.

This study has utilised a mixed inductive-deductive approach to explore the semantic content of the data presented by participant's accounts of their experiences and therefore did not actively pursue implicit meaning or interpretations within the data (Braun & Clarke, 2006). Therefore the analysis aimed to explore what is already known about in the topic area, whilst allowing new concepts to be generated. A semantic approach was chosen over a latent approach to advocate minimal use of subjective interpretation. This allowed the first author to identify common semantic themes and reduce potential biases of the researcher as much as possible. Furthermore it was thought that a semantic approach would reflect participants with IDs own concrete representations of themselves and their experiences. The first author liaised with the second author through supervision and the use of reflective diary to reduce the impact of research biases and maximise the reliability of the analysis.

With regards to the transferability of findings, critical realism can offer a useful perspective which is based on broader ideas of consensus and coherence theories of truth (Bisman, 2010). A description or narrative is therefore believed to be worthwhile and valid if there is an overall agreement and when it is able to be compared to a theory (Lincoln & Guba, 1985). Therefore answering research questions can ensue through the exploration of common occurrences in the data that fit with an underlying theory. This is the perspective was thought to evidently fits with the methodology of thematic analysis and the aims of this research project.

2.2 Thematic analysis and methodology rationale.

2.2.1. Rationale for qualitative methods for people with intellectual disabilities. Qualitative methods are said to facilitate understanding of the experiences and processes within the research topic and it is postulated that qualitative methods are fundamental to explore individual's experiences (Harper & Thompson, 2011). As opposed to identifying the cause and effect in relationships and making predictions, qualitative approaches aim to describe experiences and explore quality and texture of topics (Willig, 2013). Recent years have seen a shift in focus towards the quality and outcomes of health services rather than simply the number of people who are accessing services (Harper & Thompson, 2011). Therefore the importance of exploring the voice of service-users has become increasingly sought after to improve services.

Historically, there have been examples where people with ID have been vulnerable to coercion, exploitation and harm in the context of research (Juritzen, Grimen, & Heggen, 2011). Consequently, from a position where people with ID could be researched without their consent, a move towards safeguarding a population of people who were all considered to be 'vulnerable' subjects as a result of their ID developed. This led to barriers being established to limit or even prevent people within this population from participating in research. Whilst such measures were put in place to protect people with ID, such exclusion meant that the accounts and experiences of people with ID are not heard and their voices are silenced. Therefore when research is concerned

with key aspects of people's lives, feelings of powerlessness and marginalisation may be reinforced and existing injustices compounded. The major issue to be addressed was whether the term 'vulnerable' can be applied broadly to all people who are deemed to have an ID. For professionals in the field, they understand that the term 'ID' encapsulates a wide range of abilities and disabilities and therefore capacity for autonomy and to provide informed consent is variable and not fixed. Capacity can vary from situation to situation and is dependent on how information is presented and understanding is promoted. Therefore the assumption that all people who have an ID are vulnerable seems inappropriate as it ignores the impact of personal characteristics of potential participants and the actions of researchers with regards to the accessibility of information. Whilst non-maleficence is a key ethical consideration that needs to be considered within research, it is often constrained to the contemplation of the potential physical or psychological harm of the research. However, there are concerns that having an ID being cited as an exclusion criterion within some research can potentially harm people with ID indirectly. Firstly, their exclusion may prevent access to some potentially beneficial interventions that are currently only available through research. Secondly it may result in crucial aspects of people's lives remaining unexamined which may prevent potential pre-existing harms from being discovered and therefore continuing to be unquestioned and unchallenged (e.g., Leutar & Mihoković, 2007). Therefore it has been argued that exclusion from research participation can be a form of vulnerability in itself (McDonald & Kidney, 2012). Qualitative research can therefore access the perspectives and accounts of oppressed groups who often lack the power and opportunity to make their voices heard (Booth & Booth, 1996). This is especially important when the research topics they are excluded from may impact on decisions made about them and the services they have access to. Furthermore, it has been found that people with an ID want to be involved in research because being listened to helped them and could help others (Tuffrey-Wijne, Bernal, & Hollins, 2008).

The aim of the current research was to explore the perspective of barriers and facilitators within therapy for people with an ID. Therefore a qualitative design was considered to be the most appropriate for this research because of the literature supporting qualitative approaches to exploring lived experiences (Willig, 2013). Furthermore Barker et al. (2002) suggested that qualitative approaches are the most appropriate when there is little pre-existing knowledge and literature in the area, which is certainly the case within this research.

2.2.2 Rationale for thematic analysis. Thematic analysis as a methodology fits within the epistemological position taken in this study because critical realism is universally accepted as a basis for studying unobservable phenomena (e.g., perceptions of therapy) both quantitatively and qualitatively (Lund, 2005) and allows acknowledgement of multiple perspectives (Pawson & Tilley, 1997). Some authors (e.g., Ryan & Bernard, 2000) have argued that thematic analysis is not a qualitative research method in its own right. However, researchers have recently aimed to provide more definition and clarity regarding thematic analysis so that the rationale for the analysis process in this methodology is more explicit (e.g., Braun & Clarke, 2006). Thematic analysis was chosen for this research project for several reasons. Firstly, one of the benefits of utilising thematic analysis is that it is not bound to one epistemological stance, it can fit within an essentialist or constructionist framework, and in this case the analysis approach was grounded within a critical realist methodology. Secondly, thematic analysis can offer a method of analysing data when the topic has yet to be studied in depth (Braun & Clarke, 2006), which is certainly the case for this area. Although the evidence within this area is sparse, there are several known assumptions about the topic. Thematic analysis allowed an integrated approach of data analysis (Fereday & Muir-Cochrane, 2008) of both inductive, in which themes are related to the data collected (Boyatzis, 1998) and deductive, in which themes are theory-driven from relevant literature (Crabtree & Miller, 1999). This was a strength within this study, which utilised a flexible method of inductive-deductive procedures which enables the research to address questions around the known assumptions about optimising therapy for people with LD, whilst allowing the researcher to explore the narratives and experiences of people with ID who have not had

many opportunities to express their views. Some alternative methodologies, such as content analysis may arguably enable better generalisability of the results. However, it was believed to be too reductionist for this study by favouring frequency of codes over salience (Buetow, 2010). One advantage of utilising thematic analysis is that it enables the saliency of data to be taken into account rather than simply the frequency as with content analysis.

2.2.3 Alternative methodological approaches considered. Different qualitative methods are better suited to answering different kinds of research questions (Tuckman & Harper, 2012). Although the epistemological position bear importance on which data analysis approach to take, it does not indicate one specific analysis method. It has been argued that thematic analysis, interpretive phenomenological analysis (IPA) and grounded theory can all be underpinned by a critical realist position (Braun & Clarke, 2013).

One alternative method that was considered for this study was IPA. This is a similar qualitative approach which also utilises semi-structured interviews to explore and work towards an understanding of individuals experiences and how they generate a meaning for that experience (Smith, 2004). Like thematic analysis, IPA describes patterns within data, however IPA is theoretically bounded and more commonly utilises an interpretive phenomenological epistemology (Braun & Clarke, 2006). Therefore IPA is concerned with how the person relates to the world through the meaning they make and the significance it has for that individual (Larkin & Thompson, 2011). Conversely to thematic analysis, within IPA the researcher aims to make sense of a person's accounts by interpreting their interpretations (Howitt, 2010). Whereas as previously noted, it is thought that a semantic level of thematic analysis may better reflect the person with ID's concrete representations of the world and their experiences. Furthermore, within its pure style, IPA would use very few prompts within interview schedules in order to allow for a more free expression of participant's experiences that the individual perceives to be relevant (Smith & Osborn, 2003). When interviewing people with ID, this could be a problem as people may need

some closed questions, prompts and probes to better enable their ability to engage in interviews.

A further potential approach that was considered for this study was grounded theory. Grounded theory is a systematic and inductive approach which is concerned with facilitating the development of a theory through data saturation (Willig, 2013). Although there are different approaches to grounded theory which can be underpinned by different epistemological perspectives (Charmaz, 2002), grounded theory overall involves analysing the data on an ongoing basis and the data then guides the next phase of data collection (Howitt, 2010). It is postulated that this approach is well suited to research questions that are apropos aspects that influence phenomena and social procedures that underlie such phenomena (Braun & Clarkem 2013). This enables grounded theory to examine how society and relationships impact on behaviour and appraisals (Tweed & Charmaz, 2012). This study aimed to explore people's experiences of therapy in terms of factors they thought facilitated therapy and factors that they thought were barriers within therapy, it did not aim to generate a theory of their experience and therefore grounded theory was not thought to be the most appropriate approach for this research question.

2.2.4 Rationale for individual interviews. Individual interviews can be conducted from different epistemological positions (Frith & Gleeson, 2011) and are often viewed as the 'gold standard' method for qualitative approaches (Novick, 2008). The use of telephone, email and online video interviews are being utilised more-and-more (Sturges & Hanrahan, 2004) and were considered within the current research as they reduce cost and travel, allow participation from a greater geographical region and greater ensures the safety of the interviewer (Novick, 2008). However, this was not considered to be appropriate due to the disadvantages of telephone and email interviews that they lack visual cues (Garbett & McCormack, 2001) which may be particularly problematic for people with ID. Visual cues can make it easier for people with ID to understand the content of the questions asked, and it is further reasoned that participants are more likely to divulge sensitive information and convey emotions on face-to-face interviews (Groves, 1990; Henson, Cannell, & Roth, 1978). Furthermore

the lack of visual prompts is posited to negatively influence the informal communication, contextual information, development of rapport and cause misinterpretations of responses (Chapple, 1999; Sturges & Hanrahan, 2004). Face-to-face interviews are believed to be a suitable approach for examining experiences and generating rich and detailed data (Braun & Clarke, 2013). Semi-structured interviews enable a flexible method as open-ended questions allow participants to offer new information that may not have previously been considered within the literature. Therefore the researcher is able to follow-up useful anecdotes for further information. As face-to-face interviews generate rich and detailed data, it is posited that fewer participants are required to provide sufficient data in comparison to other methodologies (Braun & Clarke, 2013).

Lewis (2002) postulated three key principles when interviewing people with an ID: authenticity, validity, and reliability. Firstly authenticity, which means to ensure that the participant's accounts are representative of their beliefs, indicates that the researcher is expected to verify that the account is not merely specific to one context or strategy. Secondly, it is essential that the accounts are valid and credible and therefore the researcher should check whether the interpretation of the views expressed is correct. Thirdly, reliability and trustworthiness with regards to whether responses are typical of the person's beliefs should be considered. When considering methodological challenges when interviewing people with an ID the social and historical context should be reflected upon as "individuals need to have self-esteem to believe that their views are valid and important [...and] to believe that they will be listened to, responded to and understood" (Lewis & Porter, 2004, p.195). People with an ID may lack such experiences and may therefore benefit from gaining emotional support from a carer during the interview process (Nind, 2009). When interviewing 27 individuals with an ID, Clarke, Lhussier, Minto, Gibb, and Perini (2005) found four areas of difficulty originally identified by Booth and Booth (1996). The first is people with ID's difficulty in articulating themselves, which is associated with poor language skills, low self-esteem, isolation and anxiety. Secondly, people with ID may not be responsive and might find it difficult to answer open-ended questions. This stems from difficulty in drawing on

knowledge from experience to answer interview questions. Thirdly, thinking in abstract terms may be problematic for people with ID who may have more concrete thinking styles. Finally, conceptual difficulty around time may make it difficult for people with ID to reiterate events that have occurred in the past. As a result Booth and Booth (1996) advised that direct questioning without abstract concepts or time-orientated questions should be used, the researcher should work towards encouraging a trusting relationship, the researcher and participant should set the agenda together and the researcher should seek corroboration from carers where helpful. Furthermore, it has been expressed that people with an ID are not a homogenous group and therefore there are no safe or set formulae when interviewing people with an ID (Goodley, 1998). Goodley (1998) further posits that it may be that trust needs to be fostered over time and after several meetings, and that the researcher should adapt their style based on the person. For example, at times direct questions are useful, whereas sometimes a more effortless interview style is more appropriate. This incorporates questions and statements that are probing and sometimes leading so to lay the foundation for shared narratives based on 'natural exchanges'. Finally, Goodley (1998) argues that the presumption that participants with an ID require a set interview approach may be a more significant constraint on the interview than any factor that the participant might bring. The current research therefore sought to incorporate these concepts when devising the interview schedule and during data collection. As a result, a flexible approach to the interviews and continuous reflection throughout the research process was essential to manage differences in abilities.

2.3 Rationale for recruitment procedure.

2.3.1 Sampling and recruitment. The service from which participants were recruited covers a large county in the UK which offers a wide range of psychological interventions for a variety of presenting problems. The service provides psychological assessment, formulation and intervention suited to the individual which is dependent on the person's needs. When developing this project the service was assessed for suitability for recruitment, including: ethical considerations, appropriate recruitment strategies, an assessment of how open

to research the service was, and an estimation of how many people it would be possible to recruit within the study's time frame. With regards to recruitment numbers the following data were found: the five CPs within this service have an average caseload of 30 clients and the service discharges approximately 45 clients over a three month period. With consideration to Wechsler's (2008) normal distribution of IQ, it was estimated by the service manager that approximately 7-12 of these participants would have a level of cognitive functioning that is associated with the abstract reasoning and verbal abilities to have capacity to consent to participate in this research. Therefore a sample of 7-12 potential participants with ID every 3 months meant that it was thought to be a viable service to recruit an appropriate number of clients from.

A purposive sampling method was used in which the goal is not to randomly select participants, but rather create a sample that focused on particular characteristics of a population of interest as defined by the inclusion criteria, which best enables the researcher to answer the research question. Although this sample is not therefore representative of the population, this is not considered a weakness within qualitative research because with homogeneous purposive sampling participants are selected based on their having similar characteristics because they are of interest. The characteristic of interest for the initial recruitment was clinical psychologists in the service for which ethical approval was gained. This allowed the recruitment of the three CPs which then enabled the next phase of recruitment for the client participants (see figure 6 for a diagrammatic representation of recruitment of participants).

The CPs were then asked to identify their most recently discharged clients within the last three months. Three months was chosen because it allowed for an appropriate number of discharged patients from which to recruit but also minimised the problem of retrospective interviews for people with ID to minimise the impact of poor memory on data collection. These potential participants were then assessed by the CPs to see if they met the inclusion and exclusion criteria. The full list of criteria and justifications for these are noted below. Once potential participants were identified, the CP made initial contact with them. For confidentiality reasons, the CP gained permission from the client to pass on

their information to the researcher. The CP was also informed to approach the most recently discharged people first. This was to prevent the psychologist from ‘cherry-picking’ clients that they might prefer to participate, particularly if the CP was concerned that the participant may not shed the service in a favourable light. Participants were provided with information sheets to make them aware of what the research involves and clients with ID were also offered an audio version of the information sheet. This was in order to maximise retention of information through repeated listening in order to promote capacity to consent and to help individuals who were unable to read. Capacity to consent and how this was ensured is further discussed within the ethical considerations section.

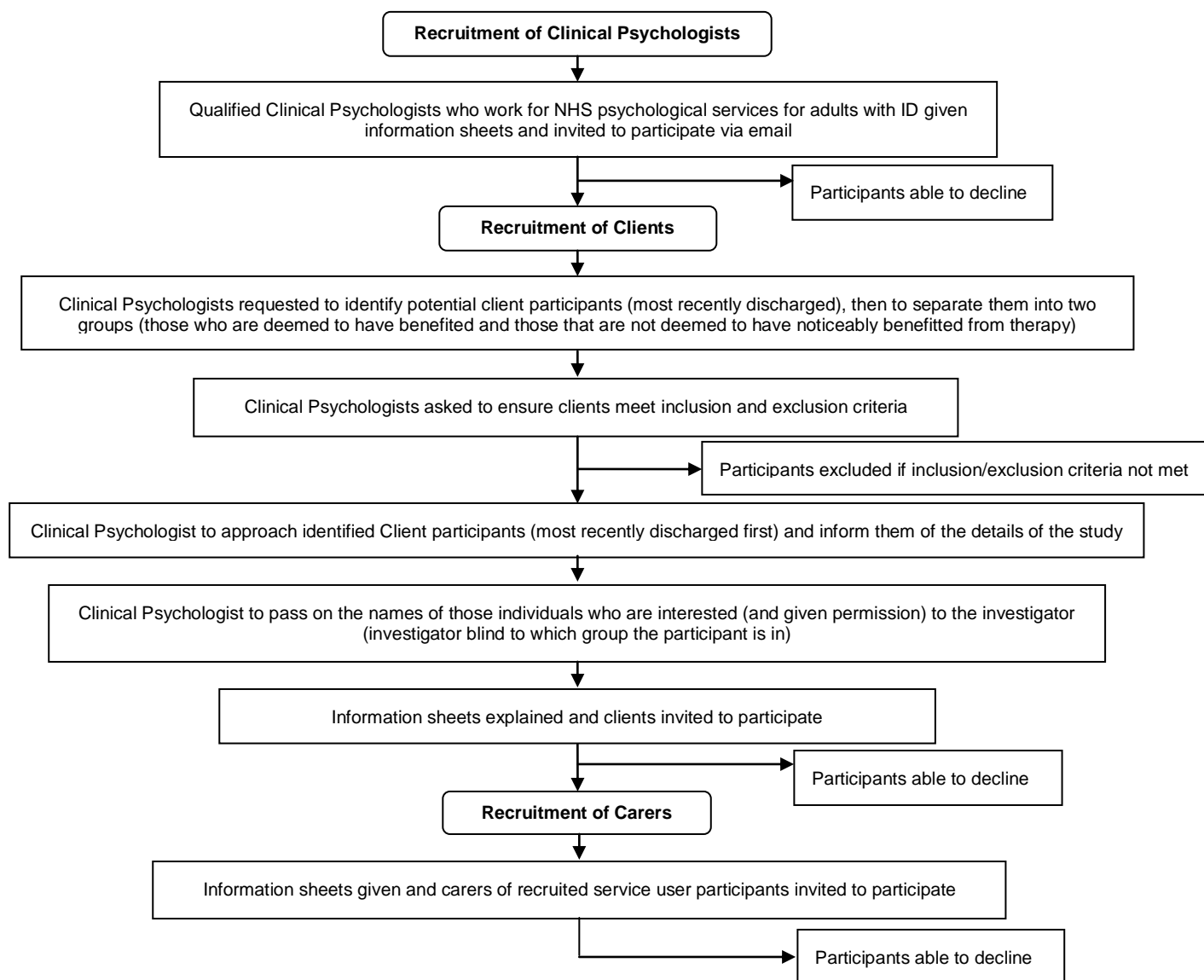


Figure 7. Recruitment Procedure

When it was recognised that all of the identified client participants were male, it was considered whether the recruitment strategy should be adapted to actively seek female participants. However, it was felt that the recruitment procedure was designed to prevent 'cherry-picking' of particular demographics and to prevent specific genders, ages, referral types or therapy outcomes being chosen over others to generate a representative sample of the clients who are accessing the service. Therefore we decided to retain the sample selected and consider why it might be the case that only male clients were identified, whether this was representative of the population and the impact of this on transferability of findings. Such considerations will be reviewed within the extended results and discussion sections.

2.3.2 Rationale for triadic case design. Multiple perspectives and triangulation of data from these different perspectives is a strength of this study as it maximises validity of the research through the checking and validation of themes. Furthermore, rather than inconsistencies between participant groups being viewed as a limitation, conversely it is thought to be a strength in order to uncover deeper meaning in the data and consider subjective nature of the themes generated. Incorporating views from clients, carers and CPs encourages a breadth of accounts. Furthermore, although it was considered important to include people with ID in research and allow people from this marginalised group to have their voice heard within research, it was thought that if this group did struggle to provide good quality data, the further views of carers and CPs could both allow for clarification of points from the client and enrich the overall volume and quality of the data.

2.3.3 Rationale for benefitted and not benefitted groups. By asking the CP to identify a benefitted and not significantly benefitted client it was thought to firstly enable recruitment of more client participants by each psychologist choosing two clients. This was because there were few CPs within the service. Secondly, it was thought to reduce the potential of the CP simply 'cherry-picking' a 'good' client that may predominantly offer facilitators to therapy and to encourage a more diverse sample that allow CPs to feel more comfortable and less exposed by only offering a 'non-benefitted' client. This

may be particularly in the light of the current climate within the NHS where CPs may feel anxious about proving their worth as a profession. The investigator remained blind to which participants were in which group until after data collection and analysis. This allowed for barriers and facilitators to be semantically extracted from the data with minimal interpretation and reduced impact of researcher expectations. Furthermore it was thought that if the researcher was aware that a particular client was in the benefitted group for example, there may be a predominant focus on facilitators and vice-versa with non-benefitted clients being overly focusing on barriers. This therefore allowed an equal focus on both aims for all participants.

2.3.4 Rationale for number of participants. There seems to be minimal evidenced based recommendations for appropriate sample sizes within a thematic analysis approach (Baum, 2002). Within the journal chosen for publication, recent studies utilising a thematic analysis methodology with people with and ID have utilised samples ranging from nine (e.g., Carlson, Armitstead, Rodger & Liddle, 2010) to 13 (e.g., Kilcommons, Withers, & Moreno-Lopez, 2012). The concept of 'data saturation' is often noted within qualitative research which postulates that recruitment of participants should continue until no new codes are discovered within the data (Patton, 2002). On a practical level, this results in it becoming difficult to predict how many participants may need to be recruited at the start of research requires the initial phases of data collection to occur in parallel to data analysis. Guest, Bruce, and Johnson (2006) completed an analysis of saturation within thematic analysis over the course of 60 interviews. They found that within the first six transcripts 73% of codes were ascertained, whilst 92% of codes became established after a further six transcripts. They further reported that the codes developed after the 12 transcripts showed good internal reliability with regards to overall frequency (Cronbach's alpha > .70). As the current study investigated a relatively homogenous sample, using a more structured interview schedule for client participants, and because the overall sample size is small, it was initially thought that a target of three clinical psychologists would be appropriate and achievable. This would therefore further provide six clients (two clients from each CP) and six carers (each client selects one carer each). Therefore the

target was 15 participants. Codes were generated after each interview was conducted and transcribed as to check data saturation. After the tenth and eleventh interviews, a very small number of new codes were identified. Furthermore, the final two interviews found no new codes.

2.4 Inclusion and exclusion criteria. The inclusion criteria are the main characteristics of the target population that must be met in order to answer the research question. There are also a number of exclusion criteria that indicate individuals who would have been suitable, were it not for characteristics that may interfere with the quality of the data or that put them at risk of adverse effects (Hulley, Cummings, Browner, Grady, & Newman, 2007).

2.4.1 Clinical Psychologists.

Inclusion criteria:

- Fully qualified CP
- Registered practitioner with the Health Care Professions Council

Exclusion criteria:

- Did not work for the selected ID service (that ethical approval was gained for)

Justification: Due to resources and practicalities of recruitment ethical approval was gained for one NHS Trust only.

- If they provided support and guidance to the researcher regarding study procedure (i.e. field supervisor).

Justification: Possibility of conflict of interest and potential bias.

2.4.2 Clients with intellectual disabilities.

Inclusion criteria:

- Met the criteria for a global ID (as defined in introduction)
- Recently received therapy by Psychological services

Exclusion criteria:

- Were discharged from the psychology department for longer than 3 months
Justification: retrospective accounts above 3 months prior to interview may result in poor quality data with less accuracy and increased likelihood of forgetting.
- Deemed to not have capacity to consent to research participation
Justification: May be at risk of adverse effects of participation if they are unable to understand what the consequences of participation are.
- Did not complete the full therapeutic process (assessment, formulation, intervention, evaluation)
Justification: The research question related to the benefits of completion of the full therapeutic process.
- Did not receive individual talking therapy from psychology service.
Justification: The focus of this project was to explore experiences of individual therapy and therefore even partly systemic approaches were used and families and carers were involved, the clients had to have experienced some individual therapy with one-to-one sessions with the CP.
- Have previously completed therapeutic work with the researcher.
Justification: Inability to provide good quality data as likelihood of acquiescence may be increased
- Were simultaneously working with a service that is also providing psychological support
Justification: To ensure that psychological support from other services doesn't impact on the quality of the data.

2.4.3 Carers.

Inclusion criteria:

- The carer who currently and regularly support the client with ID.

Exclusion criteria:

- If they had not known and worked with the client whilst the client was working with the CP
Justification: difficulty in providing good quality data if they were relying on other peoples accounts of whether the client benefited from therapy.

2.4.4 Exclusion criteria for all groups.

- Those who did not provide informed consent
Justification: Not ethically sound to include people who have not provided informed consent as they may be open to adverse effects of participating against their will.
- Inability to speak and articulate in English language
Justification: Language barrier may lead to an inability to provide good quality data and no funding was available for an interpreter.

2.5 The triadic cases. All names have been replaced with pseudonyms to ensure participants are not identifiable. The cases are encompassed by two triadic cases nested by one CP.

2.5.1 Case 1. Figure 7 diagrammatically presents the participants within case 1 and how they relate to each other.

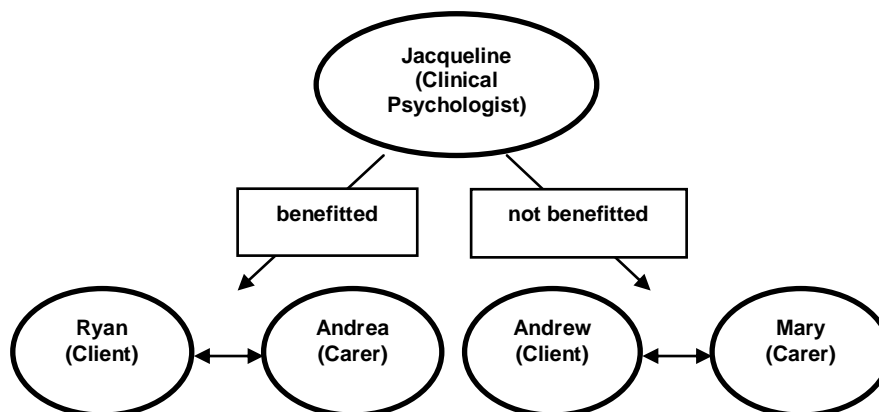


Figure 8. Diagrammatic representation of case 1

2.5.2 Case 2. Figure 8 diagrammatically presents the participants within case 2 and how they relate to each other.

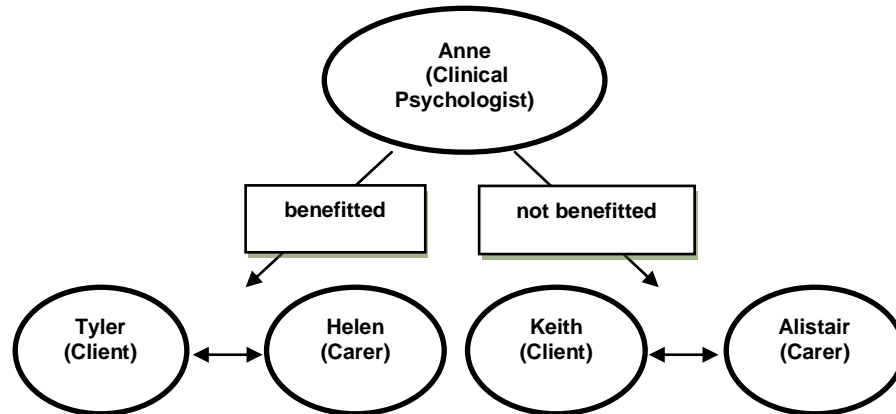


Figure 9. Diagrammatic representation of case 2

2.5.3 Case 3. Figure 9 diagrammatically presents the participants within case 3 and how they relate to each other.

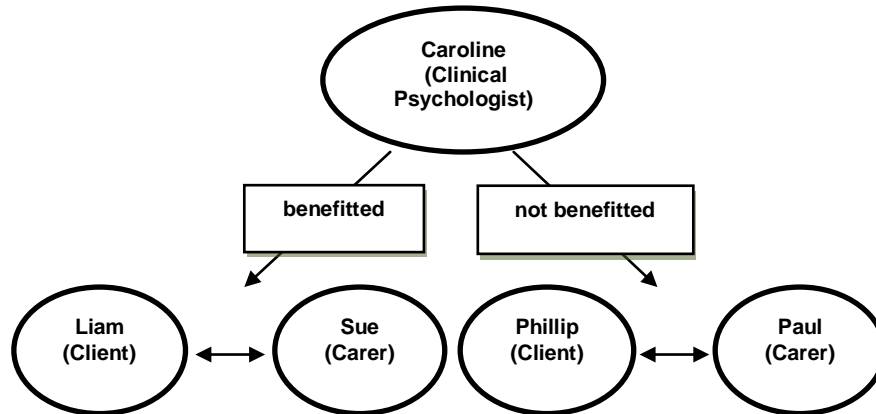


Figure 10. Diagrammatic representation of case 3

2.6 Ethical considerations

2.6.1 Ethical committee approval. This study was ethically approved by the designated authority within the health, life and social sciences faculty at the University of Lincoln and NHS research ethics service. Approval was also gained from the NHS Trust research governance officer.

2.6.2 Informed consent and participant information. The CP, client and carer were presented with separate participant information sheets and consent forms. A minimum of 24 hours between participants receiving the information sheet and signing the consent form on the day of the interview was provided.

The consent form and participant information sheet for the client was adapted to be easily understandable, using images and written English, and was offered in audio format on a CD should they wish to listen to the information again. The CP that initially identified the client was asked to explain the information sheet. This was then explained again by the researcher to ensure that the participant had every chance to understand and retain the information contained within it. ID participants were asked some basic questions and were asked to repeat some of the information they heard to ensure that they understood the information and what they were consenting to. It was recommended that a professional carer was present when informed consent was obtained to ensure that consent was voluntary. Capacity to consent was determined by ability to understand and repeat information and was verified by their carer and their CP.

2.6.3 Participant withdrawal. Participants had the right to withdraw from the study at any time up to one week after the data had been collected and did not have to give an explanation for doing so. In this case all data collected from this participant would have been deleted and destroyed. Participants were made aware, via the information sheet and consent form that this could be done by contacting the researcher via the contact details stated on the participant information sheet.

2.6.4 Adverse effects of participation. Although no adverse effects were anticipated for prospective participants, it was a potentially sensitive discussion topic for people with an ID, and this was made clear in the information sheet. While every effort was made to provide support during the interview, participants with ID were referred to an appropriate member of their care team if further support was required. It was made clear on the participant

information sheets and consent forms that participation was entirely voluntary. Additionally, if clients decided not to participate, the quality of services they received would not have been affected. Interviews were arranged at times and locations that were most convenient for the participant.

2.6.5 Risk to researcher. The researcher was provided with clinical supervision to raise issues if topics discussed during the interviews were distressing. Due to potential difficulty of travel for people with ID, some interviews took place in participant's homes. In this case, relevant lone working policies were followed.

2.6.6 Confidentiality. The individual from the transcription service who transcribed the data was required to sign a confidentiality agreement before they were permitted to listen to any interview recordings. This information was also made clear to participants prior to the interview. For the client with ID, a confidentiality agreement was made with their CP prior to the commencement of therapy. Participants were therefore asked to provide written consent for their carer and CP to be asked questions about them and their therapy during the interview, and specifically consent to their CP breaking this confidentiality agreement.

2.6.7 Data protection. In accordance with the Data Protection Act (1998), all information about participants has been kept confidential and securely stored in a locked file cabinet. Interview transcripts and copies of questionnaires have been made anonymous by assigning participant numbers and pseudonyms. Electronic versions of anonymous transcripts have been kept on a password protected computer. All identifiable data including: signed consent forms, participant names and contact details, assigned participant numbers and pseudonyms, are stored separately to anonymous data. Electronic audio recordings of the interviews were held securely on an encrypted USB stick and password protected. Only the researchers and administration staff on the Trent Doctorate in Clinical Psychology course have access to the data. In compliance with the Data Protection Act (1998), audio

files, interview transcripts and completed questionnaires will be retained for minimum 7 years at the University of Lincoln. Anonymous quotations from the interviews have been used in the written report as examples of themes that arise. Participants were made aware that although these are anonymous, there is a possibility that their client, carer or CP may recognise them from what they have said. The researcher has strived to minimise this risk as much as possible.

2.6.8 Acquiescence. Acquiescence is the tendency to answer 'yes' regardless of what is being asked, and has been identified as concern when interviewing people with ID (Rapley & Antaki, 1996). However, by avoiding closed questions, balancing questions for positive and negative responding, and ensuring that questions are easily understandable, research suggests that this is less likely to occur (Sigelman et al., 1981). These recommendations were considered throughout the research process.

2.7 Study procedure and rationale

2.7.1 Service user involvement. Clients, carers and Clinical Psychologists were asked to review the suitability of the participant information sheets, consent forms and interview schedules. Specifically they were asked to ensure that the information is clear and easily understandable for people with ID.

2.7.2 Demographic interview. Demographic information was collected at the beginning of the interview and recorded using a portable Dictaphone. The demographic interview schedule was designed to collect the relevant information from the different participant groups including: age, gender, ethnicity for all participants; level of ID, longevity of therapy and type of therapy for clients with ID; number of years as a qualified CP and number of years' experience for CP participants; and number of years working as a carer and length of time the carer has known the client for carer participants.

2.7.3 Semi-structured interview schedule. Three separate semi-structured interview schedules were designed for each client group. These were developed with the level of ability of the client group in mind and were designed to be used flexibly to take into account the variance in participant's abilities. The interview schedules were used to guide and open dialogue about barriers and facilitators to therapeutic change and were not used rigidly. The participant's personal experiences shaped the interview as an exploratory method to capture diversity of accounts. Participants were encouraged to provide in-depth responses through open-ended questions to discuss aspects that were important to them (Braun & Clarke, 2013). Prompts were available to aid the engagement of clients with ID. Probes were also utilised to encourage more detailed descriptions and paraphrasing, and reflective statements were used for clarification and to check the researchers understanding.

2.7.4 Interviews. Figure 10 is a diagrammatic representation of the interview procedure. The interviews were completed between February 2014 and April 2014, by the first author. All interviews were conducted face-to-face. For clients with ID the interviews lasted between 40 minutes to one hour and all took place in the participant's home due to the difficulty participants had in travelling to the researcher's base. This is also reflective of their therapy as the CPs completed home visits within the therapy for all of the clients. Furthermore, clients were given the opportunity to have their carer sit with them to support them within the interview. All clients chose to complete the interviews one-to-one with the researcher. All of the carer interviews lasted approximately one hour and all took place in the client's home after the interview with the client. All of these interviews took place without the client being present. Finally, the six interviews with the three CPs (each CP was interviewed twice as each client was discussed separately) lasted between one to two hours. All three CPs chose to complete both interviews in the same day with a short break in between. Two of these interviews took place in the CPs home due to difficulty in finding available rooms in NHS bases and one interview took place in the CPs staff base. A reflective diary was kept after each interview, during transcription and throughout the analysis. If any issues or queries arose as a result of the

interviews then participants were sign-posted to the appropriate authority or service.

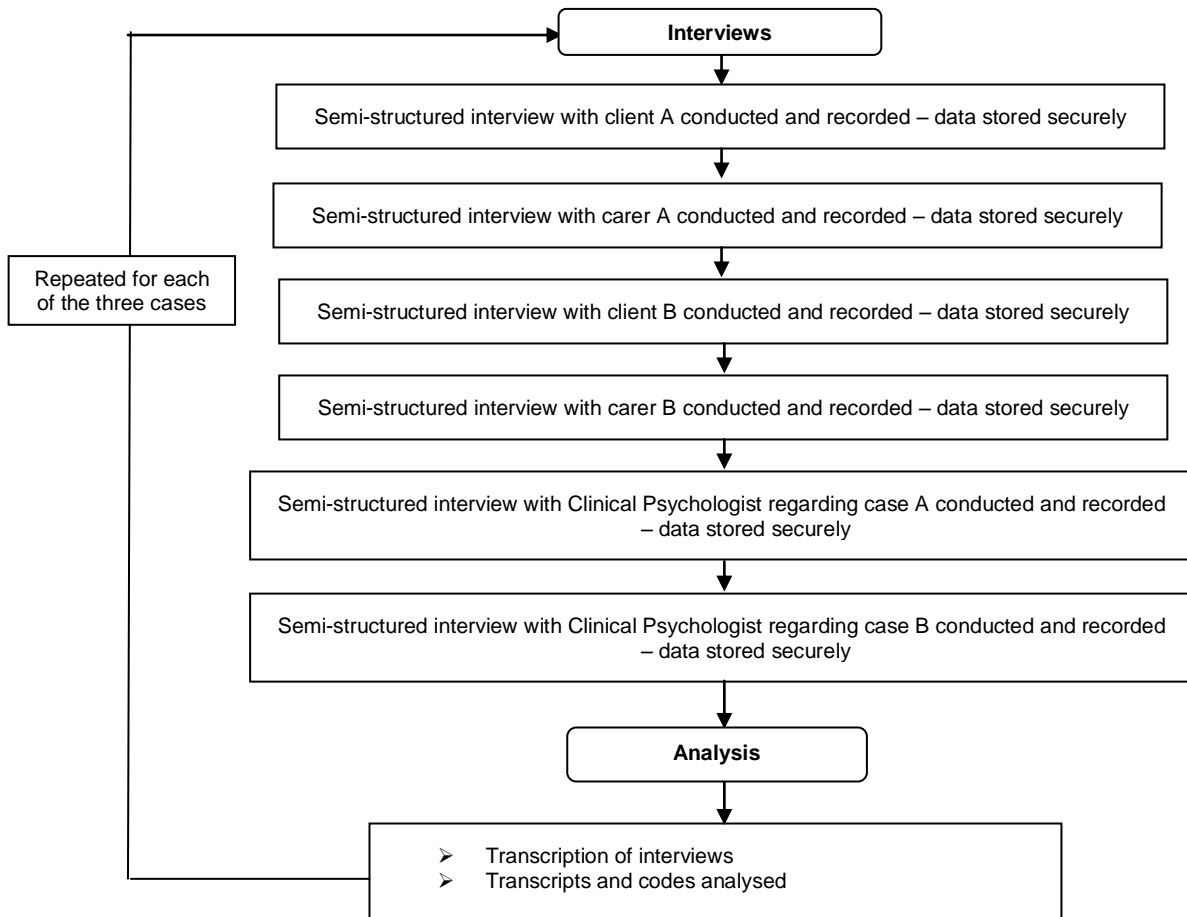


Figure 11. Research Procedure

2.7.5 Transcription. All interviews were audio recorded and transcribed verbatim. Ten interviews were transcribed by a transcription service and eight interviews were transcribed by the first author. Accuracy of interview transcripts was checked against the audio recordings. This also helped the researcher become familiarised with the data.

2.7.6 Thematic analysis procedure. Braun and Clarke (2006) outlined a six phase guideline for data analysis that was utilised within this analysis procedure. This was used flexibly and stages were returned to as transcripts

and codes were checked for accuracy, consistency and coherence throughout (Braun & Clarke, 2006). The six phases were:

1. Familiarising self with the data: The interviews were transcribed; transcriptions were checked for accuracy and then were read and re-read for this purpose.
2. Generating initial codes: each transcript was systematically analysed on a line-by-line basis and initial codes were manually typed next to each line within the word documents. Initial codes were also checked by the second author and any discrepancies were discussed and resolved.
3. Searching for themes: initial codes were physically collated together into potential themes by copying and pasting codes into separate word documents. It was determined *a priori* that a theme constituted data that was considered important in relation to the research question (Braun & Clarke, 2006). All codes were separated into word documents, printed off and organised into theme piles. This allowed links to be made between codes to enable the identification of super-ordinate themes and sub themes. The super-ordinate themes were then considered in terms of their relationship to each other.
4. Reviewing themes: Themes were reviewed for internal homogeneity and external heterogeneity to ensure that there were clear distinctions between the themes and that each theme was coherent. Transcripts and collated codes were reviewed again and checked for coherence and accuracy. At this stage appropriate quotes were selected from the data and the quotes were checked to ensure that they coherently represent the corresponding theme. Themes were then organised into a thematic map. Furthermore each subtheme was checked that it is representative of all three groups. Subthemes that were dominant for only one group of participants were to be discussed in the extended paper only.
5. Themes named and defined: Themes were checked and named so as to guarantee that the real meaning of the theme was portrayed.
6. Production of the report: It is important to ensure clarity of themes and that appropriate quotes from the data are utilised that address the aims of the research and validate the analysis process within the report.

2.8 Reliability and validity of qualitative research. Qualitative research has seen a shift away from a positivist paradigm and as such it has become increasingly problematic to measure reliability and validity of research. Whether findings are able to be replicated and whether the research measures reality accurately are the usual measures for reliability and validity within quantitative research. Conversely, qualitative research has seen a drive towards research being: credible, authentic, critical, and having integrity (Whittemore, Chase, & Mandle, 2001). Yardley (2000) postulated four key principles to assess quality of qualitative research including: context sensitivity; commitment and rigor; transparency and coherence; and impact and importance. Context sensitivity refers to an acknowledgement of theories and wider literature which are relevant to the research as-well-as taking into consideration the situation of participants, their standpoint and ethical considerations. Within this study, this was verified by the development of rapport between the researcher and participants and furthermore the interview schedule was developed with cognitive abilities of participants in mind. The researchers were also dedicated to being honest, transparent, having integrity and promoting equality and mutual respect with all participants. The second criterion postulated by Yardley (2000), namely commitment and rigour, can depend on the quality of sample as well as the comprehensiveness of the analysis process. Within the current study, the sample was larger than many qualitative studies utilising thematic analysis and was deemed to be sufficient to ensure data saturation based on literature exploring how many interviews are required for this purpose (Guest et al., 2006), whilst maintaining as representative homogenous sample as possible. Thirdly, transparency and coherence was ensured through the examination of the themes to ensure that they were convincingly presented and evidenced with appropriate quotes from the data. It is clear that the researcher's background, principles, beliefs and hopes for the research are likely to have an impact on the analysis process. Whilst the aim is to become immersed in the data and semantically remain close to participants accounts, it is crucial to be aware and reflect on such potential biases and researcher assumptions (Krefting, 1991). For this purpose

the researcher developed a reflective concept map that was constantly reviewed so that the researcher remained mindful of such potential biases⁴². Furthermore, a reflective diary was kept which commented on thoughts, assumptions, emotions and reactions to the interviews and the analysis process. This further aided the enhancement of the reliability of the analysis and credibility of findings (Krefting, 1991). In addition, the researcher was blind to whether clients were in the 'benefitted' or 'not significantly benefitted' group, to reduce the impact of any expectations of the researcher during data collection and analysis. Finally, an audit trail of decisions made was completed which noted not only the decisions but also the process of revisions. To establish reliability and validity of data analysis, investigator triangulation (Thurmond, 2001) was used with the first author and the second author, and inconsistencies in codes or themes were discussed and reconciled. The integration of multiple perspectives increases validity of this study and is considered more representative of the social phenomenon of therapy for people with ID than if one perspective was explored (Hammersley, 1990). The final criterion reported by Yardley (2000), the impact and importance of the findings with regards to socio-cultural and practical terms, will be considered within the discussion.

⁴² See appendix R for concept map of potential researcher bias'

3. Extended Results

The extended results section is separated into two parts. Firstly, part one will discuss additional subthemes that add to the previously described thematic structure. Secondly, further discussion of subthemes noted in the journal paper will be considered.

3.1 Extended thematic map. The extended results outlines the five main themes and all subthemes identified in the analysis, and their inter-relationship. The additional themes presented here were deemed to be important to participants' experiences, although were not directly related to the research aims. For instance, the additional subthemes were considered to be barriers and facilitators to positive therapeutic change for one of the participant groups, but were not consistently for all groups, thus not meeting the research aim of developing a cohesive understanding of what client's carers and CPs all deem to be barriers and facilitators within therapy. Although these additional themes were not given as much attention within participant's accounts, and were not agreed upon by all groups, they are important to acknowledge due to the potential beneficial impact they might have on therapy. Super-ordinate theme one, 'what the client brings' has two additional subthemes not discussed within the journal paper. These were 'attachment difficulties' and 'risk', which were both dominant themes for CPs. Super-ordinate theme three, 'therapy factors' has three additional subthemes: 'resources', which was considered to be important for CPs and one carer; 'confidentiality', which clients considered to be important; and 'inclusion' which was reported by clients only. Finally, super-ordinate theme five, 'systemic dependency' has one additional subtheme of 'boundaries are required' which was deemed important for CPs.

3.1.1 'What the client brings': Additional subthemes.

Attachment difficulties. Attachment difficulties is a theme that was reported to be a barrier to positive therapeutic change by the three clinical psychologists but was not mentioned by anyone in any other group. Attachment difficulties is a factor that the client brings to therapy which is based on their past experiences of relationships and was mostly discussed with consideration to the impact on the therapeutic relationship. In some instances, it was thought that the person's attachment style meant that they would find it difficult to build an attachment. This was thought to have more of an impact on the therapy adaptations of lengthening therapy to overcome this barrier. For example: "it took a while to develop that rapport, yes it took a while to get that therapeutic relationship because of his attachment problems... but he's got used to me going now" (Jacqueline).

Conversely, there were some examples of clients having the opposite attachment pattern and being over trusting and over attached. This was thought to be more likely to result in systemic dependency.

That kind of attachment to me was so quick it was really surprising. I'm still shocked by how much he trusts me. I think because of his attachment difficulties he is more likely to get over-attached and he really didn't want to be discharged. (Caroline)

Within one example, a psychologist felt that attachment difficulties meant that there was no therapeutic relationship whatsoever. This psychologist believed that this was the main barrier which resulted in the client not benefitting from therapy. For example: "it kind of supersedes everything; he can't make that attachment with people. I don't think he's actually got any attachments with anyone but it means there's no therapeutic relationship there either" (Caroline).

Further to attachment having an impact on the therapeutic relationship, it was also thought to be a significant factor within people's difficulties, which can be a

barrier that would need to be overcome in order to progress in therapy. For example:

During the time I was seeing him for the self-injury, it was the anniversary of his mum's death, but he'd never been to see her grave and he hadn't gone to her funeral. So I think attachment came into it, and particularly with staff. I think there was a lot of triggers in staff's behaviour.

Overcoming relational stuff and attachment stuff with him was quite key.
(Anne)

Finally, all three psychologists reported that attachment difficulties impacted on the client's level of risk, predominantly to themselves but also risk to others with regards to lashing out on others and risk from others with regards to vulnerability to abuse. For example one psychologist states: "the attachment is such that if his mother goes away, it's almost as if she's his security blanket. His mother had gone away when he attempted suicide and he was upset that he wasn't invited to go with her" (Jacqueline).

Risk. Risk is a theme that the client brings with them to therapy that was also mentioned by the three CPs as an important consideration within therapy. Although this subtheme is considered a useful consideration within therapy, participants spoke of this theme as more of a barrier to ending therapy, or accessing therapy in the first place, rather than a barrier to change within therapy per-se. Risk was the reason for referral for all six clients, one due to risk to others (sexual offending), two due to risk to others (arson; assault) and risk to self (self-harm), one due to risk to self only (suicide ideation) and one due to risk from others (sexual, emotional and financial abuse) and risk to self (suicide ideation). Risk was not only an important consideration within the work in terms of therapy goals but was also considered to be one of the biggest contributors to systemic dependency. As a result of risk, longevity of therapy was increased as CPs felt anxious about discharging these clients until they felt confident that risk had drastically reduced if not been eliminated altogether. This theme was in some cases considered to be a facilitator to accessing therapy as some participants felt that these clients had been neglected by services for years and

were only identified and gained access to services once there was a risk issue. Not only were they referred to the psychology service, but all of a sudden many services became involved. For example:

I think sometimes people become lost in the system, they are ignored or just not identified, and then something big happens, someone is abused in the community, or starts self-harming, and then all of a sudden services jump in and start questioning the practice of carers. Carers go from practically begging for help and not getting anywhere to suddenly being overwhelmed by the amount of input. If people are risky, they get access to services straight away (Caroline).

Once people have accessed the appropriate services, CPs felt that risk was one of the biggest influencing factors for longevity for therapy and such clients are often kept on caseloads for a very long time. This was often a result of anxiety on the part of the CPs to ensure that people are kept safe and the potential consequences if the person is discharged and then the person is harmed or harms someone else. For example:

It's about two and a half years since I started seeing him. But the reason why we kept involved was because of the seriousness of the initial problem [suicide attempt]. We feel like we get so far but we've never really solved the problem, yes, OK he's a lot better, but I still feel we seem to go round in circles. It still worries me now. What if he does it again and I have discharged him. That's why I haven't officially discharged him from the service even though I have stopped seeing him. So I can keep checking up on him. (Jacqueline)

Even when people are discharged from services, CPs actively encourage clients and carers to be proactive with re-referrals as it is felt that when risk is involved, it is crucial to intervene quickly before risk increases. For example, one CP stated:

It's useful to get involved as soon as possible, so we can immediately jump in quick before it gets worse, and you can say well OK, so here we are again. You're sitting next to the guy on the bus, what made you think

that was a good idea to give him £20 when he asked for it. And would you ever invite him home? Why not? So before he actually invites him home and then gets into a situation that's more serious. So yes, I think, I'd rather be re-referred and get involved than them say, oh well, you know, it's happened again. (Jacqueline)

Risk can also impact on the CPs role as a mental-health 'GP' as it can influence their role with coordinating the wider system to ensure that all of the client's needs are met in order to reduce risk as much as possible. Furthermore, the wider system can become anxious about the work that the CP is completing and it seems that sometimes the multi-disciplinary team want the work to be completed, but the client may not be prepared to engage with therapy. This can result in the CP feeling pressured to achieve the goals of the wider system rather than what is in the best interest of the client. For example:

I have a remit to do, I'm supposed to do offence work with him, and people look to me for that. Well they didn't welcome when I said, we have to wait until he's ready. They didn't see that, they didn't understand the whole motivational state of change. Until we'd addressed all these other things, he was going to be in no position to be able to talk about his offence. So to him, that made him look bad, if you are somebody that's got really low self-esteem, really it's going to make you feel even worse, it just doesn't work. That may have not helped the therapy because it put me under pressure. (Anne)

3.1.2 'Therapy factors': Additional subthemes.

Confidentiality. This theme of confidentiality is a therapy factor that the client participants felt was important for them to develop an honest and open therapeutic relationship in which they feel safe enough to disclose personal things. Several participants felt that confidentiality was a problem within services and they felt confused by what confidentiality meant and what the limits to confidentiality were. This was particularly problematic in the two instances where the clients had committed a criminal offence and had been involved with the police. Even though the criminal case had been resolved, the clients felt

concerned that by talking about the offence they might go to prison. For example: “I found it hard to talk about the past at first. I was worried that if the police found out then I would have to go to court again and I would end up in prison” (Tyler).

Furthermore, some client participants were concerned that personal things would get back to people that they didn’t want to be involved, such as parents, and what the consequence of disclosure would be:

I didn’t have the confidence to talk much and I think sometimes my mum is very controlling and she likes to control people and I was scared to be honest because I was worried that it would get back to my mum. (Ryan)

Therefore, although confidentiality is explained to participants, it was clear that the clients included in this study were confused by the limits of this because their past experiences left them feeling out of control apropos what information is shared with carers, family and services. Although there were no examples of breaches in confidentiality within this study, the fear of this was enough to create a barrier within therapy.

Inclusion. Inclusion was another theme within therapy factors that clients deemed to be a facilitator. This could have been because for carers and CPs, inclusion seems to be an obvious factor within people’s care. This could explain why clients felt that the importance of this may be taken for granted. For example:

It’s very good because they keep you informed about what they are doing and they don’t, like doctors in the hospital, talk to your social workers or carers, but the psychologist keeps me informed and involved and it’s about me. That’s why I don’t like it in hospital because no one tells me what’s going on. They don’t explain. They talk to your mum or social worker. I don’t think [Jacqueline] realised how important this was for me it’s just normal for her. (Ryan)

Resources. The resources sub-theme reflects the impact of a lack of sufficient funding and resources on the ability of CPs to provide the most

appropriate service. Furthermore, CPs reflected on a lack of an evidence base on which to inform their practice. Thus resources were deemed to be a barrier to offering clients the best service in order to facilitate positive therapeutic outcomes. CPs and one carer participant reflected on the impact of a lack of resources including not enough staff and psychologists not having enough time. For the carer, she had noticed a reduction in the number of CPs in the area and an increase in the caseload of CPs. She felt that this was having a negative impact on the care provided to clients, but also she thought that carers were missing out on a useful resource to help them care for their clients better. For example one carer reflected:

Some [psychologists] who have got a larger caseload don't put as much time in, but I do think it is important because not just to help the client but to help the staff and help us adapt our way of working to individuals. It helps us progress in the service we can offer. (Sue)

Furthermore, all three psychologists reported lack of research and resources for psychologists working in ID settings being a huge barrier for them and their work. For example:

There ought to be a lot more training around therapeutic approaches that are adapted to people with learning disabilities... and the research element and writing more papers to heighten our profile of what psychologists in learning disabilities do and what we're capable of doing, and sharing that. Because, you know, we don't have set measures a lot of the time, we don't have set assessments that are appropriate. So I think it's sort of having all the tools and resources isn't it, to do your job. And having that more specialised training I suppose, that would be all the things that could improve. (Jacqueline)

Similarly, another CP reflected on the difficulty of whether theories utilised within the general population can be suitably transferred to ID settings. For example: "I mean there are lots of theories about it [fire-setting] but sometimes it is difficult to transfer these in LD. I think we need more research about LD population specifically" (Anne).

3.1.3 'Systemic Dependency': Additional subthemes

Boundaries are required. As a result of attachment difficulties meaning that clients become overly attached to the CP through the therapeutic relationship, a systemic dependency is formed and this CPs felt that boundaries are required to prevent this. By inputting boundaries, it was felt that the attachment between themselves and the client would be an appropriate one which promotes independence and the development of new and healthy relationships with others. One CP felt very strongly about putting in boundaries and she felt that this enables ending therapy to be managed better in comparison to previous cases when she didn't input these boundaries. For example:

I think I'm quite mindful of keeping that role now, that boundary. Although I'm helpful, I have to be quite, for example, I won't do personal Christmas Cards or, I suppose I just keep the boundaries. I've found it makes things much easier since doing that. (Anne)

Conversely, other CPs felt that they employed far fewer boundaries than when they worked in general adult mental-health. They felt that this was required on one level but was fostering too strong an attachment on another level. She reported:

It happens all the time that we step outside our boundaries. It's not the same as if you work in adult mental-health, you see that person, usually in isolation, for an hour a week. And you work on one issue. Whereas in LD, we don't tend to do that, we look at a whole person, we're much more holistic. And we do bits of lots of different issues. So I do have very different boundaries in this role, both with the client and with the rigidity of my role. So I'm wondering whether me, myself, although on one hand I'm maintaining him at a controllable level, on the other hand I'm probably keeping it going as well through his attachment to me. (Jacqueline)

One CP also reflected on how one client in particular craved those boundaries in the relationship because his relationships in childhood had very few boundaries and there were very few rules. The input of boundaries enabled him to feel safe in the relationship and know what is expected of him. For example:

I felt it was quite a good therapeutic relationship once we'd got the rules. We had to set boundaries and rules. I was hugely surprised; I thought it would be really difficult to put boundaries in place. But he actually likes them and he tells me that. I think he actually felt really unsafe as a result of not having any boundaries at all. (Caroline)

3.2 Further discussion on journal subthemes.

3.2.1 Intellectual disability. There was another factor related to having an ID that was deemed to be a barrier within therapy for CPs, however no clients or carers reflected on this. This was a lack of insight and ability to self-reflect, as well as an inability to recognise and regulate their emotions and this was considered by CPs to be a significant barrier to progress in therapy. Not being able to have that insight was thought to be problematic apropos managing psychological distress. If people are unable to recognise their emotions, then it would be hard for them to learn adaptive strategies to manage them. For example:

To be able to recognise even something as simple as, that he feels sad or that actually he's angry or he's missing somebody, even a physiological. Yes, I couldn't get any of that insight which made therapy so much harder. He just couldn't engage with it. (Anne)

Furthermore, clients felt that simply having an assessment of their cognitive function was a facilitator for positive therapeutic change. They felt that being provided with a label and a better understand of the aspects of functioning that they need more support with and aspects that are their strengths enabled carers to support them better. One client gave an example of this: "I tell you a positive note she diagnosed me with my IQ because I've got a higher

intelligence than people thought. So my carers know what I can do by myself and what I need help with” (Ryan).

3.2.2 Support Network. Although having friendships was a positive factor for participants and deemed to be a facilitator for positive therapeutic change and overall psychological wellbeing, client participants reflected on the barrier to developing a support network and making friendships. For several clients, they felt a desire to have friendships with people outside of their intellectually disabled peers. However despite wanting this, clients reported that this made them feel more vulnerable. For example:

I’m not lonely I’m surrounded by friends... but sometimes when someone new that hasn’t got a disability comes into your life you’re wondering why you would want to befriend me. What’s in it for you? (Ryan).

This is a factor that reflects the vulnerability of people with ID and their expectation that they will be abused in some way due to past experiences. Five of the six clients reported having experienced abuse including physical, emotional, sexual and financial abuse. Even for participants who had a small or non-existent support network outside of their paid carers, client reported that they wanted a larger support network, but specifically wanted friends who did not have an ID. Although client participants reported that the label of ID was a facilitating factor in terms of positive therapeutic change, they felt that this was a barrier to feeling accepted by society. This meant that when social opportunities were offered, if they included other people with ID they were not favourable. For example one carer stated:

We have said to him go to this session or this is going on would you go and he thinks if there is anyone that is mentally disabled there he doesn’t put himself in that category. So he wouldn’t go to anything like that anyway. It’s strange actually, he wants to know what’s wrong with him and was relieved to know what it was that was wrong but when you put him in a category of similar people he thinks he’s not like that. (Mary)

3.2.3 Influence of others. As well as the influences that others have on clients that were noted within the journal paper, clients noted the controlling impact that other people have on them. This was particularly in relation to the parents of clients, even when they did not live with their parents. One example of this was with regards to a client's mother because he felt that whenever he made progress in therapy, her controlling behaviour and negative attitude was a barrier to maintaining the positive changes. For example:

Mum gets in the way some times. I can't sneeze without her panicking and she wants to know my every move. Sometimes anything I want to do my mum shoots down in flames. I feel like she controls me a lot. Just when I start to get somewhere she pulls me back down. (Ryan)

3.2.4 Therapeutic Relationship. Although participants across all three groups reflected on the importance of the therapeutic relationship and people reported whether the relationship was a 'good one' or not, interestingly, it was clients who actually articulated the factors that they thought constituted a good therapeutic relationship. The clients felt that the important aspects for a positive therapeutic relationship were: trust, for example: "I know with [Caroline] that I can trust her, I trust her opinion and she's always got my best interest at heart" (Liam); empathy and feeling understood, for example: "just seeing her and being able to talk to her. Someone that knows and she totally understands what I'm going through" (Andrew); and someone who listens: "She listened to me she helped me with stuff which made me feel safe" (Tyler).

3.3 Service Data. As all the recruited clients within this study were male, it was thought to be useful to review the data from the service to consider whether this was reflective of their referrals. Specifically, I was interested in whether the referrals were dominated by males or whether there were other factors that impacted on the gender bias in recruitment. As can be seen from table 6, 58% of the referrals to the service in 2014 were male and 42% were female. The most common reasons for referral for females were 'behavioural', dementia, IQ assessments and anxiety. The most common reason for referral for males was 'behavioural', anxiety, IQ assessments, anger and bereavement. As this data was collected from the administrator's log of referrals, it is unknown

what is meant by 'behavioural' and the difference between 'behavioural' and 'challenging-behaviour' is unclear. It seems from the data that the reasons for referral and number of referrals are generally comparable between genders.

Table 9:

Reasons for referral and number of referrals for males and females

Reason for referral	Female	Male	Total
Anger	8 (5.2%)	14 (6.7%)	22 (6.1%)
Anxiety	10 (6.5%)	26 (12.4%)	36 (10%)
Attachment with Staff	2 (1.3%)	0	2 (0.6%)
Challenging Behaviour	8 (5.2%)	10 (4.8%)	18 (5%)
Behavioural	30 (19.5%)	42 (20%)	72 (19.8%)
Bereavement Counselling	6 (3.9%)	14 (6.7%)	20 (31.3%)
Inappropriate Sexual/sexualised behaviour	0	6 (2.9%)	6 (1.7%)
Capacity Assessment	14 (9.1%)	10 (4.8%)	24 (6.6%)
Counselling for various reasons	4 (2.6%)	4 (1.9%)	8 (2.2%)
Dementia	20 (13%)	14 (6.7%)	34 (9.4%)
Depression	8 (5.2%)	10 (4.8%)	18 (5%)
In-Patients	0	2 (1%)	2 (0.6%)
DISCO (Autism Assessment)	2 (1.3%)	8 (3.9%)	10 (2.8%)
Sex Education	2 (1.3%)	0	2 (0.6%)
Help for family/staff in managing behaviours	6 (3.9%)	8 (3.9%)	14 (3.9%)
Self-harm	6 (3.9%)	2 (1%)	8 (2.2%)
IQ Assessment (WAIS)	18 (11.9%)	16 (7.7%)	34 (9.4%)
Help with Relationship Issues	2 (1.3%)	8 (3.9%)	10 (2.8%)
Risk	4 (2.6%)	8 (3.9%)	12 (3.3%)
Safeguarding	2 (1.3%)	0	2 (0.6%)
Safety Issues	2 (1.3%)	4 (1.9%)	6 (1.7%)
Inappropriate Referral to our Service	0	4 (1.9%)	4 (1.2%)
Total number of referrals	154 (42%)	210 (58%)	364

Table 7 shows the discharge rate of males and females over each month in 2014 for the service. It seems that more males were discharged from this service over the year than females. 73% of the discharged clients were male and 27% were female. Possible hypotheses and implications of this will be discussed in the extended discussion.

Table 10:**Frequency of discharges from the service for males and females per month in 2014**

Month	Female	Male	Total
January	3 (6%)	11 (8.3%)	14 (7.7%)
February	5 (10%)	10 (7.5%)	15 (8.2%)
March	2 (0.6%)	12 (9%)	14 (7.7%)
April	5 (10%)	11 (8.3%)	16 (8.7%)
May	2 (4%)	15 (11.3%)	17 (9.3%)
June	5 (10%)	9 (6.8%)	14 (7.7%)
July	4 (8%)	11 (8.3%)	15 (8.2%)
August	7 (14%)	8 (6.1%)	15 (8.2%)
September	3 (6%)	13 (9.8%)	16 (8.7%)
October	4 (8%)	9 (6.8%)	13 (7.1%)
November	6 (12%)	11 (8.3%)	17 (9.3%)
December	4 (8%)	13 (9.8%)	17 (9.3%)
Total number of discharged clients	50 (27%)	133 (73%)	183

3.4 Client data. Table 8 reports the WAIS-IV full scale IQ (FSIQ) scores for each of the participants and whether they were in the benefitted or not significantly benefitted group. This information was collected after data collection and analysis. Clients consented to the researcher completing a file review and recording data from any psychometric measures. With the exception of the WAIS-IV, there were no available psychometrics measures within the files. This suggests that psychometric measures are not utilised regularly within the practice of CPs in this service.

Table11:**Client group, WAIS-IV scores**

Client	WAIS-IV FSIQ score
Benefitted Clients	
Ryan	69
Tyler	63
Liam	56
Not-benefitted Clients	
Andrew	70
Keith	54
Phillip	59

4. Extended Discussion

4.1 Discussion of extended themes.

4.1.1 Attachment difficulties. CP participants reported that all six clients within this study were deemed to have 'attachment difficulties' that were thought to create barriers within therapy. Five participants were reported to have an avoidant attachment style in that they find it difficult to trust others and as a result would avoid the expression of emotion in order to maintain proximity to people (Ainsworth et al., 1978). This can therefore be problematic as it can take longer to develop a trusting therapeutic relationship and it can take time for the client to get used to talking about their emotional experiences (Willner, 2005). This is consistent with research that suggests that people with an avoidant attachment style have experienced neglect or criticism in childhood as all of these participants have a history of abuse and neglect (Crowell & Treboux, 1995). This is also in-line with research that highlights that people with an ID are more likely to experience abuse and trauma in comparison to people within the general population (Deb et al., 2001). Furthermore, it may be in-keeping with research that suggests that disruption in the formation of attachments is more likely to occur if a person has experienced abuse or been raised within an abusive environment (Murphy, 2014).

One participant was deemed to have an ambivalent attachment style in that they presented as being overly aware of their emotions and would keep their emotions close to the surface as to gain the response they seek (Ainsworth et al., 1978). As a result, this client was thought to be overly compliant within therapy which was thought to be a barrier to therapeutic change. Interestingly this was the only participant who still lived with his parents. This may highlight the impact of environment on attachment style. Research suggests that people with ID who live in residential homes can experience disruptions in attachment if people are receiving inconsistent care and reduction in opportunities to form meaningful and consistent attachments (Murphy, 2014). It could be that people who live within residential homes are more likely to develop an avoidant attachment style if they experience emotional neglect or are unable to form

meaningful relationships. Whereas it may be that the participant who lived with his parents developed an ambivalent attachment style as a result of the way his parents responded to him, rather than due to inconsistencies in caregivers.

4.1.2 Risk. Risk was the reason for referral for all six clients within this study. CPs reflected on risk as being a facilitator to receiving appropriate care as well as a barrier to ending therapy specifically. When risk issues are present, clients tend to be prioritised as to prevent a serious incident from occurring and to safeguard those involved. However, risk factors meant that the CPs felt anxious about discharging clients even when risk has decreased in case they were to return to their previous risk behaviours (e.g., self-harm or offending behaviour). Therefore CPs behaviour of keeping people on their case-load for long periods of time was negatively reinforced (Skinner, 1937) as they were avoiding a serious incident occurring by staying involved and furthermore avoid the professional repercussions if an incident was to occur post therapy discharge. From a CBT perspective (Beck et al., 1979) it was the CPs thoughts and meanings put to discharging 'risky' clients rather than the clients themselves that mediates the emotional response of anxiety for the CP and the behaviour of avoiding discharging clients. Some CPs reported some catastrophic thoughts related to this including 'If I discharge them and then they engage in risky behaviours then I will be responsible for someone getting hurt and I will lose my job'. Therefore rather than risk being an issue for clients, CPs reflected that risk was currently being managed well and the concern was what would happen if they were discharged from therapy. Therefore risk was thought to increase systemic dependency by keeping people on caseloads for extensive periods of time when no further input was required.

4.1.3 Confidentiality. Confidentiality and the limits of this is an important aspect of psychological therapy with any population (Knapp & VandeCreek, 2006). Usually all aspects of the discussions within therapy are confidential unless there is concern regarding risk to self or risk to others, at which time confidentiality is breached in order to safeguard those involved. As working with families, carers and the wider system is common in ID settings, confidentiality is

an important issue. Consequently it is important to ascertain who within the larger network and systems is important to the person and thus who they are happy to involve. It is thought that including paid carers, families and the overall system can offer useful perspectives to aid therapeutic progress. As such, it is crucial when involving other parties that the client has agreed to what is shared and all those involved are aware of and in agreement with confidentiality and that this is made explicit (Baum, 2006). Although there was no evidence of breaches of confidentiality within this study, and it is unclear whether confidentiality was fully explained to clients, it was clear that client participants felt confused and concerned about this. The results of this study therefore indicate that CPs should ensure that clients fully understand confidentiality and the limits of this, with regards to what will be shared and who with and furthermore this should be constantly reviewed and repeated throughout the therapy process. Participants suggested that if they felt more confident about confidentiality then they would have felt safer and better able to disclose emotions, thoughts and experiences with the therapist that can aid therapeutic change.

4.1.4 Resources. The findings of this study are in-keeping with previous research which suggests that resources and policy limitations have a strong contextual impact on therapy for people with ID (e.g., Pote, 2004). Pote (2004) found that such factors shaped the families and professionals experiences of the wider professional system and individuals interactions with the system during therapeutic work. Similarly to the findings of this study, it was found that a lack of resources limit the therapists ability to facilitate change within therapy. Furthermore, it was postulated that a lack of resources available to therapists to appropriately support clients can cause a crucial dilemma for CPs with regards to how they position themselves in relation to the client, carers and wider system. Pote (2004) found that the CPs concerns about whether the wider system is able to meet the needs of the client due to lack of resources led the CPs to align themselves with clients and carers and oppose themselves to the wider system. This alignment can be problematic when having to work with the wider system and facilitate communication to ensure the client's needs are met. To address this misalignment, consultation and reflection of conflicts can enable

communication and devise methods of working together effectively (Pote, 2006). It is clear that more research is required for working in ID settings for the specific process and efficacy of therapy in order to meet the demands of clinical governance and evidence-based culture of clinical psychology services (Roth & Fonagy, 2005), to increase accessibility of therapy for this population and further optimise therapy. Participants within this study expressed views that were in-line with these perceptions that more research is needed to enable them to carry-out their role more effectively.

4.1.5 Inclusion. The client's emphasis on the importance of being included in their care is in line with the valuing people white paper (DoH, 2001b). The results of this study suggest that professionals working with people with ID are working in line with such government incentives and this has not gone un-noticed by service-users. The fact that only clients highlight this theme suggests that this is potentially an automatic aspect of the CPs work and it is therefore potentially under-estimated in terms of a facilitator within therapy. As inclusion is a fundamental aspect of therapy, it is clear that clients felt empowered by this. It also seems evident that the client participants were not used to experiences of inclusion and empowerment. Conversely, their usual experience from health services was people talking to their families or carers and they are excluded, isolated and confused about what is happening. This is in-keeping with evidence that postulates that deprivation of human rights that are often taken for granted with people in the general population is simply part of the everyday life of people with ID (JCHR, 2008). In summary, although it seems that ID specialist services are following guidelines with regards to the inclusion and empowerment of people with ID, participants within this study felt that general health services often succumb to stereotypes that all people with ID are unable to comprehend information and they are therefore not included in decisions regarding their care. As such, one client participant recommended that CPs offer training to doctors and nurses who work within generic health care on working with people with ID.

4.1.6 Boundaries are required. As attachments from clients with ID are stronger and often quicker than those in people in the general population, therapists are urged to be stronger in boundaries and utilise supervision (Hurley et al., 1998). This was one adaptation that was posited as necessary by CPs but was only put in place by one CP. This was thought to be a barrier to ending therapy rather than a barrier to progress within therapy as such. Traditional views posit that the ending therapy phase offers both consolidation of the therapeutic work and opportunity for therapist and client to work through issues of separation and loss (Cangelosi, 1997; Levinson, 1977; Novick, 1997). Within children's services for example, boundaries for endings have proven less rigid, with the recognition that the child may need to return to therapy because their development is incomplete (Cangelosi, 1997; Chazan, 1997). This may also be the case for people with ID because people grow within attachment relationships, not by leaving them, thus contradicting a model of therapy that emphasises detachment (Shapiro, 1995). Therefore it seems that flexibility is required when working with people with ID and although boundaries are required, it should also be noted that returning to therapy is not considered a failure of previous therapeutic input, but rather is thought to be necessary and appropriate for people in this population. However, with regards to the revolving door within therapy, if more boundaries were in place within therapy then there may be a reduction in inappropriate re-referrals and creating an unhelpful level of dependency can be avoided.

4.2 Trans-theoretical model of change for people with intellectual disabilities. The need to 'convince' someone to change when they have not referred themselves was not considered an issue for participants in this study, and it was thought of as a typical process in ID services. With this in mind it is likely that psychological theories of change will need adapting for people with ID in a therapy context. A widely cited model of change in the trans-theoretical model (Prochaska, 1979; Prochaska & DiClemente, 1983; Prochaska, et al 1992) in which change is divided into five stages or "levels of motivational readiness" (Heimlich & Ardoin 2008, p. 279). These stages are: pre-contemplation, contemplation, preparation, action and maintenance. The results of this study suggest that 'contemplation' did not happen and people come into

therapy in the 'pre-contemplation' phase. Rather, than contemplation, participants experienced some level of 'convincing' or sometimes participants skipped straight into 'action' as the preparation phase may be completed by the CP. This was the case for the entire sample of client's in this study, and yet three participants were deemed to have benefitted from therapy, therefore suggesting that people do not need to go through all the stages for change to occur. For those that benefitted from therapy, 'maintenance' of change was evident post therapy; at least until the context changed and people were then unable to transfer the skills (e.g., change of staff groups). In such instances people with ID are often re-referred into services. For those that did not benefit from therapy, any progress that was noted during therapy, immediately ceased once they were discharged. It was suggested that these participants did not maintain change because the 'convincing' phase was unsuccessful. A further criticism of this theory is that it is egoistic (centred on the self) and therefore misses the wider system and environmental and social factors which affect an individual's ability to change behaviour, this is particularly crucial for people with ID. The findings therefore suggest that theories of change will need to be adapted for people with ID if they are to help psychologists formulate barriers to engagement or therapeutic change.

4.3 Further discussion of clinical implications and recommendations. Barriers and facilitators cannot be assumed to be the same for this homogenous group. However this research has offered some insight into factors that should be considered. This suggests that barriers and facilitators should be formulated as well as the presenting problems so as to explore avenues for change and overcome potential barriers. Having said that, the literature on the use of formulation within psychological therapy is still growing and therefore it is recommended that the formulation literature needs to continue to be developed as to prove its worth within the toolkit of CPs.

It seems from this research that presenting problems for people with an ID cannot be compartmentalised into separate entities. The concrete thinking style of people with ID seems to make it difficult for people to consider problems as

separate issues that need to be addressed by different services. Thus a more holistic approach seems to be necessary to ensure wider needs are met as to progress in individual therapy. It is currently unclear whether CPs specifically must fulfil the role as a care coordinator due to their specialist knowledge and skills to consider not only specific needs but needs in the broader context of health and social care. People with ID already have care coordinators and yet for people within this study, this role was not fully successful. Is this a result of a lack of specialist skills and psychological mindedness of the current care coordinators? Or is this simply a case of minimal resources and funding which means care coordinators are unable to effectively complete this role due to high caseloads? It is recommended that this role is further assessed to explore whether this is a function that CPs need to be funded to meet, or whether it would be more cost effective for other professionals to complete this role. It may be that CPs possess the skills and resources to effectively coordinate the needs of people with ID which may in the longer term be more cost effective through reducing the client's dependence on the system and reducing re-referral rates to services. Conversely, it may be that other professionals are able to effectively complete this role with the appropriate resources, in which case this would be the most cost-effective option. Such considerations require further investigation through good quality research.

4.4 Further critique of methodology. This research offers an important exploration and awareness of un-evidenced assumptions on barriers and facilitators to positive therapeutic change for people with ID. Further to the novelty and timeliness of such a study, a number of factors contribute to the strengths of these findings. Firstly, as participants were able to impart their own subjective accounts of their experiences, it is recognised that there were likely to be differences of opinion between the participant groups which can be difficult to manage. However, the critical realist epistemological position allows for multiple perspectives of reality around a single event to exist. As a result it is understood that each participant has provided their own 'true and valid' description of their experiences, whilst also acknowledging that clients, carers and CPs may well interpret events differently. The recruitment of the three participant groups is thought to be a strength of this study as it offered a broad

range of multiple perspectives on barriers and facilitators to change for people with ID. Furthermore, as there were few inconsistencies in accounts in that many themes were agreed by participants across all three groups, the validity and reliability of themes is likely to be increased. This study also offered an understanding of some themes that were dominant for only one participant group which enables the consideration of the differences in perspectives and allows the acknowledgment of differences in perceptions of events by groups. Conversely, one of the benefits of only asking for accounts from carers would have been to further understand the barriers and facilitators for people with more profound ID. However, despite this it is thought that the recruitment of the triad was a strength to enable the development of a common language, promote equality and empower people with ID to have a voice in research.

Secondly, it was ensured that all decisions throughout the process were transparent and justified as to minimise the risk of the researcher's biases impacting on the development of the results. The potential for researcher bias is a limitation to all qualitative research. However, within qualitative research for people with ID, researcher bias is specifically a potential issue during the interview process due to the vulnerable nature of people within this population. Some research has postulated that people with ID perceive a power imbalance when in interview scenarios and thus are likely to acquiesce (e.g., Porter & Lacey, 2005). A systematic literature review of the phenomenon of acquiescence in people with ID was completed prior to the interviews by the first author. The findings of this review indicated that yes-no questions appear to elicit more contradicting responses than either-or questions. Therefore suggesting that although more difficult to answer, either-or questions may yield more valid responses. Additionally, either-or questions were more likely to encourage reliable and consistent answers (Sigelman et al., 1981). Another finding from the systematic review was from Rapely and Antaki (1996) who posited that participants in their study perceived the interview to be a test, which could have potentially serious consequences for them. Therefore it was suggested that the context of the interview can impact on a person's tendency to respond in an acquiescent manner. Finally, it is worth noting that one study (Matikka & Vesala, 1997) reported gender differences in acquiescent

responses, with more women responding this way than men. Interestingly though, the direction of the difference was dependent on the gender of the interviewer. Acquiescent responses were more frequent when the interviewer and interviewee were of the same gender. Therefore the fact that the interviewer within this study was female and all participants with ID were male may have increased the validity of responses by reducing the likelihood of acquiescence. With these findings in mind, the risk of acquiescent responses was minimised during the current research as the interviewer was careful in the phrasing of questions, their physical and verbal responses to participants accounts and through checking the person's willingness to say 'no' to leading questions. Finally, it was often reiterated throughout the interview the confidentiality of their responses and the limits of this, thus reinforcing the lack of consequences to their disclosures. Therefore it is thought that the results represent accounts that are faithful to the experiences of participants.

4.5 Transferability of findings. A limitation of this research is the inclusion of participants from only one NHS trust. Furthermore, although the size of the sample was considered adequate for the methodological approach taken within the research, the sample sizes within qualitative methods overall question the wider generalisability of the findings. A strength of this study that goes some way to overcome such potential limitations is the homogenous nature of the sample and therefore representativeness of the ID sample. As all CP participants worked for the same service and were the same gender, participants with ID had similar presenting difficulties, were the same gender and were all involved with the service for lengthy periods of time and the carer participants all had similar responsibilities within their carer role, implies a homogenous sample within each participant group. Similarly, all ID participants were known to have a mild ID according to the WAIS-IV rather than a borderline range of intellectual functioning which is not always the case with research with people with ID. It should be noted that all the participants were assessed as having an ID and therefore eligible for the service based on IQ alone. As previously noted within the extended introduction section, it cannot be assumed that the person will have a deficit in social adaptive function as well. It is therefore not guaranteed that the participants within the current study meet all

three criteria in the definition of ID. With regards to the gender of clients with ID, the data from the service shows that the gender ratio of referrals to the service are relatively equal (42% female; 58% male). Furthermore, the reasons for referral were relatively consistent across genders. However there seems to be a considerable bias towards males being discharged from the service, in comparison to females who are kept on caseloads for longer. Therefore, it seems unsurprising that males were generated through the recruitment procedure. This sample seems representative of the service, but it is unclear whether this gender bias in discharge rates is a consistent finding across other services. If this is a consistent finding it would be interesting to consider the processes underlying this bias. It may be that females are perceived by CPs as more vulnerable than males and therefore kept on caseloads for longer as a result of the anxiety of CPs apropos risk. Further research could go some way to better understand this bias.

The homogenous sample reduces the extent to which findings can be transferred to other samples. For example, female clients may well face additional, fewer or different barriers and facilitators to change and it cannot be assumed that no gender differences would be present. Furthermore, the study only included participants who had been involved with the service for a lengthy period of time and as such the client participants had developed strong attachments to their CP. Therefore it may be the case that people who disengaged from therapy sooner may have offered more negative accounts of therapy. Similarly, given the considerable inconsistencies in provision of services throughout the UK, it cannot be assumed that findings from one county and one NHS trust can be generalised to a wider population of service-users with ID. Having said that, the result of this study have taken a tentative step to beginning to develop an understanding of barriers and facilitators in therapy that can aid professionals who work with people with ID, provided that results are transferred across services with caution.

5. Critical reflections

Within the epistemological position of this research, namely critical realism, it is acknowledged that there are multiple versions of the truth that are influenced by the individual's beliefs attitudes and experiences. Within this, it is therefore recognised that the researcher brings their own beliefs and interpretation of experiences to the analysis process. Therefore when exploring the narratives of participants, the researchers understanding of their accounts and pre-conceptions will be influenced by not only the personal experiences of the researcher, but also their theoretical and clinical knowledge. The use of the reflective concept map and reflective diary enabled the impact of these pre-conceptions to be minimised to maximise the validity of the analysis. However, complete objectivity is not possible and the findings become a co-construction of the researcher and participants. This reflective diary will now be discussed.

I initially explored the origins of my attitudes regarding people with ID in order to be more mindful of my potential assumptions and biases. This is shown in the following early extract of my reflective diary:

When completing my masters in Clinical Research I was put on placement within an ID service and I completed my masters thesis on people with ID. Subsequently, I gained a post as an assistant psychologist within an ID service. My experience of working with people within this population was a positive one and I found myself drawn to advocating for this stigmatised group. What I felt was a sense of frustration as a clinician so early in my career that I was not able to rely on or refer to as extensive an evidence base as people who work within the general population. This also triggered a sense of injustice on the behalf of people with ID that CPs working within this population may be limited in their work and that from a research perspective people with ID were somewhat ignored. Furthermore I felt that more funding was required to be able to better support people with ID and that the best way to encourage this is through evidence-based practice. I also felt at times ambivalent in that although I strongly hoped and wished to believe that working with a psychologist was helpful for people with ID, sometimes I

felt hopeless as some clients really struggled to benefit from therapy through either the barriers that they bring (e.g., memory) or because of barriers that I brought with regards to my lack of experience. It was particularly frustrating when I would go to a session and say 'can you remember what we talked about last week' and they were unable to remember. I often left sessions thinking 'am I actually helping here or am I just making them more dependent on me'. Another difficulty I encountered within this post was related to the high re-referral rate for one particular client. When reviewing the waiting list my supervisor suggested I pick up this client, even though he didn't really need any more work because he has seen so many Trainee Clinical Psychologists in the past for CBT that he could almost 'teach me CBT'. I felt uncomfortable with this. Was this an appropriate justification to accept a referral? Is this not just increasing his dependence on the system as in his words 'I re-referred myself because it had been a while and I like to talk to someone'? It was this that initiated my interest in researching therapy for people with ID and how it can be optimised for people within this population.

As well as my prior experience, I thought about my current role as a trainee psychologist and whether this would influence the process. I reflected on this within my diary shortly before I began data collection:

I have now arranged my first interview and I am a bit anxious about it. I really want it to go well. By that I mean that I want to enable people with ID to engage in the interview, understand what I am saying and I want them to add valuable insights into my research question. I am also anxious about the overall impact of the data collection phase on passing my thesis. If I bias the interviews in some way, I cannot redo them and this would be a fundamental flaw in my project. I also wonder whether my concern about biasing the interviews and passing my thesis may in itself be a potential bias in my pursuit of getting the 'correct answer' or an outcome that is in line with my hopes, especially because people with ID may be more vulnerable to response bias'. Furthermore I wonder how

my role will impact people's accounts of services. I wonder whether they may focus on only negative things and barriers to therapy if they know that a psychologist is someone that you talk about problems to. Conversely, knowing that I am a psychologist asking about how they found working with a psychologist will they only focus on the positives? Does this matter? I need to make sure that they feel comfortable to share both positive and negative stories if that is their true experience.

As the interviews progressed I reflected on how they were going, whether my attitudes may be biasing the study and my reactions to participants. I reflected on such concepts after each case. After case one I reflected:

I can't help but feel that my first few interviews could have gone better. I feel like I have been able to develop a good rapport with all of the participants but I am unsure about my interview schedules. When I developed them I completed the schedule for clients with ID first. As a result I think the schedules for carers and CPs entailed too many questions and prompts. I think I put a lot of questions in my interview schedules to ease my anxiety regarding gathering good quality rich data. I think I underestimated my ability as an interviewer and the interview schedule made the interviews a bit clunky as they lacked continuous flow. I did follow the participant's narratives and I did gain new insight that would not have been gathered by simply asking the questions on the interview schedule. However, when I came back to the interview schedule I found that we had already covered most of it simply by allowing participants to guide the interview I then felt anxious and lost with regards to where to take the interview next.

After case two (12 interviews) I reflected:

I now feel much more confident about how the interviews are going. I have developed a strategy of utilising my interview schedule as more of a prompt or checklist and allowing participants to generate their own accounts as well as ensuring that participants are asked about the assumed barriers and facilitators from the literature. I have found that this

has made the interviews flow much better and it has felt more natural with the participants which has helped further develop a good rapport.

When I came out of one interview with a client I felt really frustrated because he was so articulate when I met him to gain informed consent and he was able to offer some great insights into barriers and facilitators within therapy. However, once I turned on the Dictaphone he became very quiet and anxious. I reflected this to him and asked if he was happy to continue and he stated he was fine. I was conscious that he may be acquiescing so I reiterated his ability to stop the interview or have a break if he wished. I was disappointed that he wasn't able to offer the rich data and insight I was expecting. When I asked him about this when the interview was complete, he stated that the recording device reminded him of when he was questioned about his criminal offence by the police and he was concerned that they would re-open the case and he would go to prison. I felt guilty that I hadn't considered this possibility. He stated that he knew that the interview was confidential but he couldn't help but think that the worst case scenario would happen. When I asked if there was anything that I could have done to help, he stated that he would have found it useful if he could have seen the interview schedule before hand and he could have made some notes of what he wanted to say. This seemed like a good idea and I felt frustrated that I hadn't thought of it myself.

After the third case (18 interviews) I reflected:

I have now finished all of the interviews and I have already begun to make links between what has been said in previous interviews and themes have begun to emerge in my head. I decided to make note of these and then try to forget them and allow the data to develop the themes. I have been so pleased with how all participants, but especially people with ID were able to tell their stories. My main worry within the interviews was enabling participants with ID to engage in the interviews acquiescing. My confidence that this has been achieved has grown as

the interviews progressed and I feel happy with the outcome. It is difficult to know whether this was a reflection of my increasing confidence and competence as an interviewer or because clients in later interviews were more cognitively able.

When I completed the data analysis I kept my concept map of my potential biases and a print out of my research aims in front of me to remain mindful of these. When it came to choosing quotations to support the themes that were identified, a new wave of anxiety was generated. I reflected on this in the following diary extract:

I have been having some doubts about how to manage the multiple and on occasion contradicting perspectives of participants across the three groups. Having said that, my concerns about understanding the reality are somewhat eased by my epistemological position. Through critical realism I can accept that multiple valid perceptions of reality exist which are based on each individuals thoughts and interpretations. The results reflect what all participants experienced which has true implications to their emotional and behavioural response.

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6. Extended references

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Appendices

Appendix A – Invitation to Participate for Clinical Psychologists



Trent Doctorate in Clinical Psychology



UNIVERSITY OF
LINCOLN

DClinPsy
Faculty of HLSS
University of Lincoln
1st Floor, Bridge House
Brayford Pool
Lincoln
LN6 7TS

Invitation to take part in research for Clinical Psychologists

My name is Sarah Ramsden. I am a Trainee Clinical Psychologist studying for a Doctorate in Clinical Psychology at the University of Lincoln. I am doing some research that is concerned with the perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: client, carer and Clinical Psychologist perspectives. I would like to invite you to participate in this study.

Please take time to read the Research Information Sheet. If you are interested, please contact me on the number below and I can arrange a meeting to discuss participation further, including what I would be asking you to do, and give you the opportunity to ask any questions before you make your decision.

Thank you for taking the time to read this letter.

If you have any questions about the study, please contact me.

My telephone number is:

01522 886029

Please ask for:

Sarah Ramsden

Appendix B – Participant Information Sheet for Clinical Psychologists



Trent Doctorate in Clinical
Psychology



Participant Information Sheet for Clinical Psychologist Participants

I would like to invite you to take part in my research study. Before you decide it is important for you to fully understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have.

Purpose of the study

I am a first year Trainee Clinical Psychologist at Lincoln University and am completing this research as part of my studies. The purpose of this study is to explore, compare and contrast the perceptions of Clinical Psychologists, clients with Learning Disabilities and their carers as to what are facilitators and barriers to positive therapeutic change for people with Learning Disabilities.

Why have you been invited?

You are being invited to take part as you are a Clinical Psychologist that working in Psychological services for adults with Learning Disabilities.

Do you have to take part?

Taking part in this study is entirely voluntary - it is up to you whether you decide to be involved. If you decide not to take part you will have no further contact with the study.

What will you have to do?

If you decide to take part, you will first be asked to identify your most recently discharged clients (within the last 3 months) that meet the following inclusion and exclusion criteria:

Inclusion criteria:

- Meet the criteria for a global Learning Disability
- Have recently received therapy by Psychological services

Exclusion criteria:

- Have been discharged from the psychology department for longer than 3 months
- Deemed to not have capacity to consent to research participation
- Did not complete the full therapeutic process (assessment, formulation, intervention, evaluation)
- Have previously completed therapeutic work with the researcher.
- Were simultaneously working with a service that is also providing psychological support (e.g., Community Assertive Support Team in Lincolnshire)

You will then be asked to separate the clients into two groups; those that have benefitted from therapy and those that have not significantly or noticeably benefitted from therapy and list them in order starting with the most recently discharged. You can use your professional judgment and any outcome measures used to decide this. You will be asked to approach these clients to ask if they are interested. Two names of clients that are interested in taking part will be passed to the researcher, one from the 'benefitted' group and one from the 'not significantly benefitted' group. The researcher will be blind to which group the client is in, until after data collection and analysis. The identified clients and their carers will be interviewed first. Your clients will be asked to consent to you breaking the confidentiality agreement you made so that you are free to discuss them and the therapy you offered during the interview. The

interview is expected to last for between one to two hours. The interview will take place in a location, date and time that is most convenient for you. The interviews will be audio recorded, but no-one outside the research team will have access to them. The recording will be kept in a secure, locked area and will be destroyed 7 years after the research is completed. All information about you will be handled in confidence.

What are the possible benefits from taking part?

It is hoped that the results of the study will highlight ways in which the positive effects of therapy can be optimized for people with intellectual disabilities. This will inform clinical practice, add to the currently limited evidence base in this area and be the foundation for future research in order to gain further understanding of the therapeutic process with people with Learning Disabilities. The ultimate goal for research projects such as this is to improve treatment outcomes and reduce the re-referral rate in intellectual disability services.

What are the possible risks/disadvantages from taking part?

It is expected that potential disadvantages will be minimal. The key disadvantage for you is the time it will take out of your busy schedule to participate. Interviews will be arranged at a time and place that is most convenient for you.

What if you don't want to carry on with the study?

You have the right to withdraw from the study at any time up to one week after the interview has taken place and you do not have to give an explanation for doing so. In this case you can contact the chief investigator using the contact details at the bottom of this information sheet and all data collected from you will be deleted and destroyed. It will not be possible for you to withdraw from the study from one week after the interview because your interview will have been transcribed and analysed. Please be aware that if you withdraw, all collected

information from your clients and carers will also be destroyed as your participation is tied to their participation.

Will your participation be kept confidential?

Yes. However, if you disclose any information during the interview that highlights that yours or other people's safety or well-being is at risk, then I will have to pass that particular information to your supervisor so that it can be managed appropriately.

I will record the interviews and they will be written out word for word by either myself or a transcription service. The individual who is to transcribe the data will be required to sign a confidentiality agreement before they are permitted to listen to any interview recordings. The recordings will be kept in a secure locked area at the University of Lincoln. Only people from the research team will have access to them. The recordings will be destroyed 7 years after the research is completed.

Results of the study and anonymity

I hope to publish the results of the study when it is finished and this will involve using direct quotes of what people have said in interviews. I will change the names and identifiable or personal information of everyone who has taken part and will make sure that all quotes are kept anonymous. Although every precaution will be taken to avoid this, it is possible that your clients and their carers may recognise you from what you have said.

Who has reviewed the study?

All research in the NHS is looked at by a Research Ethics Committee to protect your safety, rights wellbeing and dignity. The study has been reviewed and given favourable opinion by the Lincolnshire NHS Research and Development

department, East Midlands Leicester REC Committee and Lincoln University Research Ethics Committee (chairman is Patrick Bourke).

What should you do if there is a problem?

If you have any concerns about the study you should speak to the researcher who will do her best to answer your questions (contact details below). If you have any outstanding concerns, you should contact the researcher's supervisor at Nottingham University, Dr Anna Tickle (email address: anna.tickle@nottingham.ac.uk; Telephone number: 0115 846 6646). If you are still unhappy about the research and wish to complain formally, you can do this through the NHS Complaints Procedure.

If you choose to take part in the study, you will be given a copy of this letter and a copy of the consent form that you will have signed.

Thank you very much for your time.

Sarah Ramsden, Chief Investigator

If you have any questions, please contact:
Sarah Ramsden (Trainee Clinical Psychologist)
Department of Psychology
University of Lincoln
LN6 7TS

Tel: 01522 886029
Email: 07070771@students.lincoln.ac.uk

This research will be approved by:
School of Psychology Ethics Committee
University of Lincoln
Patrick Bourke (chairman)
pbourke@lincoln.ac.uk

Research and development (R&D)
department of Lincolnshire Foundation (NHS)
Partnership Trust

East Midlands Leicester REC Committee
have reviewed this study

Appendix C – Consent Form for Clinical Psychologists



Trent Doctorate in Clinical
Psychology



Consent Form for Clinical Psychologist Participants

Title of Project: Perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.

Name of researcher: Sarah Ramsden

	Please initial
1. I confirm that I have read and understood the information sheet dated 27/11/2013 (version 3) for the above study. I have had the opportunity to think about the information and ask questions, and have had these answered to my satisfaction.	
2. I understand that I do not have to participate in this study, and that I can withdraw from the study up to one week after the interview without giving a reason, and that this will not affect my rights or treatment in any way.	
3. I agree to have my interview audio recorded. I understand that may include recording personal details, but that this will only be accessed by members of the research team. I also understand that the recording will be securely stored in a locked area and that it will be destroyed 7 years after the study is completed.	
4. I agree that direct quotes of things I have said may be used in the publication of the study results, but that these will have any identifiable information changed to protect my identity and to preserve confidentiality. I understand that although every	

Appendix D – Invitation to Participate for Clients



**Trent Doctorate in Clinical
Psychology**



DClinPsy
Faculty of HLSS
University of Lincoln
1st Floor, Bridge House
Brayford Pool
Lincoln
LN6 7TS

Invitation to take part in research for Clients with Learning Disabilities

My name is Sarah Ramsden. I am a Trainee Clinical Psychologist studying for a qualification at the University of Lincoln. I am doing some research. My research is asking the question: What are the things that help, and what are the things that make it hard for people with intellectual disabilities to benefit from therapy? You have been given this letter because you are a person with an intellectual disability who has recently worked with a Psychologist.

Please take time to read the Research Information Sheet. If you like you can ask family and friends what they think. You can ask me for a copy of the information on CD if it is easier.

If you are interested, you can tell the staff member who gave you this letter. I will visit you and we can talk about whether or not you want to take part.

Thankyou for taking the time to read this letter.

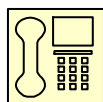
Contact for further information:

If you have any questions about the study, please contact me.



My telephone number is:

01522 886029



Please ask for:

Sarah Ramsden

Appendix E – Participant Information Sheet for Clients



Trent Doctorate in Clinical
Psychology



INFORMATION SHEET FOR CLIENT WITH LEARNING DISABILITIES

What is the study about?

My name is Sarah Ramsden. I am a trainee clinical psychologist at the University of Lincoln. I would like to invite you to take part in my research study. Before you decide it is important for you to fully understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have.

I would like to find out what it has been like working with a clinical psychologist. I will meet with you to ask you some questions about you, the therapy you have had and the staff that you have worked with. This will help me to find out how you got on with staff and how they helped you. I will record our talk on tape so that later I can listen to it again and remember what we talked about.

I contacted your Clinical Psychologist and asked them to pick two people that they worked with. They picked you and asked you if you would be interested in taking part. They also asked if your carer was interested in taking part. Then they passed on your name to me. I would like to ask you, your carer and your clinical psychologist some questions. I will also be asking some other Clinical Psychologists, people with intellectual disabilities and their carers to take part too.

What will you be asked to do?

I would like to have a look at your notes to find out about what sort of things you are good at and what you find a bit more difficult. I would also like to find out about the therapy you had and how it helped you. I would like to meet with you to ask you some questions. This will take one and a half hours at the most. The

interview will take place in a location, date and time that is most convenient for you. For example, the interview can take place in your home or at the Learning Disability Psychology office at Long Leys Court in Lincoln. This will be arranged with you.

Everything will stay confidential. That means that your name will stay secret. If you tell me something that might make me worry about your safety or well-being, or the safety and well-being of someone else, then I will talk to you first and then to the staff you work with to see what we can do to help. If you tell me something that might make me worry about the way people care for you or something bad that has happened in your home then I will talk to you about it and then I might talk to some people that can help protect you and improve the way you are cared for. All the information will be kept in a safe place. The tape of our meeting will be kept for seven years. After that, I will destroy the tape, when I don't need to look at it any more.

Do you have to take part?

You can choose whether you take part or not.

If you decide not to take part in the study, then nothing will change. If you decide that you do want to take part in the study, then also, nothing will change. If you decide to take part in the study and then change your mind that is okay too. You can tell me if you change your mind at any time, but if you tell me more than one week after our talk, I will still use some of the things we talked about in the study.

What is the goal of the study?

When I have talked to lots of people, I will write a report.

I hope that I will find out how we can help people with an intellectual disability get better help from a Clinical Psychologist, and that I can find out a good way for Clinical Psychologists to work with people.

What will happen next?

If you say YES to taking part in the study, I will ask you to sign a consent form. A family member or support worker can be with you when you do this. A family

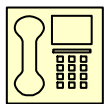
member can sign on your behalf if you are unable to sign it yourself. If you want, I will give you a CD of this information so that you can listen to everything again. If you change your mind, you can tell me by calling me on the number below. Or you can ask a family member or a support worker to tell me. If you change your mind, this means that your carer and Clinical Psychologist will no longer take part.

Who has reviewed the study?

The study has been checked over by the Lincolnshire NHS Research and Development department, East Midlands Leicester REC Committee have reviewed this study and Lincoln University Research Ethics Committee (chairman is Patrick Bourke). These are groups of people who make sure that research is useful and safe to take part in.

Contact for further information:

If you have any questions about the study, please contact me.



My telephone number is:

01522 886029

Please ask for: Sarah Ramsden

My supervisor's telephone number

is:

0115 846 6646

Please ask for: Anna Tickle



Appendix F – Consent Form for Clients



Trent Doctorate in Clinical Psychology



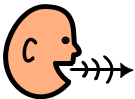

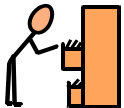
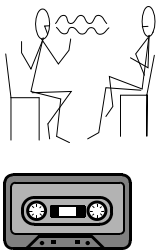
CONSENT FORM FOR CLIENT WITH LEARNING DISABILITIES




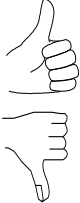
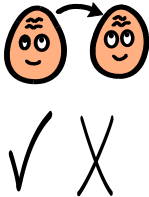

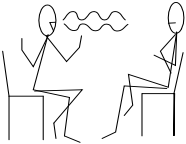

Title of Project:

Perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.

Name of Researcher:

Sarah Ramsden, Trainee Clinical Psychologist

		Please tick box	
		YES	NO
	Sarah has explained to me about the study		
	I understand the information sheet		
	I understand Sarah will look at my notes		
	I understand that Sarah will talk with me about how I have found working with a Clinical Psychologist and it will be recorded on a tape		

	<p>I understand that Sarah will talk to my carer about me</p>		
	<p>I understand that Sarah will talk to my Clinical Psychologist about me</p>		
	<p>I agree for my clinical psychologist to break our confidentiality and privacy agreement</p>		
	<p>I understand that it is my choice to say YES or NO to take part in the study</p>		
	<p>I know that I can change my mind about taking part and can withdraw my data up to one week after my interview.</p>		
	<p>I understand that my name won't be used with the data but it is possible that my carer and clinical psychologist might recognise me from what I have said</p>		
	<p>Somebody I know was here with me when I signed this form.</p>		
	<p>I agree to take part in this study</p>		

Name of Person with
Learning Disability

Date

Signature

Name of Researcher

Date

Signature

Participant number:

If you have any questions, please contact:

Sarah Ramsden (Trainee Clinical Psychologist)

Department of Psychology

University of Lincoln

LN6 7TS

Tel: 01522 886029

Email: 07070771@students.lincoln.ac.uk

This research will be approved by:

School of Psychology Ethics Committee

University of Lincoln

Patrick Bourke (chairman)

pbourke@lincoln.ac.uk

Research and development (R&D)

department of Lincolnshire Foundation (NHS)

Partnership Trust

East Midlands Leicester REC Committee

have reviewed this study

Appendix G – Invitation to Participate for Carers



Trent Doctorate in Clinical Psychology



UNIVERSITY OF
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DClinPsy
Faculty of HLSS
University of Lincoln
1st Floor, Bridge House
Brayford Pool
Lincoln
LN6 7TS

Invitation to take part in research for Carers

My name is Sarah Ramsden. I am a Trainee Clinical Psychologist studying for a Doctorate in Clinical Psychology at the University of Lincoln. I am doing some research that is concerned with the perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: client, carer and Clinical Psychologist perspectives. I would like to invite you to participate in this study because a person with a Learning Disability that you care for has agreed to participate, and I would like to have your opinion on what it was like for them to have therapy, and what it was like for you to support someone who was undergoing therapy.

Please take time to read the Research Information Sheet. If you are interested, please contact me on the number below and I can arrange a meeting to discuss participation further, and give you the opportunity to ask any questions before you make your decision.

Thank you for taking the time to read this letter.

If you have any questions about the study, please contact me.

My telephone number is:
01522 886029

Please ask for:
Sarah Ramsden

Appendix H – Participant Information Sheet for Carers



Trent Doctorate in Clinical
Psychology



Participant Information Sheet for Carer Participants

I would like to invite you to take part in a research study. Before you decide, you will need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You may find it useful to talk to other people about the study, and whether or not you would like to take part.

Purpose of the study

I am a first year Trainee Clinical Psychologist at Lincoln University and am completing this research as part of my studies. The purpose of this study is to explore, compare and contrast the perceptions of Clinical Psychologists, clients with Learning Disabilities and their carers as to factors that optimize the positive effects of therapy for people with Learning Disabilities and what factors are boundaries for change.

Why have you been invited?

You are being invited to take part because you are a carer of a person with intellectual disabilities and the person you care for has agreed to take part in this research.

Do you have to take part?

Taking part in this study is entirely voluntary - it is up to you whether you decide to be involved. If you decide not to take part you will have no further contact with the study.

What will I have to do?

If you decide to take part, you will be invited to an interview which is expected to last for between one to two hours. The interview will take place in a location, date and time that is most convenient for you. For example, the interview can take place in the home of the person you care for or at the Learning Disability Psychology office at Long Leys Court in Lincoln. This will be arranged with you. The interviews will be audio recorded, but no-one outside the research team will have access to them. The recording will be kept in a secure, locked area and will be destroyed 7 years after the research is completed. All information about you will be handled in confidence.

What are the possible benefits from taking part?

There are no individual benefits to you, but I hope that an increase in knowledge in this area will help to develop our understanding of how Clinical Psychologist work with people with Learning Disabilities.

What are the possible risks/disadvantages from taking part?

It is expected that potential disadvantages will be minimal. Arranging the times for interviews may be inconvenient, although I will try to make them at a time and place that suits you.

What if you don't want to carry on with the study?

You have the right to withdraw from the study at any time up to one week after the interview has taken place and you do not have to give an explanation for doing so. In this case you can contact the chief investigator using the contact details at the bottom of this information sheet and all data collected from you will be deleted and destroyed. It will not be possible for you to withdraw from the study from one week after the interview because your interview will have been transcribed and analysed. Please be aware that if you withdraw, all collected information from the person you care for will also be destroyed as your participation is tied to their participation.

Will your participation be kept confidential?

Yes. However, if you disclose any information during the interview that highlights that yours or other people's safety or well-being is at risk, then I will have to pass that particular information to the appropriate authority so that it can be managed appropriately. I will record the interviews and they will be written out word for word by either myself or a transcription service. The individual who is to transcribe the data will be required to sign a confidentiality agreement before they are permitted to listen to any interview recordings. The recordings will be kept in a secure locked area at the University of Lincoln. Only people from the research team will have access to them. The recordings will be destroyed 7 years after the research is completed.

Results of the study and anonymity

I hope to publish the results of the study when it is finished and this will involve using direct quotes of what people have said in interviews. I will change the names and identifiable or personal information of everyone who has taken part and will make sure that all quotes are kept anonymous. Although every precaution will be taken to avoid this, it is possible that you clients with

intellectual disabilities and their Clinical Psychologist may recognise you from what you have said.

Who has reviewed the study?

All research in the NHS is looked at by a Research Ethics Committee to protect your safety, rights wellbeing and dignity. The study has been reviewed and given favourable opinion by the Lincolnshire NHS Research and Development department, East Midlands Leicester REC Committee and Lincoln University Research Ethics Committee (chairman is Patrick Bourke).

What should you do if there is a problem?

If you have any concerns about the study you should speak to the researcher who will do her best to answer your questions (contact details below). If you have any outstanding concerns, you should contact the researcher's supervisor at Nottingham University, Dr Anna Tickle (email address: anna.tickle@nottingham.ac.uk; Telephone number: 0115 846 6646). If you are still unhappy about the research and wish to complain formally, you can do this through the NHS Complaints Procedure. If you choose to take part in the study, you will be given a copy of this letter and a copy of the consent form that you will have signed.

Thank you very much for your time.

Sarah Ramsden, Chief Investigator

If you have any questions, please contact:
Sarah Ramsden (Trainee Clinical Psychologist)
Department of Psychology
University of Lincoln
LN6 7TS
Tel: 01522 886029
Email: 07070771@students.lincoln.ac.uk

This research will be approved by:
School of Psychology Ethics Committee
University of Lincoln
Patrick Bourke (chairman)
pbourke@lincoln.ac.uk

Research and development (R&D)
department of Lincolnshire Foundation (NHS)
Partnership Trust
East Midlands Leicester REC Committee
have reviewed this study

Appendix I – Consent Form for Carers



Trent Doctorate in Clinical
Psychology



Consent Form for Carer Participants

Title of Project: Perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.

Name of researcher: Sarah Ramsden

	Please initial
1. I confirm that I have read and understood the information sheet dated 27/11/2013 (version 3) for the above study. I have had the opportunity to think about the information and ask questions, and have had these answered to my satisfaction.	
2. I understand that I do not have to participate in this study, and that I can withdraw from the study up to one week after the interview without giving a reason, and that this will not affect my rights or treatment in any way.	
3. I agree to have my interview audio recorded. I understand that may include recording personal details, but that this will only be accessed by members of the research team. I also understand that the recording will be securely stored in a locked area and that it will be destroyed 7 years after the study is completed.	

<p>4. I agree that direct quotes of things I have said may be used in the publication of the study results, but that these will have any identifiable information changed to protect my identity and to preserve confidentiality. I understand that although every precaution will be taken to avoid this, it is possible that the person I am a carer for and their Clinical Psychologist may recognise me from what I have said.</p>	
<p>5. I agree (with the full permission of the person with intellectual disabilities that I care for) to discuss them and the therapy they had in the interview.</p>	
<p>6. I agree to take part in the above study.</p>	

.....
Name of participant

.....
Date

.....
Signature

.....
Name of Person
taking consent

.....
Date

.....
Signature

When completed: 1 copy for participant, 1 copy for research files, 1 copy for medical notes

Participant number:

If you have any questions, please contact:
Sarah Ramsden (Trainee Clinical Psychologist)
Department of Psychology
University of Lincoln
LN6 7TS
Tel: 01522 886029
Email: 07070771@students.lincoln.ac.uk

This research will be approved by:
School of Psychology Ethics Committee
University of Lincoln
Patrick Bourke (chairman)
pbourke@lincoln.ac.uk

Research and development (R&D)
department of Lincolnshire Foundation (NHS)
Partnership Trust
East Midlands Leicester REC Committee
have reviewed this study

Appendix J – Ethical Approval Letters

NRES Committee East Midlands - Leicester

The Old Chapel
 Royal Standard Place
 Nottingham
 NG1 6FS
 Telephone: 0115 8839425

Miss Sarah Ramsden
 Trainee Clinical Psychologist
 Lincolnshire Partnership NHS Foundation Trust
 University of Lincoln
 Faculty of Health, Life and Social Sciences
 Bridge House, Brayford Pool,
 Lincoln
 LN6 7TS
 03 December 2013

Dear Miss Ramsden

Study title:	Perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.
REC reference:	13/EM/0396
IRAS project ID:	125033

Thank you for your letter of 21 November 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Wendy Rees, NRESCommittee.EastMidlands-Leicester@nhs.net.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

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

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		07 October 2013
Evidence of insurance or indemnity		19 July 2013
Evidence of insurance or indemnity	AON	29 July 2013
Interview Schedules/Topic Guides	2 - Learning Disabilities	20 November 2013
Interview Schedules/Topic Guides	2 - carers	20 November 2013
Interview Schedules/Topic Guides	2 - Clinical Psychologists	20 November 2013
Investigator CV		26 September 2013
Letter of invitation to participant	Clinical psychologists 1	15 April 2013
Letter of invitation to participant	Clients with intellectual disabilities 1	15 April 2013
Letter of invitation to participant	Carers 1	15 April 2013
Other: CV - Academic supervisor		26 September 2013
Other: Research Procedure Flowchart		07 October 2013
Other: Ethical approval from: Human Research Projects		20 November 2013
Other: Audio CD - Information Sheet for client with Learning Disabilities		27 November 2013
Other: Cover letter		27 November 2013
Participant Consent Form: Client with Learning Disabilities 2	2	20 November 2013
Participant Consent Form: Clinical Psychologists3	3	27 November 2013
Participant Consent Form: Carers3	3	27 November 2013
Participant Information Sheet: Client with Learning Disabilities	1	15 April 2013
Participant Information Sheet: Carers	2	20 November 2013
Participant Information Sheet: Clinical Psychologist	125033/510435/1/215	08 October 2013
Protocol		15 May 2013
Protocol		
REC application		21 November 2013
Referees or other scientific critique report		
Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research

Ethics Committees in the UK.

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/EM/0396

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

Professor Geoff Dickens
Chair

Email: NRESCommittee.EastMidlands-Leicester@nhs.net

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Sara Owen
Mrs Dianne Tetley, Lincolnshire Partnership NHS Foundation Trust

NRES Committee East Midlands - Leicester

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

14 November 2013

Miss Sarah Ramsden
Trainee Clinical Psychologist
Lincolnshire Partnership NHS Foundation Trust
University of Lincoln
Faculty of Health, Life and Social Sciences
Bridge House, Brayford Pool, Lincoln
LN6 7TS

Telephone: 0115 8839425

Dear Miss Ramsden

Study Title:	Perceived barriers and facilitators to positive therapeutic change for people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.
REC reference:	13/EM/0396
IRAS project ID:	125033

The Research Ethics Committee reviewed the above application at the meeting held on 01 November 2013. Thank you for attending to discuss the application.

Documents reviewed

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		07 October 2013
Evidence of insurance or indemnity	AON	19 July 2013
Evidence of insurance or indemnity		29 July 2013
Interview Schedules/Topic Guides	Clinical psychologists 1	15 April 2013
Interview Schedules/Topic Guides	Learning disabilities 1	15 April 2013
Interview Schedules/Topic Guides	Carers 1	15 April 2013
Investigator CV		26 September 2013
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Letter of invitation to participant	Clients with intellectual disabilities 1	15 April 2013
Letter of invitation to participant	Carers 1	15 April 2013
Other: CV - Academic supervisor		26 September 2013
Other: Research Procedure Flowchart		
Other: Ethical approval from: Human Research Projects		

Other: Audio CD - Information Sheet for client with Learning Disabilities	1	07 October 2013
Other: Cover letter	1	15 April 2013
Participant Consent Form: Clinical psychologists	1	15 April 2013
Participant Consent Form: Learning Disabilities	1	15 April 2013
Participant Consent Form: Carers	1	15 April 2013
Participant Information Sheet: Clinical psychologists	1	15 April 2013
Participant Information Sheet: Learning Disabilities	1	15 April 2013
Participant Information Sheet: Carers		15 April 2013
Protocol		07 October 2013
REC application	125033/509887/1/920	08 October 2013
REC application	125033/510435/1/215	15 May 2013
Referees or other scientific critique report		

Provisional opinion

- The chair introduced themselves and the committee and thanked you for attending the meeting
- The chair advised you that there are a number of changes that will be required in the Patient Information Sheet but this will be put in writing along with the decision letter
- The committee asked you who is the academic supervisor for the study, you advised that this is Dr Anna Tickle who is based at the University of Nottingham, the committee queried if support is on hand by another supervisor as they are at different university sites, you advised that there is support on hand with other team members but Dr Tickle is very accessible for support
- The committee advised you that the committee would need to review the final interview schedule through a sub-committee before this can be used, you agreed that this would be done
- The committee asked you where will the participants be interviewed for the study, you advised that participants will be living in either supported living accommodation or residential homes, but the interviews can be conducted at the clinics and transport will be covered, participants can decide where they will feel most comfortable
- The committee asked you about the recruitment of participants to the study, you advised that the clinical psychologists will recruit participants directly, then a referral will be made to you, the committee suggested that no reference of a service user to you be made until the carer has also indicated willingness to proceed.
- The committee asked you if you have received GCP training, so that you are able to assess a participants capacity to consent, you advised that you have conducted capacity assessments on a regular basis but had not received the recommended GCP training, you agreed to undertake the training as this could be done online
- The committee queried why the pictorial Consent Form, did not give reference to you and the role that you would have around conducting interviews, you advised that there appears to be pages missing from the form and the questions asked by the committee are covered in the document, you agreed to send another copy of the document into the office
The committee advised you that the tick boxes are missing on the Clinician and Carers Consent Forms

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

The Patient Information Sheet

1. Clients Information Sheet does not mention an invitation to participate, please insert at the start of document
2. Insert page numbers of all of the Patient Information Sheets
3. Provide information about where the interview can take place if not at the participants home
4. Explain the full extent of what the study entails within the patient group
5. Insert Page numbers throughout the documents
6. Provide a contact telephone number for Dr Tickle Advise that if the service user withdraws from the study then the carer and clinical psychologists will also withdrawal from the study
7. Advise that the East Midlands Leicester REC Committee have reviewed the study
8. Insert guidance on how participants will be supported if there are safeguarding or care concerns that are raised during interviews
9. Advise service users that a family member can sign on their behalf if the service user is unable to sign for themselves

Other

1. Provide a copy of the Consent Form for the client, missing information when documents received for review
2. Consent Form – for both Clinical Psychologist and Carers, insert initial boxes to the document Provide a final copy of the interview schedule
3. Update the protocol to include information that participants will be recruited before the carer is invited to participate

The Committee delegated authority to confirm its final opinion on the application to the Chair.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact REC Manager nrescommittee.eastmidlands-leicester@nhs.net

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

Membership of the Committee

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 December 2013.

The members of the Committee who were present at the meeting are listed on the attached sheet.

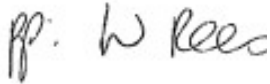
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

13/EM/0396

Please quote this number on all correspondence

Yours sincerely



Professor Geoff Dickens
Chair

Email: NRESCcommittee.EastMidlands-Leicester@nhs.net

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to:

*Sara Owen
Mrs Dianne Tetley, Lincolnshire Partnership NHS Foundation Trust*

Ref:13/EM/0396
Date 11th December 2013

Miss Sarah Ramsden
Trainee Clinical Psychologist
University of Lincoln
Faculty of Health, Life and Social Sciences
1st Floor Bridge House
Brayford Pool Campus
LINCOLN
LN6 7TS

Research and Effectiveness Team
Trust Headquarters
Unit 9, The Point
Lions Way
SLEAFORD
Lincolnshire
NG34 8GG

Tel: 01529 222206
Fax: 01529 222226

Dear Sarah Ramsden

Study title: Barriers and facilitators in therapy for people with Learning disabilities
Chief Investigator: Sarah Ramsden
REC No:13/EM/0396
Date of permission: 11th December 2013

List of all site(s) for which NHS permission for research is given: Lincolnshire Partnership NHS
Foundation Trust

NHS permission for the above research has been granted by Lincolnshire Partnership NHS
Foundation Trust on the basis described in the application form, protocol and supporting
documentation.

Permission is granted on the understanding that the study is conducted in accordance with the
Research Governance Framework, ICH GCP and NHS Trust policies and procedures (available
at <http://www.lpt.nhs.uk/>).

Permission is only granted for the activities for which a favourable opinion has been given by the
REC [and which have been authorised by the MHRA]

List of any conditions of approval: None

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research
site, may take appropriate urgent safety measures in order to protect research participants
against any immediate hazard to their health or safety.

The Research and Effectiveness office should be notified, at the address above, that such
measures have been taken. The notification should also include the reasons why the measures
were taken and the plan for further action. The Research and Effectiveness Office should be
notified within the same time frame of notifying the REC and any other regulatory bodies.

Any research carried out by a Trust employee with the knowledge and permission of the employing organisation will be subject to NHS indemnity. NHS indemnity provides indemnity against clinical risk arising from negligence through the Clinical Negligence Scheme for Trusts (CNST). Further details can be found at Research in the NHS: Indemnity arrangements (Department of Health 2005).

All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please inform the Research and Effectiveness department of any changes to study status.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

We are pleased to inform you that you may now commence your research. Please retain this letter to verify that you have Trust permission to proceed. We wish you every success with your work.

Yours sincerely



PP

Dianne Tetley
Assistant Director Research and Effectiveness
Lincolnshire Partnership NHS Foundation Trust

Cc Academic Supervisor – Dr Anna Tickle
Clinical supervisor – Dr Samantha Harris
Sponsor – University of Lincoln

Enc: Data Protection Guidance on the transportation of personal identifiable data

www.lpft.nhs.uk

RESPECT



Chairman: Eileen Ziemer
Chief Executive: Chris Slavin



UNIVERSITY OF
LINCOLN

15-05-2013

Dear Sarah Ramsden,

The Ethics Committee of the School of Psychology would like to inform you that following the changes that you made after our April 30th meeting your proposed research '*exploring the perceived barriers and facilitators to positive therapeutic change of people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.*'

is:



approved

It has been allocated the reference 130430-4-b

Yours sincerely,

A handwritten signature in blue ink that reads "Patrick Bourke".

Patrick Bourke, PhD

Chair of the Ethics Committee
School of Psychology
University of Lincoln
Brayford Campus
Lincoln LN6 7TS
United Kingdom
telephone: +44 (0)1522 886140

02-05-2013

The Ethics Committee of the School of Psychology would like to inform you that at our April 30th meeting your proposed research 'exploring *the perceived barriers and facilitators to positive therapeutic change of people with Learning Disabilities: Client, Carer and Clinical Psychologist perspectives.*'

Dear Sarah Ramsden,
was:

approved

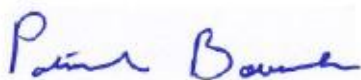
approved subject to the following conditions:

- (1) Change 'who has reviewed this study' to correct for current Chair i.e. Patrick Bourke with contact details in case of complaint.**
- (2) Typos fixed on information sheet i.e. drop 'that' from 'why have you been invited'**
- (3) Clarify/confirm that you are happy with the wording on the 'information sheet for carers' - will your participation be kept confidential' is appropriate for family members who are careers i.e will they have 'supervisors'**

Ethical approval will be given once these changes are made. To complete this process please Email the Chair (pbourke@lincoln.ac.uk) specifying the changes made.

It has been allocated the reference 130430-4

Yours sincerely,



Patrick Bourke, PhD

Chair of the Ethics Committee
School of Psychology
University of Lincoln
Brayford Campus
Lincoln LN6 7TS
United Kingdom
telephone: +44 (0)1522 886140

Appendix K – Interview Schedule for Clients

INTERVIEW SCHEDULE FOR CLIENTS WITH LEARNING DISABILITIES

This interview schedule will not be used verbatim. This is a prompt for participants to provide relevant information. The researcher will ensure that when asking these questions and prompting for further information that data collection will be specifically follow the aims of the research to gather information about facilitators and barriers to therapeutic change.

Topic 1: Background information

Name

Age

Level of Learning Disability

Living arrangements

Education

Mental Health

Physical Health

Have you seen a psychologist before? If yes what for?

Topic 2: Decision to see a psychologist

Can you remember why you came to see a psychologist?

- Was it you that wanted to come or was it a carer?
- If it was your carer, did you know about it? If yes, how did you feel about it? (prompt - ok/happy/sad/angry)
- Were you given any information to help you decide if you wanted to see a psychologist?

If yes, what was it? Was it helpful?

If no, what would you like to have been told about?

Did you think you needed support from a Psychologist?

Did you talk to other people about seeing a psychologist before you saw them?

- Professional/family member/ key worker?
- What did they say?

- Did this change your thoughts about seeing a psychologist?

Topic 3: Expectation of seeing a psychologist

Did you know what a psychologist was before you met X?

What did you think might happen when you saw the psychologist?

- What did you think the psychologist could help you with?
- What did your carer think the psychologist could help you with?

How did you feel about going to see a psychologist?

- Prompt: excited/grateful/ scared/worried/happy

Topic 4: Experience of therapy

What was it like to meet the psychologist?

What was your psychologist like?

What was it like to work with X?

Do you know what type of therapy you had? If yes, what was it?

Was it how you thought it would be?

What things did you talk about with the psychologist?

Did you feel that the psychologist understood your problems? If yes, what did the psychologist do or say that made you think she understood?

Did you feel you were able to talk to your psychologist about anything that was bothering you?

Were there things in therapy you found difficult? (If yes, what?)

Were there things in therapy you found easy? (If yes, what?)

Did you feel like you learnt anything? (If yes, what?)

Did your carer help you practice the things you learnt in therapy when you were at home? Did this help you?

Did anything help you to remember things you talked about in therapy?

Did the psychologist give you anything to help you remember?

What was the ending of therapy like?

Did anything change because of therapy? (If yes, what?)

What made the change happen?

What stopped any or more change from happening?

Is there anything that stopped things from changing?

Topic 5: Most helpful experiences

What has been the most helpful thing about how the psychologist worked with you?

Have there been any other ways the psychologist has been helpful?

How did the psychologist involve your carer?

How would you have liked the psychologist to involve your carer in the process (more/less/differently to how they did)?

How did the psychologist support your carer to help you (if at all)?

Are there other ways that you would have liked the psychologist to help your carer support you? If so what are they?

Topic 6: Least helpful experiences

What has been the least helpful thing about how the psychologist worked with you?

Have there been any other ways the psychologist has been unhelpful?

What would you like to have been different about your work with the psychologist?

Topic 7: Future Plans

If you needed to, do you think you might see a psychologist again in the future?

Overall, what do you think is good about the way psychologists work with people with intellectual disabilities?

Overall, what do you think could be better about the way psychologists work with people with intellectual disabilities?

Is there anything else you would like to tell me about?

Appendix L – Interview Schedule for Carers

INTERVIEW SCHEDULE FOR CARERS

This interview schedule will not be used verbatim. This is a prompt for participants to provide relevant information. The researcher will ensure that when asking these questions and prompting for further information that data collection will be specifically follow the aims of the research to gather information about facilitators and barriers to therapeutic change.

Topic 1: Background information

Name

Age

Carer type (e.g., family member, professional)

Education

Number of years experience with people with ID

Length of time known the client

Topic 2: Decision to see a psychologist

Who made the referral?

- If it was you, why was the referral made?
- If it wasn't you, how much did you agree with the referral?

Did you talk to the person you care for about the referral?

Do you think the person understood the reasons for referral?

How much do you think the person agreed with the referral?

Topic 3: Expectation of seeing a psychologist

Did you talk to the person about what a psychologist was?

-How much do you think they understood about what a psychologist does?

What did you think the psychologist could help the person with?

- What did the person you care for think the psychologist could help you with?

- What were your expectations about how the psychologist would involve you?

Topic 4: Experience of therapy

What was it like to support the person while they had therapy?

Were you involved in the therapeutic process? How?

Do you know what type of therapy they had?

What was it like for you working with a clinical psychologist?

Did you notice whether the person found particular things difficult? (If yes, what?)

Did you notice whether the person found particular things easy? (If yes, what?)

Did the person find it hard to remember things they talked about in therapy?

Do you think they learnt any new skills through therapy? (If yes, what?)

Were you able to help the person practice skills learnt in therapy?

Did the psychologist give you anything to help you support the person?

Did you feel like the psychologists understanding of the person was similar to your understanding of the person?

Did you think anything changed as a result of therapy (If yes, what?)

Did change happen the way you expected them to?

What facilitated change?

What were the barriers to change?

Is there anything that you would have liked to have changed that didn't?

Topic 5: Most helpful experiences

What has been the most helpful thing about how the psychologist worked with the person?

Have there been any other ways the psychologist has been helpful?

How did the psychologist involve you in the process?

How would you have liked the psychologist to involve you in the process (more/less/differently to how they did)?

How did the psychologist support you to help the person (if at all)?

Are there other ways that you would have liked to have been supported by the psychologist? If so what are they?

Topic 6: Least helpful experiences

What has been the least helpful thing about how professionals have worked with the person?

Have there been any other ways the psychologist has been unhelpful?

What would you like to have been different?

Topic 7: Future Plans

Do you think the person might see a psychologist again in the future if they needed to?

Overall, what do you think is good about the way psychologists work with people with intellectual disabilities?

Overall, what do you think could be improved about the way psychologists work with people with intellectual disabilities?

Is there anything else you would like to tell me about?

Appendix M – Interview Schedule for Clinical Psychologists

INTERVIEW SCHEDULE FOR CLINICAL PSYCHOLOGISTS

This interview schedule will not be used verbatim. This is a prompt for participants to provide relevant information. The researcher will ensure that when asking these questions and prompting for further information that data collection will be specifically follow the aims of the research to gather information about facilitators and barriers to therapeutic change.

Topic 1: Background information

Name

Age

Qualifications/ training

How long have they been qualified?

How many years experience have they had working with people with intellectual disabilities?

Topic 2: Reason for referral

What was the reason for referral?

How was it decided that the person was eligible for services?

Had they accessed psychological services previously?

Who made the referral?

Did the client know about the referral?

Did the client agree with the referral?

Did the person think they needed support from a Psychologist?

Did the person understand what a psychologist was?

What were you initial assumptions about the client?

Topic 3: Experience of therapy

What were the presenting problems?

What psychological approach and theory was used?

How did you adapt this for someone with an intellectual disability?

How many sessions were provided?

What assessment methods did you use?

What were the therapeutic goals?

What formulation model did you use?

How did you explain formulation to the client?

Who else did you share the formulation with?

What intervention strategies were used?

Were there things they found particularly difficult?

Were there things they found particularly easy or grasped quickly?

Were the therapeutic goals met?

Did the client meet your expectations and initial assumptions?

Topic 4: Possible facilitators to therapeutic change

How did you feel about the therapeutic relationship?

What were your opinions of the client's motivation, engagement and commitment to therapy?

What do you think were the most helpful aspects of this therapy?

What impacted on the person's ability to benefit from therapy?

What were the positive outcomes of therapy?

Can you highlight any other facilitators to change?

Topic 5: Possible barriers to therapeutic change

Was there anything that you were hoping would change but didn't?

Were there any negative outcomes of therapy?

How much do you think the person's cognitive abilities impacted on their ability to understand and utilise therapy?

Did the person have specific cognitive deficits that made it more difficult for them?

How were these cognitive deficits overcome? What strategies were used?

What did you think were the least helpful aspects of this therapy?

What would you have done differently?

Were there any factors outside of therapy that you felt impacted on the person's ability to benefit from therapy?

Are there other aspects that you felt were barriers to positive therapeutic change?

Topic 6: Involvement of carer

How much did you involve the carer?

In what ways was the carer involved?

Did you feel that the carer provided adequate support and reinforcement outside of therapy?

Topic 7: Overall

Overall, what do you think is good about the way psychologists work with people with intellectual disabilities?

Overall, what do you think could be improved about the way psychologists work with people with intellectual disabilities?

Is there anything else you would like to tell me about?

Appendix N - Client Interview Extract with codes (Liam – Case 3)

		Initial codes	Secondary codes
250	I: Yes ok. But it took a bit of time to build the trust with [Caroline]?		
251	P: Yes it was really hard. It's not nice at all. Sometimes it can be really hard to talk	Really hard to trust	Trust in therapeutic
252	about it all. Even though I really liked [Caroline] and I wanted her help, there were	Hard to talk about it	relationship
253	times when I used to dread her coming because I felt like I don't want to talk about	Liked her; wanted help	Hard to talk
254	it today. But obviously if I was ill then she wouldn't come out but honestly there is	dread her coming	Wanted to engage
255	no excuse and I have never had a day off unless I've been ill.	no excuse for day off	Important to attend
256	I: Is that because you felt it was really important.		
257	P: Yes it was really important to get sorted.	important to get sorted	Motivated to engage
258	I: Yes. Was there any times when you did get really upset talking to [Caroline]?		
259	P: No at first cos we were only doing the general things but when we started to do	talking about general	Different topics harder
260	bigger things I did. I know with [Caroline] that I can trust her.	things is ok; bigger	to talk about
261	I: Yes. So do you think it was good that you had quite a long time to build up the	things upsetting to talk	
262	trust to get to that point?	about	Trust takes time –
263	P: Yes.	trust	therapeutic relationship
264	I: Yes. Sounds as if its been really helpful. I think it would have been a lot harder if	long time to build trust	Eased in to hard topics
265	you had just gone straight into the really difficult things.	wouldn't have coped	
266	P: Yes. I wouldn't have coped.	going straight to hard	

267	I: But after time you felt that you could cope with it. Did you feel ready?	topics ready to do what was needed work with psychology for life; go back if needed discussed endings will work with her again if I need her she will come out struggle with ending don't like it when they break up from me upsetting; rarely talk to people didn't want to get better didn't want her to go	Ready to change Psychology for life Re-refer if needed Endings Will be re-referred If I need her Endings are a struggle Don't like losing relationships Rarely talk to people Didn't want to change Didn't want to end
268	P: I was ready to do the things that I needed to do.		
269	I: Ok. So how long did you think you would carry on working with [Caroline] for?		
270	P: I reckon its life. But obviously she has gone away but will come back if I need		
271	her.		
272	I: Ok. So has she talked to you about that?		
273	P: Yes.		
274	I: Yes. So you think you will get to a point where you will work with her again.		
275	P: Yes and obviously if I need her again she will come out.		
276	I: So you know you can always refer yourself again if you need to. Did you worry		
277	about when things ended because you have got quite close to [Caroline]?		
278	P: Yes thats the thing I can't, thats the thing I struggle with. Because when they		
279	break up from me I just don't like it.		
280	I: How do you react?		
281	P: I get very upset. I don't.. It's very rare I talk to somebody.		
282	I: Yes, so you were a bit worried when it will ended even though you know you can		
283	contact her again if you need her but it will still be really hard not to see her.		
284	P: Yes. It sometimes made me feel as though I don't want to get too much better		
285	because I didn't want her to go.		

Appendix O - Carer Interview Extract with codes (Sue – Case 3)

		Initial codes	Secondary codes
98	and not what he has done in the past. But we are straight with [Liam] and we don't	<i>straight with him</i>	Adaptations –
99	give him complicated words and consistency in the staff team is important. The	<i>no complicated words</i>	communication,
100	training helped with that consistent approach and also when we get new staff	<i>consistency with staff</i>	consistency, training,
101	[Caroline] is more than happy to come in and do the training again so everybody is	<i>training helped with</i>	hand-outs
102	aware of everything that they need to know. They know how to work with [Liam]	<i>consistent approach</i>	
103	and [Liam] is accepting of that. And that is something that we don't get very often.	<i>do training again</i>	
104	She gave a handout sheet and what was needed and it didn't go into his history but	<i>handout sheet</i>	
105	the way that [Caroline] has worked with him and his traits. We have been involved	<i>not history but traits</i>	
106	more than what we would have expected to and having that shared understanding	<i>involved more than</i>	Staff involved
107	has been invaluable. And she's left numbers and we know that we can contact her	<i>expected</i>	
108	but we haven't had to. She has an outstanding relationship with [Liam] where she	<i>shared understanding</i>	Shared understanding
109	clearly cares which is so refreshing. And she really puts the time in that not	<i>contact her</i>	Can contact her
110	everybody has the opportunity to do with other professionals but she always makes	<i>outstanding relationship</i>	Therapeutic relationship -
111	the time to spend with [Liam] which is positive and quite rare.	<i>really cares</i>	She cares, Got time
112	I: Have you noticed whether [Liam] ever struggled to remember any of the work	<i>always got time</i>	
113	P: He is really good at remembering and he likes to stick to dead-lines and meet	<i>good at remembering</i>	No problem with memory
114	the goals that they set because he doesn't like to disappoint. I think he is proving	<i>stick to deadlines; meet</i>	Doesn't want to

115	himself that he is listening and he does want to change and that is so important.	<i>goals</i>	<i>disappoint</i>
116	I: What do you think has been the most beneficial aspect of the work done	<i>doesn't like to disappoint</i>	
117	P: The fact that she has been honest she has been opened she has never mixed	<i>proving himself; wants</i>	<i>Prove himself</i>
118	her words, he understands her entirely and the fact that she is there should he ever	<i>change; honest with him</i>	<i>Willingness to change</i>
119	need her and that's really important to him. And that is not something that he hasn't	<i>open; understands her</i>	<i>Therapeutic relationship-</i>
120	had in the past. It helped that endings were weaned off rather than just stopped but	<i>there if he needs her</i>	<i>She's open and honest</i>
121	from his relationship with [Caroline] he has learnt how to develop good relationships	<i>not what he's had in the</i>	<i>There for him, different to</i>
122	with the staff that he works with everyday so that helped. He can trust us and talk	<i>past</i>	<i>past experiences</i>
123	to us and knowing that he can contact [Caroline] should he ever need to again. I	<i>endings weaned off</i>	<i>Weaned off endings</i>
124	think if he didn't have that to fall back on he would have struggled more. It	<i>learnt how to develop</i>	<i>Therapeutic relationship</i>
125	reassures him.	<i>relationships; can trust</i>	<i>– taught him how to</i>
126	I: What do you think has learnt from the work he has done with [Caroline]?	<i>contact her again if needs</i>	<i>develop relationships –</i>
127	P: He has learnt what is acceptable in society and what's right and wrong. He	<i>fall back on; reassurance</i>	<i>trust</i>
128	learnt that some of his actions could have been avoided in different circumstances	<i>learnt what is acceptable</i>	<i>Reassurance of re-</i>
129	but unfortunately you can't change what's happened but he doesn't want to go	<i>in society; right and</i>	<i>referral option</i>
130	back to that and he understand that his actions are answerable and he is	<i>wrong</i>	<i>Learnt social rules</i>
131	responsible for them entirely.	<i>actions could be avoided</i>	<i>Relapse prevention</i>
132	I: So they have done a lot of work around his index offence then	<i>doesn't want to go back</i>	
133	P: Yes relapse prevention but also dealing with his feelings about it now that he	<i>responsible for actions</i>	
134	knows that it was wrong. He doesn't want to go back to that.	<i>relapse prevention</i>	

Appendix P - Clinical Psychologist Interview Extract with codes (Caroline – Case 3)

		Initial codes	Secondary codes
1435	P: Yes, I think if you're not careful you can quite easily foster dependency, we do	Foster dependency	Foster dependency
1436	have an issue with that in a learning disability. People are more dependent. They	People more dependent	Need help
1437	feel less able to cope with life and like they need more help, and you can become	Less able to cope	Attachment
1438	that help but they will attach to you very strongly. And then to end sessions when	They attach to you when	Impacts on endings
1439	somebody has attached to you has to be really thought through or you are going to	you help; means endings	Endings need thinking
1440	have problems. I've actually had people say it to me 'I'm not going to get better	need thinking through	through
1441	because then you'll stop seeing me'. But then I just tell them, because I work in LD	If get better, then stop	Endings make people not
1442	that's fine, they can call me and they can come back whenever they need to. And	being seen; in LD you	want to change
1443	then, funnily, they get better, which is really good once they know it's not forever,	can re-refer; they get	Can re-refer
1444	that they can never see me again.	better; not forever	
1445	I: So having that flexibility of knowing that it's easy to re-refer?		
1446	P: Yes, I mean I'm really lucky, where I work as well is great because I'm actually	Lucky to be embedded in	
1447	embedded into community teams. So we're based in a day centre, so they know	community teams	Clients can re-refer
1448	where to find me. They can actually see me there, you know, I'm part of that team,	Based in day-centre	independently
1449	they know where the social work team is, they know where they can get hold of me	Know where to find me	
1450	if they need to, that really does help.	How to get hold of me if	
1451	I: So do you think the fact that you cover a certain area, and that if they were to re-	needed	

<p>1452 1453 1454 1455 1456 1457 1458 1459 1460 1461 1462 1463 1464 1465 1466 1467 1468 1469 1470</p>	<p>refer, they know they're going to get you because you cover that area, does that help?</p> <p>P: Yes, I do think so, you know, with all of my service users that I've worked with, I've been very clear about where I work and where I go. And going back to [Liam] he initially refused to move to [confidential] because he thought that would mean he couldn't see me anymore. When I told him I'll keep working with him, he was happy to go. But it would just be, it's not so much about me even, it would just be about him having to meet a new person.</p> <p>I: Yes and he's come so far with you, it would be hard for him to have to get used to somebody else?</p> <p>P: Yes, that continuity of care is important. I have a few service users who know that they can re-refer themselves as well. So if they have a problem, they come to me and we deal with that problem and then they're discharged. And then they can come back, and they can do it themselves, they don't need somebody else to do it for them, they can come and say, I want to talk to you, and they do and that's quite nice. This criticism of the high re-referral in intellectual disabilities, this idea of the revolving door, it's not actually a problem, I actively encourage it, if input is needed again. I think it's called life. You just have to accept that people with intellectual disabilities have less of resources than people in the typical population.</p>	<p>Covering one area helps Clarity with clients Refused to move if meant sessions end Having to meet a new psychologist would be hard Continuity of care is important; a few clients who know they can re-refer; refer if they have a problem, we deal with it and then discharged they can do it themselves criticism of revolving door not a problem; its life less resources</p>	<p>Clarity with clients People don't want sessions to end Meeting new psychologist is hard Continuity of care Option to re-refer Can re-refer themselves Problems dealt with then discharged Revolving door not an issue People with LD have less resources</p>
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Appendix Q – Example of some data extracts for the code ‘endings’

		Initial code	Secondary code
353 354 355 356 357 358 359	P: When she did start to withdraw a bit she said il give it a couple of weeks or something. We found that I needed her to come before then and I would say ah whens she coming but she seems to know when its ok to leave it a bit longer. I often worried about what happens when she stops coming I: is that still a worry for you P: yeah because well there’s nobody now is there. Who do I turn to now? I just don’t know	<i>Started to withdraw</i> <i>I needed her to come</i> <i>When is she coming</i> <i>Knows when to leave it</i> <i>Worry about ending</i> <i>Nobody now</i> <i>Who to turn to?</i>	<i>Withdrawal from therapy</i> <i>Phased Ending</i> <i>Worry about ending</i> <i>Alone</i>
298	P: I thought I would keep seeing her	Thought I would keep seeing her	Didn’t know it would end
666 667 668 669 670 671	P: I’m alright about it but I still think she needs to come and see me I: How did you feel about it ending P: Thinking about it scares me I don’t know what I’ll do yet. I: so endings are really hard? P: yeah I didn’t want her to stop coming. I’m not well enough for her to stop coming and I will prove I’m not.	Still needs to come Ending scares me Don’t know what I’ll do; Didn’t want her to stop; Not well enough and I will prove it	Still needs support Endings are scary Didn’t want to end Not well enough to be discharged
234	I: What was it like when you stopped seeing your psychologist?		

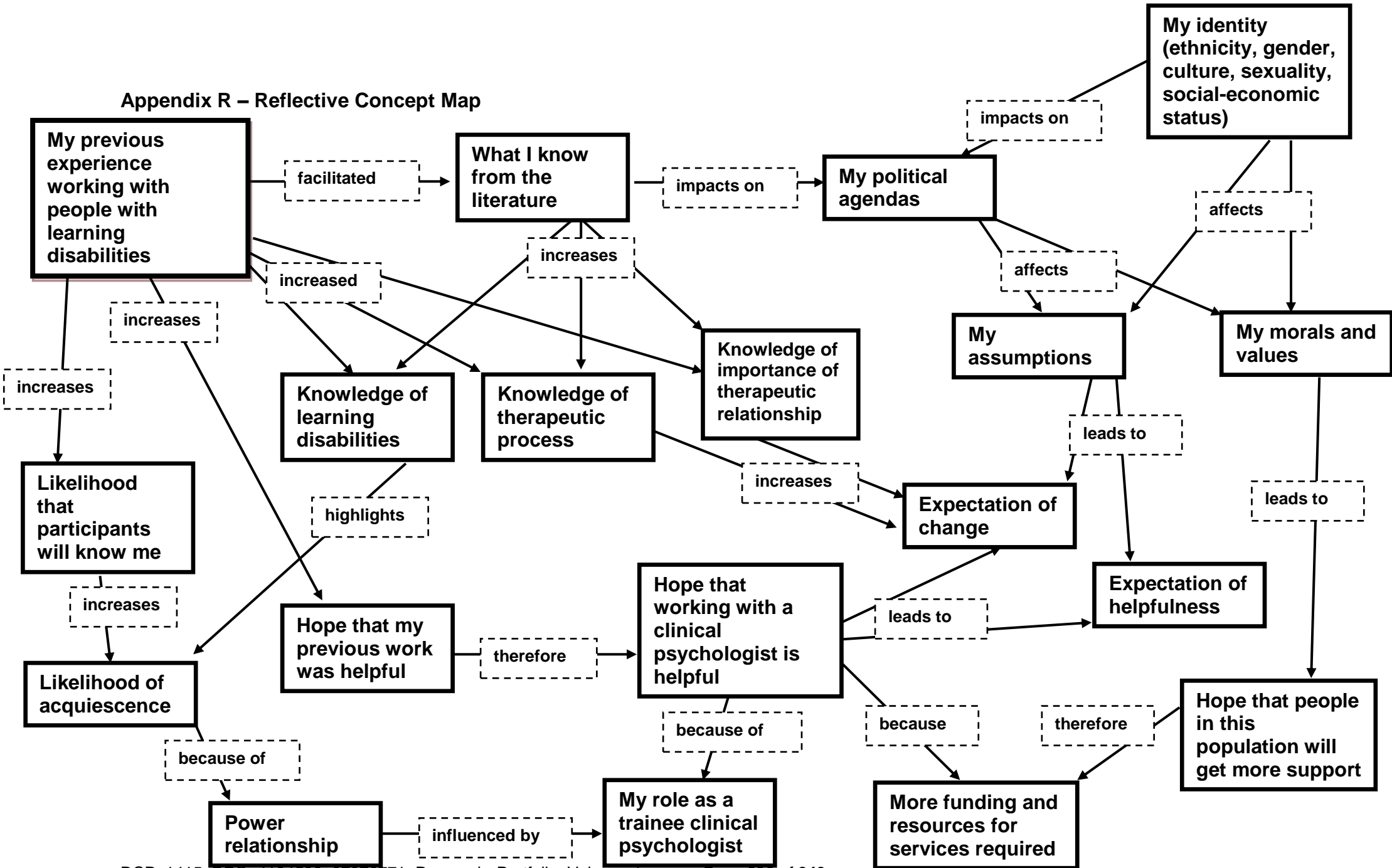
235 236 237 238 239	P: I was well then I hadn't got into my scrapes again so I didn't mind because I always know that if things aren't going well I can contact her. My carers have got her number and I can ring her and she'll come back and see me if I need her to. So it wasn't too scary when she left. I'm more in control now.	Things aren't going well I can contact her Ending not too scary I'm more in control	Can be re-referred if needed Re-refer option makes endings easier
306 307 308	P: Endings can be a barrier. Yes, I think they are in this case, because I don't feel, you know, I feel, yes OK, yes we've come somewhere, but I just do feel that in other respects, have we, do you know what I mean?	Endings can be barrier come somewhere questioning whether change happened	Endings as barrier questioning whether change happened
121	It helped that endings were weaned off rather than just stopped	<i>endings weaned off</i>	<i>Ending weaned off</i>
276 278 279 280 281 282 283 284 285 286	I: So you know you can always refer yourself again if you need to. Did you worry about when things ended because you have got quite close to [Caroline]? P: Yes that's the thing I can't, that's the thing I struggle with. Because when they break up from me I just don't like it. I: How do you react? P: I get very upset. I don't.. It's very rare I talk to somebody. I: Yes, so you were a bit worried when it will ended even though you know you can contact her again if you need her but it will still be really hard not to see her.	will work with her again if I need her she will come out struggle with ending don't like it when they break up from me upsetting; rarely talk to people didn't want to get	Will be re-referred If I need her Endings are a struggle Don't like losing relationships Rarely talk to people Didn't want to change

287 288	P: Yes. It sometimes made me feel as though I don't want to get too much better because I didn't want her to go.	better didn't want her to go	Didn't want to end
77 78 79 80	I: Why did the sessions stop? P: She stopped them I: How did you feel about the sessions ending P: Didn't mind	She stopped sessions Didn't mind ending	Psychologist ended Didn't mind ending
1439 1440 1441 1442 1443 1444 1445	attach to you very strongly. And then to end sessions when somebody has attached to you has to be really thought through or you are going to have problems. I've actually had people say it to me 'I'm not going to get better because then you'll stop seeing me'. But then I just tell them, because I work in LD that's fine, they can call me and they can come back whenever they need to. And then, funnily, they get better, which is really good once they know it's not forever, that they can never see me	End session when someone is attached Thought through or will have problems If get better, then stop being seen; in LD you can re-refer; they get better; not forever	Endings should be thought through Endings can be a barrier to progress Re-referral option enables people to get better

Colour code:

Clients (in bold)	<i>Carers (in italic)</i>	Clinical Psychologists (in normal text)
Andrew; Ryan; Liam; Phillip	<i>Mary; Sue</i>	Jacqueline; Caroline

Appendix R – Reflective Concept Map





Perceived Barriers and Facilitators to Positive Therapeutic Change for People with Learning Disabilities: Client, Carer and Clinical Psychologist Perspectives



Sarah Ramsden, Dr Anna Tickle, Dr David Dawson & Dr Samantha Harris

Background

Successful outcomes of psychological therapy have been highlighted for people with Intellectual Disabilities (ID; e.g. Beail, 1998). However, the processes underlying these successful treatments are uncertain (Beail, 1998). There is a substantial gap and an increasing need for research that identifies conditions under which the effects of therapy are optimised for people with ID through the exploration of barriers and facilitators to positive therapeutic change. Assumptions from current literature of barriers and facilitators (Willner, 2005): therapeutic relationship, motivation to engage in therapy, cognitive ability and the extent to which carers support the transition of skills from therapy into the client's everyday life.

Aims

- Explore facilitators of positive therapeutic change
- Explore barriers to positive therapeutic change
- Integrate the perceptions of clients, carers and Clinical Psychologists (CP) to move towards a cohesive understanding of barriers and facilitators to positive therapeutic change.

Qualitative Methodology

Three triads (CP, clients with ID and carer) were nested by one CP (see figure 1). 3 cases were recruited with 15 participants. Thematic analysis (Braun & Clarke, 2006) was used to analysis transcripts of the semi-structured interviews, five super-ordinate themes and once central theme were identified.

Results



Discussion

Although cognitive deficits were a barrier, participants felt that as a result of therapy adaptations, the impact of this was minimal which is not fully in-keeping with the literature (e.g., Taylor, Lindsay & Willner, 2008). CPs were skilled at overcoming barriers within therapy; however there is no straight rule as to what constitutes a facilitator or a barrier. Barriers and facilitators should be assessed and formulated in detail and psychologists should be utilise clinical supervision to reflect on barriers to therapeutic change and facilitators that may offer avenues to change. The concept that for therapeutic change to occur, more basic needs must be met is in-line with Maslow's (1943) hierarchy of needs. As a result, CPs become a mental health 'GP' to coordinate the wider system to ensure all their needs are met. It is currently unclear whether the specialist skills and training of CPs are required to formulate broad and specific needs for clients or whether it would be more cost-effective for other professionals to fulfil this role.



Figure 1. Diagrammatic representation of a single case

Summary of Service-Related Research and associated Impact (SSRI)

Trainee(s)	Supervisor(s)	Placement	Cohort	Date Completed
Sarah Ramsden	Noel McGrath	Adult Mental Health, Discovery House	2012	16/10/2013

Research background and context

It was noted in one CPA meeting that a number of patient's on the female ward in an inpatient rehabilitation unit have a dual diagnosis of a personality disorder and an eating disorder or generally have difficulties with their weight and food. It was also noted that the patient's seemed to be comparing and competing with each other with regards to calorie intake and weight which was exacerbating the situation. From the literature available I assessed the suitability of a Compassion Focused Therapy (CFT) group which is aimed at people who frequently experience shame and self-criticism and who find compassion, caring for themselves and receiving care from others difficult to manage. The research into the use of CFT for people with eating disorder or issues with food is growing and positive. One study reports that 73% of the people diagnosed with an eating disorder had shown clinically reliable and significant changes as a result of CFT. The group would aim to improve people's abilities to self-sooth and affiliate with others and help to cope with difficult life events, memories or emotions as well as specifically deal with issues with food and their body image. Evaluations of these treatment programs in inpatient settings (Gale, Gilbert & Goss, 2012) have shown that relationships between group members can become increasingly compassionate, validating, supportive and encouraging rather than competing and comparing. I presented this idea in a department

meeting and team members agreed that this group would be beneficial and asked me to look into developing a group program. Due to many people on the ward experiences severe self-criticism it was decided to broaden the group to cover all forms of self-criticism, however issues with food, weight and eating would also be covered.

Research aims

As this was a new group, the team were keen to formally evaluate the effectiveness of the CFT group (The Self-Acceptance Group). From this it would be helpful to know whether the group members found it helpful, whether it would be worth running again and being incorporated permanently into the range of psychology groups offered and whether the group can be adapted based on service user feedback. Local interest in evaluation was reinforced by the recent introduction of a Trust-wide initiative to systematically collect data around service-user satisfaction. I therefore examined data from the self-acceptance group to evaluate effectiveness and service-user acceptability.

What the research discovered

All group participants ($N=6$) completed the course. Poor attendance is a common problem for psychology group programmes on the female ward (usually 2 people attend other groups), so the level of engagement and commitment (3 people attended every group) was considered to be a positive outcome in itself, and programme completion may be an indicator of satisfaction and acceptability to service-users.

Five people completed the pre and post quantitative measures (one person joined the group late and therefore did not complete pre-measures). Using the Reliability Change Index (RCI; Jacobson & Truax, 1991) outcome measures indicated that 4 participants showed a reliable change in anger expression as a result of sensitivity to put-down. Additionally, 2 participants showed reliably reduced anxiety/distress as a result of being put-down by others and the same 2 participants showed an increase in their perception of themselves in

comparison to others. The outcome measure 'forms of self-criticism rating scale' highlighted that 2 participants showed reliably reduced perceived inadequacy and self-hatred. There was an overall increase in self-esteem; however this was a statistically reliable change for 2 participants. One participant showed an improvement across all quantitative measures.

Qualitative feedback highlighted an overall satisfaction with their experience of the group. Pre-group themes highlighted a strong presence of self-criticism and the impact of this has on well-being, as well as a hope for self-acceptance. Post-group themes indicated acceptance of self-critical thoughts, self-compassion and satisfaction in the helpfulness of practical strategies including the 'compassionate other'. Themes also reflected on the impact the group had on improving relationships on the ward and an improvement in support networks. Participants reported an overall satisfaction with the facilitation of the group, highlighting the importance of facilitators becoming part of the group and sharing their experiences of self-criticism. Participants reflected on the usefulness of trying something new, having a folder to remind them of the work and overall approval of the CFT model.

Qualitative feedback also highlighted barriers to self-compassion which could be considered if the group was to run again. Additionally future recommendations were noted from participants including: repetition of the group as a whole to further practice strategies and the use of homework tasks to be incorporated as to encourage the use of the skills outside of the group.

How the findings will be disseminated

The findings of the current evaluation were disseminated during the Departmental meeting in October 2013. Staff in the departmental meeting were pleased with the findings of this study and as a result put my name forward to present the findings at the Special Interest Group for psychosis which is attended by professionals from the East Midlands and South Yorkshire. This has been arranged and I will be presenting at the next meeting on 6th November 2013. A summary report has been written and disseminated to the staff on the ward. Writing the study up for publication is under consideration.

Service impact achieved by the research and future plans

The evaluation highlighted an overall improvement in relationships on the ward with people stating that they no longer felt alone with their problems and they felt more supported now. Individual gains included improvements in eating behaviours: *“Last week I had lots of self-critical thoughts and wanting to purge because I hated the way I look. I sat down and thought ‘it’s ok, I am who I am and I’ve got to accept it’. I didn’t purge”*; and the use of practical strategies to accept criticism: *“The best thing about the group was my compassionate other. I use it daily to help with self-critical thoughts”*.

The evaluation indicated that due to positive changes in quantitative measures and qualitative feedback the group would benefit from being repeated. Several group members stated that they would like the group to run again as repetition would be helpful to practice strategies so they become easier to use over time. Furthermore, future running of the group would hopefully further encourage supportive relationships on the ward that have already begun to have a positive impact. To further practice the skills, one person stated that structured homework tasks to be complete in between sessions would be helpful to transfer the skills to everyday life. For this reason, encouragement from staff on the ward and in individual therapy to use the strategies that the person found helpful would be useful to maintain positive gains. Due to the importance of repetition being highlighted in the qualitative feedback, it may be helpful for the group to be extended from 10 to 15 sessions.

Future evaluation of the group could be improved by considering the use of other measures that may be helpful to further evaluate compassion and feelings of shame and guilt. It may be helpful to collect longer-term follow-up data for outcome measures, to gauge post-group maintenance of gains. If the group was to run for longer, it may be useful to collect data midway through the group program to further assess changes and effectiveness.