



## Perceived Barriers and Facilitators to Positive Therapeutic Change for People with Intellectual Disabilities:

### Client, Carer, and Clinical Psychologist Perspectives

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## Background Literature

- Research highlights successful treatment outcomes for psychological therapies for people with ID (e.g., Beall, 1998)
- Processes underlying these successful therapies are uncertain
- Literature highlights a substantial gap and an increasing need for research that identifies conditions under which the effects of therapy are optimised
- Assumptions from current literature (Willner, 2005):
  - Therapeutic relationship
  - Engagement in therapy
  - The impact of cognitive abilities on a person's capability to understand or benefit from therapy (e.g., Taylor, Lindsay & Willner, 2008)
  - Whether lessons learned in therapy are reinforced outside of sessions by their carers (Willner, Jones, Tams & Green, 2002)

## Research Aims

This study therefore aimed to:

- Explore what are facilitators of positive therapeutic change
- Explore what are barriers to positive therapeutic change
- To integrate the perceptions of clients, carers and Clinical Psychologists to move towards a cohesive understanding of barriers and facilitators to positive therapeutic change.

## Methodology

**Design**

- A qualitative, exploratory research design
- Thematic analysis was used as a method of identifying, organising and interpreting themes within interview transcripts (Braun & Clarke, 2006).

**Population and Recruitment**



## Methodology 2

**Participants**

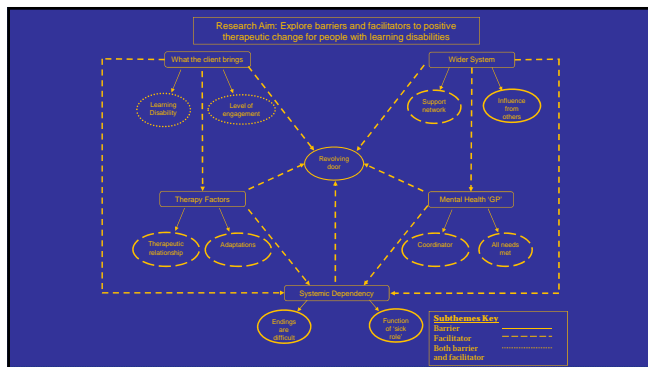
- 15 participants:
  - 3 Clinical Psychologists – female, aged 37-59 (mean age = 46.6)
  - 6 clients with mild ID – male, aged 19-43 (mean age = 30.8)
  - 6 carers – 4 female, 2 male, aged 43-67 (mean age = 52.7)

**Data Collection**

- Face-to-face, semi-structured interviews (18 interviews)
- The schedules were designed to be used flexibly depending on the ability of the participant

**Data Analysis**

- Thematic analysis – manifest level
- Combination of inductive and deductive processes analysis



## Theme: Systemic dependency

*"If you're not careful you can easily foster dependency, we do have an issue with that in learning disabilities ... 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" (Clinical Psychologist)*

### Subtheme: 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

*"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, funnyly, they get better" (Clinical Psychologist)*

*"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" (Client)*

### Subtheme: Function of 'sick role'

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

## Theme: Revolving door

The revolving door is the concept that people continue to be re-referred to psychology services. However, participants did not always see this as an issue.

*"This criticism of the high re-referral in learning 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 learning disabilities have less of resources than people in the typical population" (Clinical Psychologist)*

Although dependency on the system is expected, it can be reduced, as at times it is avoidable. For example:

*"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 ... and then you get exactly the same referral again. You end up telling the staff groups the same thing" (Clinical Psychologist).*

## Discussion of systemic dependency

### Ending Therapy

- For clients with a history of substantial loss, endings can be particularly difficult (Golland, 1997; Hill, 2005)
- Even people without substantial loss often respond to endings with a number of reactions including: loss, regression, acting out and avoidance (Levinson, 1977; Siebold, 2007)
- Ending therapy is more likely to be experienced as a loss or rejection when clients feel they cannot return. This produces more symptoms in the client including feelings of anger, rage, anxiety, mourning and abandonment (Graigge, 2002; Roe, Dekel, Harel, Fennig & Fennig, 2006)
- Therapists should consider the management of endings in relation to the client's relationship and attachment to the therapist, other attachments in the client's life and previous experiences of loss (Zilberstein, 2008)

## Discussion of systemic dependency 2

### Function of the 'sick-role'

- The 'sick role' has specific learning components that can impede treatment outcomes and maintain symptoms (Moss, 1985)
- People who frequently display 'sick-role' behaviour possess a distinct learning history (Turkat, 1982; Turkat & Gube, 1983; Turkat & Noskin, 1982; Woolley, Blackwell & Wings, 1978)
- 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 activities and responsibilities that they do not enjoy (e.g. Kinsman, Dirks & Jones, 1982; Turkat & Pettigrew, 1983; Woolley et al., 1978)

## Discussion of revolving door

- Returning to therapy has been seen as a sign of unsuccessful or incomplete therapeutic work
- "The very 'reality' that termination is something final that the patient must come to terms with is an artefact" (Wachtel, 2002, 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)
- The definition of ending implies that psychological issues will resolve in therapy, but also that endings are inevitable, permanent and feelings regarding ending should be mastered.
- Although there is currently no literature, there is generally a discourse within services that the high re-referral rates in ID services is 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, some measures can be taken to reduce the re-referral rate and minimise inappropriate referrals.

## Clinical implications

- The results of this study suggest that having a ID does not necessarily impair someone's ability to benefit from psychological therapy
- The psychologist and client become locked in a cycle of barriers and facilitators
- Barriers and facilitators should be assessed and formulated in detail and psychologists should be offered clinical supervision to reflect on barriers to therapeutic change.
- The idea that the 'revolving door' phenomenon is a problem that needs to be fixed is not necessarily the case.
- 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'.
- Psychologists can offer formulations to inform and coordinate the entire MDT to ensure that all of the client's needs are met.
- To an extent it is expected that the clients will have some level of dependency on services, just as we all do with our GP.
- Practitioners should reflect on clear justifications for re-referrals as there seems to be a fine line between promoting independence versus creating a dependency.

## Future Directions

- It would be interesting to consider the impact of diminishing day services and social groups on the well-being of people with ID.
- A necessary and familiar role for clinical psychologists in ID services is to utilise their specialist skills as a 'mental health GP' to coordinate multiple services and ensure that all the clients wider needs are met. Without further exploring and evidencing the need for this, the implementation of commissioning criteria and outcome based funding for individual therapy within services may be problematic.
- The concept of the revolving door and whether this is truly an issue that needs to be eradicated

## Questions, Comments or Queries?

Ramsden, S., Tickle, A., Dawson, D., & Harris, S. (2016). Perceived barriers and facilitators to positive therapeutic change for people with intellectual disabilities: Client, carer and clinical psychologist perspectives. *Journal of Intellectual Disabilities*, 20(3), 241-62.

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