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

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Abstract

Studies have highlighted successful outcomes of psychological therapies for people with intellectual disabilities. However, processes underlying these outcomes are uncertain. 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 intellectual disabilities. 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 intellectual disability services. 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 intellectual disabilities, results suggest these factors should be formulated as part of the therapeutic process.

Keywords

Introduction

Current literature highlights a substantial need for research to identify conditions under which the effects of therapy are optimised for people with intellectual disabilities. 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 intellectual disabilities (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 intellectual disabilities have been highlighted in a number of studies (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 (Beail, 1998), based on the concept that the therapeutic relationship is the most important facilitator for successful outcomes across all therapeutic approaches (Martin et al., 2000).

The therapeutic relationship could arguably be particularly important for clients with intellectual disabilities as they are more likely to experience relationships based on practical support rather than their emotions being the focus. Additionally, people with an intellectual disability 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 intellectual disability. There is also a lack of reported studies in which a collaborative relationship exists between clients with intellectual disabilities and their therapists (Stenfert-Kroese et al., 1997), 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 therapy (Emerson et al., 2012). In addition to the therapeutic relationship, other potential barriers and facilitators to positive therapeutic change for people with intellectual disabilities should be considered. For example, the impact of cognitive abilities on a person's capability to benefit from therapy has been debated (Taylor et al., 2008). Whether lessons learned in therapy are integrated into the client's life through the support of their carers may be worth investigation (Willner et al., 2002).

Working to optimise therapy for people with intellectual disabilities is important because of higher prevalence rates of psychiatric disorders in people with intellectual disabilities (Hatton and Taylor, 2005) than in the general population (Meltzer et al., 1995). Developing a mental-health problem is associated with a number of life events that people with intellectual disabilities are likely to experience (Brown, 2000; Gore and Dawson, 2009) including: poverty, abuse and lack of support networks (Hastings et al., 2004). Additionally, people with intellectual disabilities may find it more difficult to cope with stressful life events due to cognitive difficulties (Van den Hout et al., 2000). Clinical Psychologists are well equipped to work therapeutically with people with an intellectual disability 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 Clinical Psychologists working with people with intellectual disabilities 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). Seeking to understand barriers to and facilitators of successful therapeutic outcomes will contribute to the evidence base regarding optimal treatment.

Some studies have cited ethical concerns regarding the vulnerability of people with an intellectual disability 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 intellectual disabilities whilst also supporting their right to participate (Northway,

2014). Clinical Psychologists and carers may also offer valuable insight into barriers and facilitators to positive therapeutic change. Amering et al. (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.

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 Clinical Psychologists to move towards a cohesive understanding of barriers and facilitators to positive therapeutic change. This study sought to inform clinical practice by aiding understanding of how therapy can be optimised for people with intellectual disabilities, 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 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 social care needs.

This study aimed to take a tentative step towards improving the experience of accessing mental-health services for people with intellectual disabilities through the exploration of three different perspectives (client, carer and Clinical Psychologist). Although this triadic approach to research has not yet been utilised within intellectual disability 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 Clinical Psychologists 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 understanding.

Method

Study design

A qualitative, inductive-deductive research design was used, utilising thematic analysis (Braun and 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 it. However, a helpful understanding of a 'reality' can be ascertained through intense examination (Guba and 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 et al., 2000).

Population and sampling

Participants were recruited from a specialist intellectual disability Psychology service. Three cases (see Figure 1) of one Clinical Psychologist and two dyads of a client with intellectual disability who was deemed to have benefited from therapy and their carer, and a client who was deemed not to have significantly benefited from therapy and their carer.
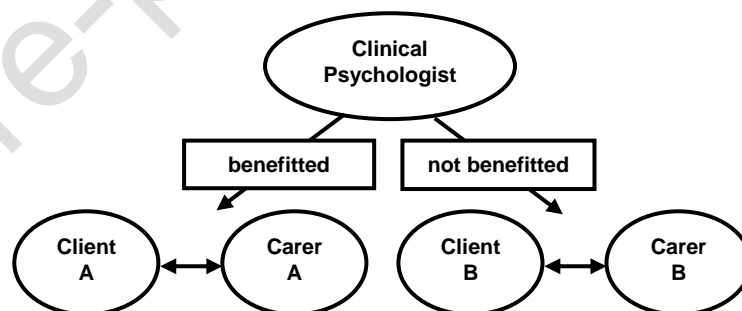

Figure 1. Diagrammatic representation of a single case

Recruitment procedure

      Recruitment of Clinical Psychologists. Qualified Clinical Psychologists were invited to participate via email. Those individuals who were interested were provided with an information sheet and were asked to provide signed informed consent.

      Recruitment of clients with an Intellectual Disability. The Clinical Psychologists were asked to identify their most recently discharged clients (within the last three months) who met all of the inclusion and exclusion criteria (detailed below). 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' by the Psychologists. The investigator remained blind to which participants were in which group (e.g. benefitted or not benefitted) until after data collection and analysis. The Clinical Psychologist then made initial contact with people they identified (most recently discharged first), invited them to participate and provided them with an information sheet and optional audio version. If permission was given, contact details were passed to the researcher and clients were then asked to provide informed consent both to participate in the study and for us to talk to their Clinical Psychologist and a carer about them.

The consent form and participant information sheet for the client were adapted to be easily understandable, using images and written English, and was offered in audio format on a CD should potential participants wish to listen to the information again. The Clinical Psychologist 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. Participants with Intellectual Disabilities 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. A professional carer was present when informed consent was obtained to address the likely power imbalance between researcher and participant and promote voluntary consent. Capacity to consent was

determined by ability to understand and repeat information and was verified by their carer and their CP.

Recruitment of carers. The client's carer who supported them during therapy was invited to participate. They were provided with a participant information sheet and asked to provide informed consent.

Inclusion and exclusion criteria

Clinical Psychologists 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 intellectual disability and had completed individual therapy within the last 3 months. Clients were to have completed one-to-one therapy sessions with the Clinical Psychologist, 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. Carers were eligible to participate if they cared for the client whilst the client was undertaking therapy with the Clinical Psychologist. Furthermore, any participants who did not provide informed consent and had an inability to speak and articulate in English language were excluded.

Participants

A total of 15 individuals participated. The three Clinical Psychologist participants (see Table 1 for demographic information) were female, ranging from age 37 to 53 years (mean age = 42.6).

Table 1. Demographic Information for Clinical Psychologist participants

Pseudonym	Age	Gender	Ethnicity	Number of years Qualified as a Clinical Psychologist	Number of years in intellectual disability 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 participated, all of whom were male and aged 19 to 43 years (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).

Table 2. Demographic information for client participants

Pseudonym	Age	Gender	Ethnicity	Level of intellectual disability	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 years (mean age = 52.7). The sample included different carer types within different types of support settings (see Table 3).

Table 3. Demographic Information for carer participants

Pseudonym	Age	Gender	Ethnicity	Carer type	Length of time known the client	Length of time working with people with intellectual disabilities
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 department. Data was collected one case at a time (interview order: client-A, carer-A, client-B, carer-B, Clinical Psychologist). Clients were interviewed first due to potential difficulties with retrospective accounts; and the Clinical Psychologists were interviewed last to reduce the likelihood that the interviewer could guess who was the 'benefitted' and was the 'non-benefited' client. Clinical Psychologists were interviewed regarding each client separately. Participants were asked their prefered interview location. All clients and carers were interviewed in the client's homes as they requested. Two Clinical Psychologist participants were interviewed in their home and one chose her staff base.

Measures

Data were collected through face-to-face semi-structured interviews. Demographic information was collected during the interviews. Interview schedules were developed with the various cognitive abilities of the participants 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 plans. Care was taken in the phrasing of questions to ensure that participants understood (Booth and 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 and Muir-Cochrane, 2006). This allowed the analysis to be based around the pre-existing theory and assumptions outlined by (Willner, 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 data and occurrences of the same code were physically collated together. Codes were then organised into potential super-ordinate and sub-themes, which were continually reviewed for internal homogeneity and external 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 codes. Inconsistencies between the authors were discussed and resolved (Fereday and 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 subthemes.

Super-ordinate theme 1: What the client brings

This theme encompasses factors that the individual clients bring to the therapy 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 intellectual disability has on therapy. 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, Clinical Psychologist)

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, Client)

Research Aim:
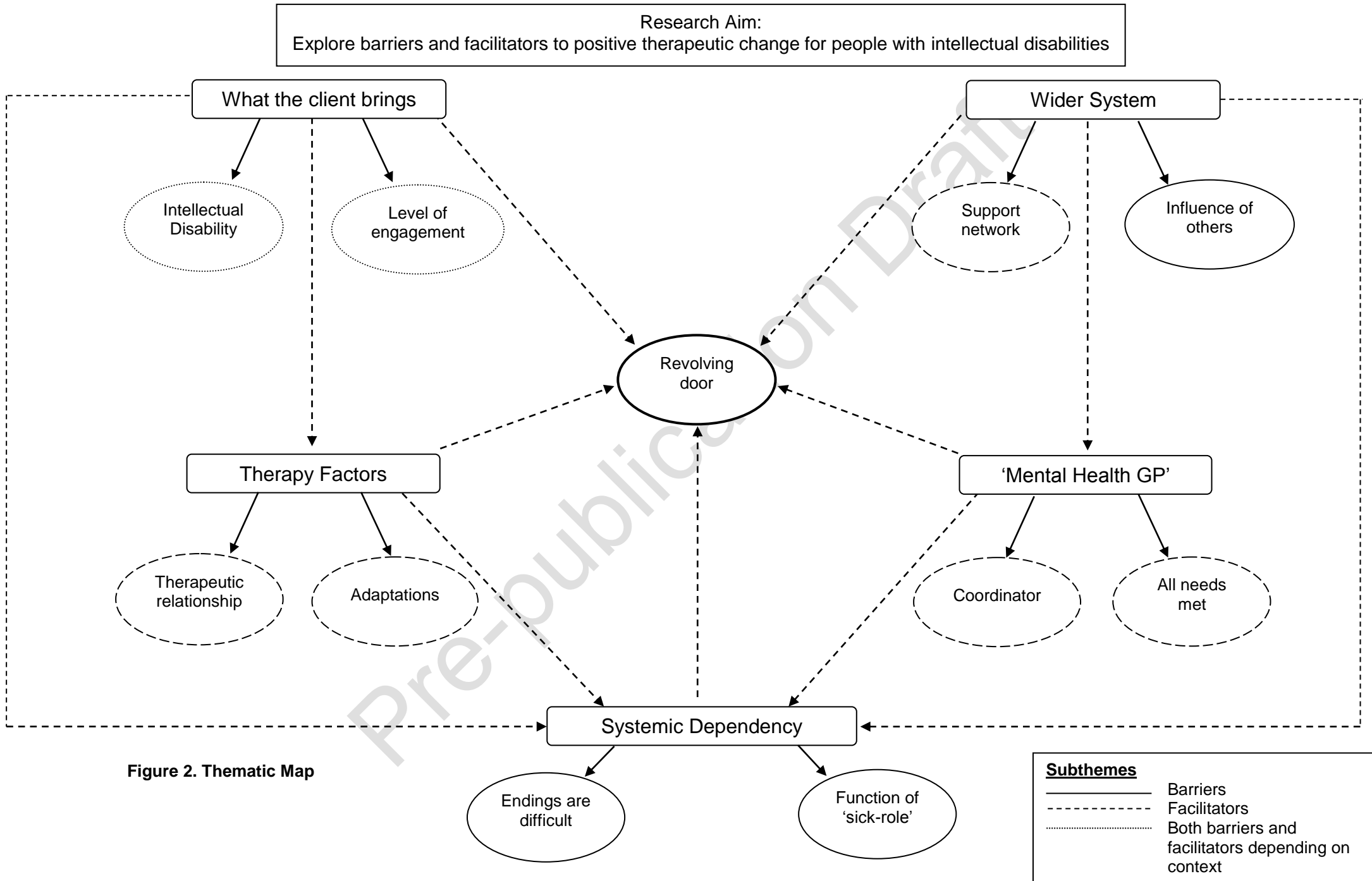Explore barriers and facilitators to positive therapeutic change for people with intellectual disabilities

What the client brings

Wider System

Intellectual Disability

Level of engagement

Support network

Influence of others

Revolving door

Therapy Factors

'Mental Health GP'

Therapeutic relationship

Adaptations

Coordinator

All needs met

Systemic Dependency

Endings are difficult

Function of 'sick-role'

Figure 2. Thematic Map

<u>**Subthemes**</u>

————— Barriers

- - - - - Facilitators

············· Both barriers and facilitators depending on context

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, Carer)

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, Carer).

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, Client)

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, Carer)

One client did not engage with therapy as a result of his belief that there was no need for individual change:

> 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. It's them that need to change.

I didn't understand why she [Caroline] was coming to see me. I'm fine. (Phillip, Client)

His Clinical Psychologist had also picked up on this belief:

He doesn't want to change; he wants the world to change around him. (Caroline, Clinical Psychologist)

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 therapist's control. The client's support network is generally perceived to be a positive influence whereas the subtheme 'influence of others' predominantly refers to 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-being. 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, Carer)

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, Carer)

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. Several felt a desire to have friendships with people other than 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, Client).

Subtheme 2.2: Influence of others. Influence from others was mentioned by all participants. Two clients and their respective carers and Clinical Psychologists 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 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, Carer)

Two further clients were actively discouraged by their families 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, Clinical Psychologist)

Carer negativity was also reported by clients and Clinical Psychologists 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, Clinical Psychologist)

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 Clinical Psychologist with regards to talking openly, feeling listened to, respected and able to trust. 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, Client)

For one client, 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, Carer).

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, Client)

For two clients, their carers were offered training by the Clinical Psychologists 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, Carer)

Super-ordinate theme 4: 'Mental-Health GP'

This theme encompasses the concept that for individual therapy to facilitate positive outcomes, it is crucial to coordinate the client's usually extensive wider system and ensure their health and social care needs are met. This requires the Psychologist to become somewhat of a 'mental-health GP' in that they formulate wider needs and signpost people to appropriate services.

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

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, Client)

Subtheme 4.2: Coordinator. The Clinical Psychologists 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, Clinical Psychologist)

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, Client)

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 intellectual disability 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, Clinical Psychologist)

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, Clinical Psychologist)

Endings being difficult was also one of the most frequent and salient themes for clients. For example, one client 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 (Andrew, Client).

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, Carer)

Central theme: The revolving door

The revolving door was mentioned by all participants 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 it's called life. You just have to accept that people with intellectual disabilities have less of resources than people in the typical population. (Caroline, Clinical Psychologist)

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, Clinical Psychologist).

This idea of the revolving door not only relates to clients 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, Clinical Psychologist)

Table 4 indicates the frequency of quotes used for each interview transcript to highlight how the data has been represented.

Table 4. Frequency of quotes from interview transcripts

Interview Transcripts	Frequency of quotes
Clinical Psychologists:	
Caroline (interview re: Liam)	3
Caroline (interview re: Phillip)	2
Anne (interview re: Keith)	1
Anne (interview re: Tyler)	2
Jacqueline (interview re: Andrew)	2
Jacqueline (interview re: Ryan)	1
Clients:	
Phillip	2
Andrew	1
Liam	2
Keith	1
Tyler	1
Ryan	1
Carers:	
Mary	2
Andrea	1
Alistair	2
Helen	1
Sue	2
Paul	1

Discussion

Results suggest that carers, Clinical Psychologists and clients are aware of factors that the client brings to therapy, which can be considered barriers and/or facilitators to therapeutic change. As a result, factors such as having an intellectual disability are perceived as minimally problematic as people actively seek to overcome related barriers. The process of achieving 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.

Subsequently, Psychologists reported feeling as though they are going round in circles within therapy, and participants across all three groups talked about maintaining the concept of the 'revolving door' into services. One example of this process from the data is as follows: the clients come to therapy with cognitive deficits. As a result, the Clinical

Psychologists 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. Tailoring therapy and iteratively assessing progress in this way poses challenges for predetermining length of therapy. Thus, less clear boundaries are enforced in relation to endings meaning that all parties 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 Clinical Psychologist. This was reported to leave Psychologists feeling anxious about discharging clients. Consequently, people are often left on their caseloads for extensive periods of time, or alternatively people are discharged with the reassurance that they can 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 et al., 2008) but seems to focus on IQ specifically. Participants in the present study specifically reflected on memory and communication difficulties as being problematic within therapy and not other cognitive skills that would comprise 'IQ'. 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 intellectual disabilities due to the increased probability that people have not referred themselves and have cognitive impairments. 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). This study would suggest that such assessment pay particular attention to memory and communication skills.

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 et al., 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, 1985, 1983), 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 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. It may be beneficial to conduct further research to explore why this might be the case and / or whether any action could be taken to mitigate such behaviour. Research could be informed by existing theory, such as Ajzen's (1985) theory of planned behaviour. This theory postulates that several factors affect the occurrence of behaviour, including: intention to do so; attitude towards the behaviour; social norms; and perception of control. It could therefore provide insights into family members, carers or significant others who do not support engagement in therapy by an individual with ID. Research in this area should also consider the likelihood that carers often feel under-trained, under-equipped, and too burnt-out to support people with intellectual disabilities (Langdon et al., 2007) 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 intellectual disabilities. Hurley et al. (1998) emphasise that all therapists should adapt their approach to every client; therefore making adaptations for people with intellectual disabilities should not be problematic. They also identified several adaptations for adults with intellectual disabilities 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 clearer boundaries in relation to endings, which may have proven to be an important factor to facilitate planned positive endings to therapy. Many studies of adaptations of therapy for people with intellectual disabilities, including Hurley et al. (1998), are determined by professional perspectives. The current study offers clients' perspectives of adaptations, which were also supported by carers and Psychologists also. The saliency of the therapeutic relationship in the analysis, adds further support to the vast body of evidence suggesting its fundamental importance to the efficacy of all psychological therapies (Shapiro and Shapiro, 1982).

Mental-health 'GP'

The concept that more basic needs must first be met for therapeutic change to occur is in-line with Maslow's (1943) hierarchy of needs, which postulates that basic lower needs must be met before progressing on to meet higher level needs towards self-actualisation. Maslow (1955, 1943) posits that every person is capable of moving up the hierarchy. However, current literature does not consider how many individuals with an intellectual disability may not be able to achieve therapeutic change because of lower level needs, or what self-actualisation might look like for people with an intellectual disability.

Further research into these issues may prove beneficial to help outline therapy goals. Although a small number, the clinical psychologists in this study were coordinating the meeting of lower level needs as a necessary step towards enabling therapeutic change. Literature is yet to explore and evidence the need for this role.

Systemic dependency

Most participants in this study referred to endings as one of the main barriers to therapeutic change and affecting the client's willingness to progress towards discharge. This is in line with literature which suggests that endings can be particularly difficult for clients with a history of substantial loss (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 et al. (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 (Schore, 1997). Such considerations would need to be made for people with intellectual disabilities and ending therapy may therefore 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 and Guise, 1983). Furthermore, several studies (e.g. Turkat and 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 Clinical Psychologists.

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 intellectual disability services, there is generally a discourse within services that the high re-referral rates in intellectual disability 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 intellectual disabilities. 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 Clinical Psychologists 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 Clinical Psychologists 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 intellectual disability 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 therapists 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 independence versus creating a dependency.

Critique of Study Methodology

Employing qualitative methods with people with intellectual disabilities was simultaneously this study's strength and weakness. Literature has commented on acquiescence (Rapley and Antaki, 1996) and inconsistent responses (McIver and Meredith, 1998) during interviews as evidence that people with intellectual disabilities are inarticulate participants and therefore are unable to provide good quality data (Booth and 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 topic.

Qualitative research can have the potential to generate themes based on the questions asked and present findings based on the pre-conceptions of the researcher (Cohen et al., 2007). These potential threats to reliability were minimised by: acknowledging the researcher's views through the development of a reflective concept map; 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 participants' narratives and the results were relatively concrete. This was thought to reflect the intellectual disability 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 discharge rate was much higher for males each month (73%) than females (27%). Further research might consider whether this is a common pattern across services and, if so, why females might be kept on Psychologists' caseloads for longer periods than males. Furthermore with regards to transferability of findings, it should be noted that the Clinical Psychologists recruited for this study were relatively newly qualified with less than five years post-qualified experience. It may be that more experienced Clinical Psychologists might offer alternative perspectives based on more extensive experience and knowledge about how services and the evidence-base for psychological therapy in intellectual disability 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 intellectual disabilities. Furthermore, accounts from participants in this study highlight that a necessary and familiar role for Clinical Psychologists in intellectual disability services is to utilise their specialist skills as a 'mental-health GP' to coordinate multiple services. Without further exploring the need for this, the implementation of commissioning criteria and outcome-based funding for

individual therapy within services may prove disastrous for the quality of clients' care. It would also be worth considering potential benefits versus disadvantages of utilising Clinical Psychologists or other professionals for this role, including cost-effectiveness. Finally, detailed consideration should be given to the repeated use of services by individuals with intellectual disability and how commissioning and service frameworks can strike the balance between supporting this and creating a sense of dependency.

Conclusions

In summary, this research provides an initial foundation for research investigating how therapy can be optimised for people with intellectual disabilities. Psychologists 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 therapists within intellectual disability services should be multifaceted and take into account wider health and social care needs of clients with intellectual disabilities. Therefore the implications of this study are that work should take on a systemic perspective beyond individual therapy. Given the potential impact of funding constraints on the role of therapists and access to psychological therapies for people with intellectual disabilities, this has important implications for the way therapists and carers work people with intellectual disabilities.

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