



# Significant therapy events with clients with intellectual disabilities

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### Significant therapy events with clients with intellectual disabilities

### Introduction

### Development of psychotherapy for people with intellectual disabilities

People with a disability face a number of challenges, such as the physical or organic aspects of disability, attitudes from society, and self-stigmatisation (Becket & Taylor, 2016). Furthermore, the Learning Disabilities Mortality Review Annual Report (Norah Fry Centre for Disability Studies, 2018), identified the persistence of health inequalities for people with intellectual disabilities (IDs), highlighting the need for further action in order to meet the health needs of this client group. Additionally, people with IDs experiencing mental health difficulties have historically been excluded from psychotherapies due to their degree of intellectual impairment (Bender, 1993). However, research has shown that individuals with IDs can recognise and experience emotions in a similar way to the non-ID population (Bermejo, et al., 2014); this indeed suggests that this client group has the ability to gain insight and develop self-awareness, factors that contribute to therapeutic change (Lacewing, 2014). Since the publication of the psychotherapy and learning disability report (Royal College of Psychiatrists Council, 2004), the evidence base has steadily grown, and substantial case study evidence exists for a number of psychotherapeutic approaches. Throughout this paper, psychotherapy has been taken to refer to all psychological approaches as follows.

Psychodynamic therapy addresses the unconscious content of a client's psyche. By helping clients become aware and bring unconscious feelings into their consciousness, the aim is to alleviate psychological tension. Whilst case study evidence exists (Jackson & Beail, 2013), in a review of the evidence, Beail (2016) found no randomised controlled trials (RCTs); only one further controlled trial conducted by Birchard et al. (1996) was identified in which a significant increase in emotional development in the therapy group compared to the control group was found. Skelly et al. (2018) conducted an open trial of psychodynamic psychotherapy in which treatment fidelity was checked and cases excluded as appropriate. They found clients did not improve while waiting for therapy and significantly improved while attending therapy; large pre-post effect sizes were reported, and improvements were maintained at six-month follow-up.

Another psychotherapeutic approach adapted for clients with IDs is cognitive behaviour therapy (CBT). CBT aims to help clients manage overwhelming problems by changing the way they think and behave in order to improve their mood (Beck, 2011). A growing number of case studies exist evidencing positive improvements for clients engaging in CBT (Wright, 2013). In a review of the available evidence for RCTs, Jahoda (2016) found only one, which was conducted by Willner et al. (2013); however, no reduction in scores of self-reported anger was found.

Cognitive analytic therapy (CAT) involves clients exploring the underlying causes of their current difficulties. In doing so patterns of relating to others are identified, enabling the client to move forward by discovering ways of doing things differently. In a review of the evidence base, Beard et al. (2016) found over 25 published papers predominantly made up of either case studies or reflective essays. Very few of these papers reported outcome data

and none contained pre-post data; however, some did report evidence of client change in revising relational patterns (Wills & Smith, 2010).

Mindfulness and acceptance-based therapies, draw upon meditation and Buddhism. Rather than attempting to change particular thoughts or behaviours, the aim is for clients to change how they experience the world by bringing their awareness to the present moment through being curious and non-judging. In a review of the evidence, Gore and Hastings (2016) found, in addition to case studies, one RCT in which clients were randomised to either meditation intervention or to a waiting list control group (Singh et al., 2013). The authors found that physical and verbal aggression reduced to zero levels at six-month follow-up, with a large effect size reported; although this shows encouraging data, this was conducted at feasibility level, with further research required.

Dialectical behaviour therapy (DBT) provides support for clients who experience intense emotions in certain situations. DBT involves supporting the client to identify and build upon their strengths, as well as learning different ways of thinking. Lippold (2016) reviewed the evidence base and found case studies, with some reporting on outcome data in which improvements were evidenced (Lew et al., 2006). Studies reporting pre-post data are lacking. Morrissey and Ingamells (2011) report preliminary outcomes based on six clients who showed significant reductions in distress; however, the fidelity of the model is questionable with the impact of medication not being separated out.

Furthermore, solution-focused brief therapy (SFBT), which involves maintaining a focus on achieving the client's vision of solutions has case study evidence available, with some reporting on outcomes (Rhodes, 2000); however, it is difficult to rule out other factors that may have contributed to reported improvements. Lloyd et al. (2016) found one published controlled trial in which a group of clients receiving six sessions of SFBT were compared to a control group receiving care as usual (Roeden et al., 2014); intervention fidelity was assessed, and cases were excluded as necessary. The SFBT group improved significantly compared to the control group, and improvements were maintained at six-week follow-up.

Thus, it is clear that such psychotherapies have been the focus of investigation, illustrating how they have been adapted in services for people with IDs. There is certainly a growing evidence base, and the level of evidence for psychotherapies varies from case studies for less established studies, to small scale RCTS. There are a few studies that demonstrate ineffectiveness, and the controlled studies that exist suggest that therapy is beneficial compared to waiting list and 'treatment as usual'. However, for many psychotherapy approaches, the evidence is preliminary, and further research spanning a range of designs is required rather than a reliance on case studies.

#### Significant therapy events research

The term 'significant therapy events' was first coined by Robert Elliott in the 1980s; these are segments of individual therapy sessions, typically lasting between 4-8 minutes, in which clients experience significant moments of help or change. Significant therapy events are an important area to explore since the occurrence of such events during the course of psychotherapy are linked to positive therapy outcomes for the client. Rather than relying on participants' memories during an interview, a method called Brief Structured Recall

(Elliott & Shapiro, 1988) is often used whereby clients and therapists separately watch a video-recording of the therapy session in order to identify and reflect on any significant events during the therapy session.

In a review of the significant therapy events research within the non-ID population, Timulak (2010) found that research has focused on a range of factors including, type of events, match between client and therapist perspectives of events, and significant events in different therapies. The impacts of client-reported significant events focused on contributions to therapeutic relationship and therapeutic outcomes. Moreover, the review revealed the complexity of the process involved in significant events, highlighting the vital need to use a more creative methodology to explore the therapeutic process. Many examples have been given regarding the different types of therapy within which significant therapy events occur, including psychodynamic therapy and CBT. This therefore seems to provide further evidence for the presence of common factors (Wampold, 2015), whereby significant therapy events can be thought of as representing such common therapeutic factors, but in greater levels of concentration. Given the many benefits of investigating significant therapy events, it seems important to consider how such events may manifest during the course of psychotherapy with clients with IDs, since little is known about the process of psychotherapy with this client group and how positive change occurs.

Significant therapy events research: involvement of clients with intellectual disabilities

Lloyd and Dallos (2008) explored the experiences of families who have a child with IDs. Seven families engaged in an initial appointment using SFBT. Along with completing the Helpful Aspects of Therapy form, participants were interviewed using structured recall. The following three super-ordinate themes were identified: solution-focused brief therapy brought to mind the idea of 'making the best of it'; examination of wishful thinking; and therapeutic relationship. This suggests, that even with a one session approach, the therapeutic relationship is a key therapeutic factor, and indeed, seems to be associated with client-identified significant therapy events. However, although the authors employed a methodology resembling some aspects of significant therapy events research, it only explored accounts of therapy from the client; by not interviewing the therapist, an important aspect of the process of therapy was not explored. Furthermore, whilst some of the initial sessions involved the child with IDs, the research interviews were conducted only with the mothers; therefore, the experiences of clients with IDs were not explored using the significant therapy events research methodology.

In a feasibility study by Burford and Jahoda (2012), clients with IDs engaging in CBT had their therapy sessions video-recorded. In a qualitative interview, clients were asked to review tapes of their fourth and ninth CBT session. Clients reported a number of helpful aspects of their therapy sessions, including: they can express themselves in sessions; they can say how they are feeling; and they feel understood. Again, this research did not specifically follow the significant therapy events methodology, since the interviews focused more generally on clients reviewing their therapy sessions, and therapists were not subsequently interviewed. It does however, provide evidence that this approach to interviewing clients with IDs is feasible.

A further criticism of the studies by Lloyd and Dallos (2008) and Burford and Jahoda (2012) is the absence of situating the findings within an attachment theory framework, despite identifying the quality of the therapeutic relationship as a super-ordinate theme, and identifying emotional expression and feeling understood as helpful aspects. Indeed, although developed for parents and children, the Circle of Security ® model (Cooper et al., 2005) is similar to the psychotherapy process and the therapeutic relationship; by the therapist 'being with' the client during their experience of emotions, the client can learn to trust, move on and feel less overwhelmed by their emotions. In order to develop more comprehensive understandings of the psychotherapy process for clients with IDs, attachment theory is undoubtedly an important theory to draw upon.

#### Aims

Hence, to date, no research could be found that explores how clients with IDs may experience significant events during psychotherapy. It has become clear from the research that the exploration of significant therapy events has made a vital contribution to furthering our understanding of therapeutic change and positive treatment outcomes for clients engaged in therapy. This creates huge potential in terms of implications for future practice with regard to psychotherapy with people with IDs. The aim of the current study is to examine client-identified significant events in psychotherapy and explore the lived experience of psychotherapy with clients with IDs.

### Methodology

### Research design

Taking a phenomenological theoretical stance to understanding significant events in psychotherapy, the research is concerned with meaning and the perspectives of the client and therapist participants. From this theoretical perspective, it was necessary to adopt a qualitative strategy; through following a longitudinal design, data was collected by conducting qualitative interviews with each participant on two separate occasions.

The Helpful Aspects of Therapy (HAT) form was completed by client participants at the end of each therapy session. The HAT form is a self-report measure, developed by Llewelyn (1988) as a means for identifying helpful and hindering events in psychotherapy. Following consultation with individuals with IDs, this form was adapted by simplifying the language used, including visual images, and making the Likert scales clearer. These adaptations were made to maximise the ease with which client participants could complete the form.

The Brief Structured Recall procedure (BSR) (Elliott & Shapiro, 1988) was followed. This involved the researcher watching the video of the therapy session with the client and therapist separately whilst asking further questions about the session; the emphasis was placed on the client identifying events to be focussed on. Two different interview schedules were used; for the client participant interview, an adapted version of the Client Event Recall Form (Elliott, 1986; 1989) was utilised, containing sections on the context of the event, the participant's experience during the event, the most helpful things about the event, and the impact of the event. For the therapist participant interview, an adapted version of the

Therapist Event Recall Form (Elliott, 1990) was followed, containing sections on therapist event intentions and feelings, the context of the event, and the impact of the event.

### Participants

A purposive sampling procedure was used to recruit participants to the study. The inclusion criteria for client participants included: identified as having mild to moderate IDs; able to give informed consent; and over the age of 18 years. The inclusion criteria for therapist participants included: working in a Community Learning Disability Team; qualified or trainee psychologist, counsellor or therapist; minimum of one year's experience of offering psychotherapy to clients with IDs, or transferable skills.

Four therapy dyads, each consisting of one therapist participant and one client participant, were recruited to the study. Client Participant 1 completed therapy, however, withdrew from the research study, and therefore completed only one research interview. All other participants took part in two research interviews each, giving a total of 15 transcripts for analysis.

### Procedure

The study commenced, following a favourable opinion from the NHS Research Ethics Committee and approval from the Health Research Authority.

Therapists matching the inclusion criteria were approached and consented in the first instance. Participants were then asked to notify the researcher when they were due to start therapy with a client matching the inclusion criteria. For each therapy dyad, once the therapist had been identified and a possible client had been found, the therapist was requested to ask the client during their assessment session if they were happy to be contacted by the researcher about a study; a consent meeting was then arranged between the researcher and the client before therapy was due to start.

All therapy sessions with each therapy dyad were video-recorded, and at the end of each session, the HAT form was completed by the client. By referring to the completed HAT forms, therapist participants were asked to select one session out of the first few sessions on which to focus the first interview. A qualitative interview was then scheduled with the client participant, and the therapist participant interview followed shortly afterwards. Later in the therapy, therapist participants were then asked to select one session out of the final few sessions on which to focus the second interview; similarly, a second qualitative interview was then scheduled with the client participant, and the therapist participant, and the therapist participant participant, and the therapist participant y second qualitative interview was then scheduled with the client participant, and the therapist participant interview followed shortly afterwards. Therefore, two therapy sessions for each therapy dyad were included in the study.

In accordance with the BSR procedure, the researcher played the recording of the session to the client until the event was located; the client was asked to describe the context of the event, the event itself and its impact. In a separate interview, the researcher played the identified event for the therapist, asking them to describe the context of the event, their intentions during the event and its impact on the client. This data collection procedure was then followed for each therapy dyad for each of the selected sessions. Because of the focus on the participants' perspective and the need for interpretation to make sense of their

perspective, interpretative phenomenological analysis (IPA) was selected to analyse the interview data. The following procedure described by Smith et al. (2009) was followed: initial case familiarisation by reading and re-reading the transcript; initial descriptive, linguistic and conceptual comments made in the right-hand margin; preliminary theme identification written in the left-hand margin; emergent themes developed; search for connections across emergent themes; continue the analysis with the other cases; and looking for patterns across cases involving further refinement of the themes into a master table of super-ordinate themes and sub-themes.

### Results

Five super-ordinate themes and eleven sub-themes were identified from the analysis.

## Theme 1: The Uniqueness of the Therapeutic Relationship – "...I'm saying things now that I would never say to anyone..." (CP3).

The first super-ordinate theme encapsulates participants' experience of the relationship they had with one another at the point of experiencing a significant therapy event.

Sub-theme 1a: 'To talk and be heard'. Client Participants seemed to be alluding to the therapeutic relationship in their narrative by exploring what it was like to talk to their therapist. One participant reported "...it was just nice to talk to someone outside the family, to talk to a stranger how I was feeling" (CP1). Another participant explained "...she listened to every single word um...if she didn't understand what I was saying she normally asked me anyway 'so you're on about this or are you on about this', so I'd be like 'no it's this' or 'it's that'" (CP3).

Sub-theme 1b: 'Importance of building trust'. Building trust with the therapist seemed to be key for enabling clients to talk more easily and freely. One participant reported "...now I know [therapist] I don't get so anxious" (CP1). Another participant described "...as I get to know you I trust you and then that's when I start letting stuff out" (CP4).

Sub-theme 1c: 'Walking in the client's shoes'. The use of empathy was also spoken about in terms of helping to build the therapeutic relationship. One participant reflected "...trying to understand that actually yes he has been through quite a lot and there are people that will can make you feel angry..." (TP2).

**Theme 2:** Using Adaptations to Express Emotions – "I wanted [therapist] to see it" (CP4). This theme reflects how client participants were able to express their emotions to their therapist, and how therapist participants focused on describing the adaptations they made in order for their client to communicate.

Sub-theme 2a: 'The process of expressing emotions'. This sub-theme reflects the importance client participants placed on expressing their emotions. One participant described "Um...get getting out how I was feeling off my chest" (CP1). Another participant spoke about drawing in their therapy session as a way of being able to express themselves "...sometimes I like just drawing on my own and have no-one see you, but obviously I want at that time I wanted [therapist] to see it" (CP4).

Sub-theme 2b: 'The shift in emotions'. Client participants reflected on noticing a change in their emotions from beginning to end of the significant therapy event. One participant reflected "...I was really angry, really annoyed, really fed up and as I talking about it and talking how I felt and yeah I reckon it is leads up to what I'm talking about...I felt more happier um...coz I let it out my feeling..." (CP3). Therapist participants seemed to become more attuned to their client's emotions; "...he did seem pleased to be able to to realise that there was something he could do" (TP1).

Sub-theme 2c: 'Making adaptations'. Therapist participants spoke about adapting the therapy to suit the needs of their client. One participant described "...so, I'm just looking at her drawing and I'm just saying I I need to go with this because she's trying to communicate something to me with drawing with the with this people and what's happening to them that um...that she can't put into words..." (TP4). Another participant reported "Um...trying to give him time to speak" (TP3).

## Theme 3: Client Behaviour/Therapist Behaviour – "...and she just started spontaneously drawing and I went with it" (TP4).

This theme illustrates the behaviours of the client and therapist during the time surrounding the significant therapy event.

Sub-theme 3a: 'Focus on coping strategies'. Learning about coping strategies to manage difficult emotions was spoken about by all client participants. One participant described "Um...talk about strategies and how to calm down by listening to music and things" (CP2). However, some participants spoke about some of the difficulties of using coping strategies outside of therapy and how their dependence on others sometimes made it difficult; "...I was like I couldn't walk away from it because I had to wait for mum to give me a lift..." (CP2).

Sub-theme 3b: 'Therapist approach'. Therapist participants spoke about the type of approach they followed when working with their client. Participants seemed to allude to taking more of a client-led approach; "...we had been using the big paper for the maintenance cycles and she just started spontaneously drawing and I went with it" (TP4).

## Theme 4: Hope and Paternalism – "I always think like maybe she's telling me, I might be wrong here, that you are not alone..." (CP3).

This theme encapsulates the tension between hope and paternalism, with client participants reflecting on their experience of having hope, whilst therapist participants alluded to the need to manage more of a beneficence/paternalism balance.

Sub-theme 4a: 'The message of hope'. All client participants spoke about experiencing hope during their therapy. One participant reported "Um...it was helpful what she said and how she um...said to how to get round it and that's when I thought 'yeah'..." (CP2). Another participant reflected "...I always think like maybe she's telling me, I might be wrong here, that you are not alone, maybe there is loads of other people out there who feel exactly the same..." (CP3).

Sub-theme 4b: 'Worry and protection'. However, in contrast, some therapist participants spoke about a need to protect their client; such responses could be likened to that of a paternal response. For instance, one participant reflected "I was worrying about the risk at the same time because when he feels very low he does self-harm..." (TP3). Another participant reported "...it had been helpful so I wanted to kind of draw that out um...draw out all the positives to help keep him safe..." (TP1).

## Theme 5: Meaning-Making – "...I want to be here. I want to be with [partner] for the rest of my life" (CP1).

This theme refers to making sense of the significant therapy event as well as the impact of the event.

Sub-theme 5a: 'Client realisation – the shift'. Client participants spoke about experiencing moments of change during therapy in which they noticed a shift in the way they appraised a situation or the way in which they viewed themselves. One participant described their thought changing; "That I want to be here...I want to be with [partner] for the rest of my life. I want to be there for my mum, because my mum's not well..." (CP1). Perhaps because this meaning-making process appeared to be internal, Therapist Participant 1 perceived their client to be passive; "Um...I think he's being a bit more passive in this session than he has been in in the last few sessions..." (TP1). Client Participant 4 alluded to experiencing some acceptance of themselves; "...coz obviously my disabilities, I can't get rid of it, all I can do is try and beat it, which is what I have been doing..." (CP4).

### Discussion

The purpose of this research was to explore significant events in psychotherapy with clients with IDs. Indeed, the results suggest that clients with IDs do experience significant therapy events. Furthermore, the research enabled insights to be gained about the process of therapy for this client group and for exploration of therapeutic factors that may be involved in facilitating a significant therapy event. Significant therapy events have not previously been explored in psychotherapy with clients with IDs, however, it has been possible to make comparisons with research focusing more broadly on the experience of psychotherapy, as well as make comparisons with research carried out within the non-ID population.

Clients spoke positively about talking in therapy, but more specifically they reflected on being heard and understood by their therapist. Framed within attachment theory, people with IDs may be at a greater risk of developing insecure strategies through not having their needs met as children; for instance, being emotionally rejected by carers may make them likely to expect such rejection from their therapist or the receipt of intermittent care is likely to make them anxious as to whether they will be heard by their therapist. Therefore, being heard and understood could be thought of as a new encounter, that contrasts to their everyday lives in which interactions are frequently marked by a lack of reciprocity and the presence of power imbalances (Jingree et al., 2005). Indeed, therapy itself is also not balanced in terms of the power dynamics, and this is especially true for clients with IDs. Clients spoke at length about being able to successfully express their emotions, which supports the existing literature (Burford & Jahoda, 2012). Clients also spoke about receiving the message of hope from their therapist. However, only one previous study involving

clients with IDs could be found that referred to clients experiencing hope; Pert et al. (2013) found clients to be cautiously optimistic about the outcomes of their therapy. The absence of hope in previous research could be a reflection of past literature not focusing on significant therapy events. Indeed, significant therapy events research within the non-ID population has found hope to be implicated (McVea et al., 2011). All clients in the current study reflected on the impact that the significant therapy event had on them, noticing a shift in the way they appraised a situation or viewed themselves. This is consistent with findings in Cahill et al. (2013), whereby helpful impacts, included 'problem clarification' in which clients gained an understanding of what needed to change through working on it in therapy. However, because therapists in the current study were not always aware of this meaning-making process for clients, it seems it could sometimes be an internal process that clients are not able to articulate. Indeed, internal meaning-making may not be expected, finding ways to open up this dialogue where it relates to the client's meaning-making could be a fruitful area to explore in future research.

Therapists spoke about building a strong therapeutic relationship with their client; this supports the existing literature on working collaboratively (Lloyd & Dallos, 2008), showing clients empathy and remaining attuned to the client's frame of reference (Balmforth & Elliott, 2012). Making adaptations in order for clients to communicate and express their emotions was also focused on by therapists, which supports existing literature in which adaptations to therapy are described (Willner & Goodey, 2006). Referring to their therapeutic approach, therapists alluded to being client-led; in a similar way to person-centred approaches, therapists alluded to focusing on their client and the way in which they perceived their world. Although therapists spoke about wanting their clients to experience hope during therapy, they also worried about their client and felt a need to protect them. It seems that therapists may have been holding on to worry in order for their clients to experience hope.

### Implications for clinical practice

This study highlights the need for therapists to work in such a way as to facilitate significant events in therapy with their clients through building a strong therapeutic relationship, making appropriate adaptations to ensure their clients can express themselves, being mindful about instilling hope, and adopting a client-led approach to provide opportunities for clients to use their initiative. It is notable that, most clients noticed a shift in the way they appraised a situation or viewed themselves, and it is therefore important to open up conversation around the experience of change. In addition, to echo the implications of the research conducted by Skelly et al. (2018), it may be helpful to have more flexibility within therapeutic relationship to be built, as well as providing the space for a client-led approach to foster client independence and moments of insight. Furthermore, therapists could use supervision to reflect on balancing empathising, protecting and helping in order to promote the process of empowerment.

### *Limitations of the study*

Whilst this research was a necessary first step, owing to the non-existence of research in this area, the sample size and qualitative design may limit any wider generalisations of the

findings. It is also noted that all client participants had mild to moderate IDs; it is therefore not known whether such findings would apply to people with IDs who are less able to express themselves. A further limitation of the study is that, whilst adaptations to the HAT form were necessary in order for clients to independently complete, it was not possible to quantitively determine whether these adjustments improved the quality of responses. Furthermore, clients completed the HAT form in the presence of their therapist, which may have made them reluctant to identify any unhelpful events. In addition, if time allowed, it could have been interesting to look at clients' perceptions across the range of recorded sessions and their perceptions of where the most helpful aspects were, rather than focusing on their identified helpful event within the session selected by their therapist.

#### Future research

This study has highlighted the need for further research of significant therapy events with a larger sample of clients with different degrees of cognitive impairment. Furthermore, new areas to explore, include examining the relationship between therapists holding worry during therapy sessions, while clients seemingly receive the message of hope. In addition, future research should seek to examine the internal meaning-making process for clients. If more were known about this process, therapists could become more aware of it and adopt strategies for exploring this change process with clients, which would be likely to strengthen the therapeutic relationship, indicate the direction that therapy sessions could helpfully take to meet client goals, and improve therapy outcomes. It would also be important to thoroughly investigate the efficacy of a client-led approach and quantitively measure its impact on the prevalence of significant therapy events and therapy outcomes by means of an RCT.

### Conclusion

The current findings provide additional evidence that significant therapy events occur for clients with IDs. Furthermore, the findings also support Bender's (1993) critique of the historic exclusion of people with IDs from accessing psychotherapy; indeed the 'therapeutic disdain' towards people with IDs has an increasingly questionable evidence base. In addition, using the significant therapy events methodology was shown to be feasible with this client group, and enabled insights to be gained about the process of therapy for clients with IDs, as well as exploration of the therapeutic factors that may be involved in facilitating a significant therapy event.

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