Psychological therapies and people who have intellectual disabilities

Edited by Nigel Beail

Commissioning Team for the Faculties for Intellectual Disabilities of the Royal College of Psychiatrists and the Division of Clinical Psychology of the British Psychological Society
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Roger Banks, Nigel Beail, Mandy Irvine, William Howie, Rajnish Attavar, & Geoff Marsden
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The purpose of this report on psychological therapies and people who have intellectual disabilities is to inform professionals, managers, commissioners, carers and service-users as to what is available, what intervention may best help with, and what the likely outcomes are. It is now over a decade since the publication of the Royal College of Psychiatrists’ Council Report CR116 *Psychotherapy and learning disability* (2004). That report was written at a time when there was interest in extending the use of psychological therapies with people who have intellectual disabilities (ID). The aims of the 2004 report were to establish the position of psychotherapy in services for people who have ID and to make recommendations for further provision and training of the workforce. In preparing the report, the working group undertook a nation-wide survey of practitioner groups in the UK and Ireland to develop an understanding of what therapy was being made available to people with ID. Unfortunately, the response rate was low - perhaps reflecting the degree of interest at the time. The authors had to challenge the myth that people who have ID are immune to emotional problems and also unsuitable for psychological therapy. In addition, the published material available at the time on prevalence and need was small. Research on the effectiveness of psychological therapies with people with ID was in its early days and the evidence base was thin. None the less, the report identified what was different about providing psychotherapy services for people who have ID from general adult services, provided a clear account of training needs and made recommendations on future training for professionals who provide psychological therapies to those with ID.

A decade on, one of the original editors of the report, Dr Roger Banks, brought together a small group to look at the need for a further report. Given developments in the area, it was felt that there was a need to review the situation. Therefore, the Executive Committees of the Faculties for People who have Intellectual Disabilities of the Royal College of Psychiatrists, and the Division of Clinical Psychology of the British Psychological Society agreed that an updated report should be commissioned - this time led by the BPS.

The report begins with an overview of research on the prevalence of mental health needs of people who have ID - needs which are now much better known and understood than in 2004. Hence the case for the provision of services to meet those needs can clearly be established.

Despite progress in knowledge about the mental health needs of people with ID, consultation for the new report showed that little progress has been made
in the area of training, Many recommendations on training for psychiatrists have not been implemented and psychotherapy training courses still struggle to address disability issues. Of the two training programmes in disability psychotherapy which were developed and validated, only one got off the ground and has produced the first disability psychotherapists (Frankish, 2013). Clinical psychology training programmes continue to have a psychological interventions focus, but sadly the six-month placement in a service for people who have ID has been dropped as a core requirement. Despite recognising the crucial role of training and the need for further progress here, it was decided to pursue this through other routes and focus the report on what has developed

Since the 2004 report, psychological therapies have moved much higher up the political agenda. Most notable has been the development and implementation of the ‘improving Access to psychological therapies’ (IAPT) programme in England, Wales and Scotland. While this programme was not originally envisaged as having an impact on services for people with ID, as the agenda around accessing mainstream services developed, it became clear that those with ID should also be included. Concurrently, it was noticeable through presentations on psychological therapies at international research congresses, such as those organised by the International Association for the Scientific Study of Intellectual Disabilities and the European Association for Mental Health in Intellectual Disability, that a wider range of psychological therapies was being made available and new approaches were becoming established more quickly than in the past.

Against this background, it was decided to invite contributions for this report from providers of a wide range of the psychological therapies which can be made available to people who have ID. Clearly, it is not possible to provide exhaustive coverage, but the contributions here are designed to introduce as many approaches as is reasonably possible.

All contributors were asked to describe their approach and how it has been adapted to enable people who have ID to access it. Contributors were also asked to provide an overview of the research and evidence base for their approach. The service-users we consulted about what they would like to see in the report suggested that we include information about their views on the psychological therapies which are provided. Fortunately, research on service-user views is now emerging, and so contributors were asked to include any information from this research that was relevant to their approaches.

In grouping the contributions, the report tries to reflect the development of approaches discussed in the 2004 document, as well as acknowledging the introduction of new approaches and also what are referred to as new wave approaches such as mindfulness and acceptance and commitment therapy (ACT). Hence, it begins with chapters on psychodynamic psychotherapy and
Cognitive Behaviour Therapy and then presents a model that draws on both approaches, Cognitive Analytic Therapy. Thereafter, the new wave approaches are presented: ACT and mindfulness, Dialectical Behaviour Therapy and then solution-focused therapy. Then we have chapters focusing on group approaches, systemic therapy and, finally, arts therapies. The 2004 report gave some guidance and examples on how psychological therapies can be delivered in services. Since then, service systems have changed and will no doubt continue to change. Therefore, in this report the issue is dealt with illustratively by showing how a long-standing service provider of psychological therapies in the NHS currently delivers these.

It becomes clear across all the chapters in this report that the available evidence for therapies comes primarily from practice-based research, and that only a small number of studies are funded. While it is good to see funded research on psychological therapies for people who have ID now taking place, it is unlikely that this alone would produce sufficient volume of evidence even over a decade. In addition, practice-based or effectiveness research is needed to compliment efficacy studies and give some social validity. As the focus of this report is delivery in clinical settings, we have included a chapter promoting and giving guidance on practice-based research. To complement this, there is also a chapter reviewing the available measures of outcome which can be used in research focusing on people who have ID. This chapter provides guidance on measure quality, notably reliability and validity, for use in practice-based and funded studies.

What is clear is that a greater range of psychological therapies is available and we know a little more about their effectiveness.
Chapter 1

Identifying and meeting the emotional and mental health needs of people who have intellectual disabilities through psychological therapies

Dr Mandy Irvine and Professor Nigel Beail

People who have ID, like anyone else, can experience psychological distress and present with mental health needs. Similarly, like anyone else they need access to a full range of psychological therapies. However, until the late 1990s, the emotional lives and needs of people with ID were largely ignored (Arthur, 2003) and any difficulties observed were assumed to be either organically mediated or environmentally contingent. At the same time, one-to-one and group verbal psychological therapies were not considered appropriate or useful interventions (Bender, 1993)

A critical review of the evidence base for psychotherapy published in the mid-nineties reported good evidence for the efficacy of psychotherapies but references to research with people with ID were notably absent (Roth and Fonagy, 1996). The Handbook of Psychotherapy and Behavior Change (Bergin and Garfield, 1994), published two years earlier, did not contain any reference to people with ID at all. There is a line in Roth and Fonagy (1996), which states, in relation to children with ID:

Although there are reports of effective psychodynamic treatment (e.g. Sinason, 1992), systematic outcome research has focused on behavioural training techniques.

(p. 312)

There is no comment on cognitive behavioural psychotherapy or on any other approaches. This reflected the state of the research literature at the time. Psychological therapies provided and evaluated for people with ID at that time concentrated on behaviour modification or behavioural skills training (Beail, 2005; Didden et al, 1997). These approaches had and continue to have their value through their development into positive behavioural support - an approach that is central to our Joint Guidance on working with people who challenge services (Ref needed). A review article on psychotherapy with people with ID published in a peer-reviewed journal in the mid-1990s found only case studies on the use of psychodynamic psychotherapy and only two
In 2004, the Royal College of Psychiatrists published a council report ‘Psychotherapy and Learning Disability’. The report acknowledged that the mental health needs of people who have ID had only very recently begun to be recognised. However, it also noted that at the time, there was a small but growing interest in extending the application of psychotherapeutic interventions to people who have ID.

**Failure to recognise mental health needs**

Failure to recognise, diagnose and respond to the mental health needs of people with ID was the result of a number of interrelated factors:

- societal and cultural beliefs that people with ID do not experience the same range of emotions as those without these difficulties;
- institutional settings served to segregate and ‘hide’ people with ID;
- the process of diagnostic overshadowing whereby all difficulties were attributed to the primary ID;
- poor attendance at primary care services which reduced opportunities for referral for specialist assessment;
- failure to diagnose mental health difficulties;
- cognitive and communication difficulties reducing the individual’s ability to express symptoms verbally thus masking their internal world;
- the fact that certain issues may manifest differently across the range of levels of ID, for example it is easier to identify problems in people with mild/moderate IDs as they are more likely to be clearly identifiable;
- lack of standardised assessment tools;
- dependence on third parties to recognise issues and access appropriate assessments;
- failure to discriminate between challenging behaviour and mental health needs in service systems; and
- lack of specialised training for professionals and researchers.

**Risk factors for the development of mental health difficulties**

People with ID can experience a range of biological, psychological and social factors which increase their vulnerability with implications for their susceptibility to the development of mental health problems.

*Biological factors may include:*

- genetic liabilities;
- biochemical and structural abnormalities;
• abnormal thyroid functioning;
• epilepsy;
• sensory impairments; and
• medication side-effects.

Psychological factors may include:

• communication deficits which lead to frustration and lack of motivation;
• specific emotional awareness deficit – difficulty understanding the emotions of others;
• limited range of coping mechanisms;
• limited outlets for expression of emotional needs;
• low self-efficacy and self-esteem;
• perceived powerlessness and external locus of control;
• difficulty forming deep friendships;
• attachment difficulties or interrupted attachments; and
• the effects of labelling and stigmatisation.

Social factors may include:

• not being held in esteem within society;
• restricted access to valued activities such as employment, marriage and parenting;
• low income and poverty;
• increased risk of physical and sexual abuse;
• impoverished support systems;
• poor quality of life – current or historic;
• lack of meaningful leisure opportunities; and
• increased exposure to negative life events, such as bullying, losses, repeated perceived failures, etc.

Prevalence of mental health problems

Epidemiological research has identified a broad range of prevalence estimates. This is due to variation in (a) the sample of service-users included (e.g. hospital population, clinical sample, population cohort, etc.), (b) the range of mental health needs included in the definition (e.g. whether challenging behaviour and/or autism spectrum disorder (ASD) are included); and (c) case-finding methods (e.g. whether file review, questionnaires or structured diagnostic assessments were used).
Population studies

Cooper et al. (2007) completed an administrative population study of all service-users with ID aged 16+ years (N = 1,025) in the Glasgow Health Board area in Scotland. Case-finding methods included individual psychiatric assessment for individuals identified with possible mental health problems. Results indicate that 40.9% of the population had an identifiable mental health diagnosis, with prevalence reducing to 22.4% if challenging behaviour and ASD were excluded.

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<tr>
<td>Problem Behaviour = 22.5%</td>
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<tr>
<td>ASD = 7.5%</td>
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<tr>
<td>Psychotic Disorder = 4.4%</td>
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<tr>
<td>Affective Disorder = 6.6%</td>
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<tr>
<td>Anxiety Disorder = 3.8%</td>
</tr>
<tr>
<td>OCD = 0.7%</td>
</tr>
<tr>
<td>Organic Disorder = 2.2%</td>
</tr>
<tr>
<td>Alcohol/Substance misuse = 1%</td>
</tr>
<tr>
<td>Pica = 2%</td>
</tr>
<tr>
<td>Sleep Disorder = 0.6%</td>
</tr>
<tr>
<td>ADHD = 1.5%</td>
</tr>
<tr>
<td>Personality Disorder = 1%</td>
</tr>
<tr>
<td>Other mental ill-health = 1.4%</td>
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Factors associated with mental ill-health were profound or severe LD; female; higher number of life events in preceding 12 months; high number of GP appointments; being a smoker; living with a paid carer; having urinary incontinence; and not having severe disability or immobility.

People who have Down syndrome

Mantry et al. (2008) analysed data from Cooper et al’s (2007) longitudinal population cohort study. They demonstrated prevalence rates of mental health problems in adults with Down syndrome (DS) (N = 186 T1; N = 134 T2) as 10.2% dealing with behaviour problems; 7% with dementia; 2.7% with depression and 2.7% with anxiety issues. It was noted that the prevalence rates varied depending upon the diagnostic classification system used (23.7% clinical criteria; 19.9% Diagnostic Classification –Learning Disabilities (DC-LD); 11.3% International Classification of Diseases -109 ICD 10); 10.8% Diagnostic and Statistical Manual (DSM-IV-TR) and that mania and schizophrenia were uncommon in DS due to hypothesised biological protection.
Autism spectrum disorder and ID  Melville et al. (2008) analysed the Cooper et al. (2007) dataset for those people with an additional diagnosis of ASD (N = 77 T1; N = 50 T2). Their findings indicate that there was no significant difference in prevalence of mental health problems compared with the total cohort sample, but that there was a higher incidence of behavioural problems. This higher incidence was not maintained when the ASD group were matched for age, gender and ability level.

**People who also have epilepsy**

Deb (1997) completed a community cohort study (N = 150) and reported no significant difference in the rate of mental health problems in adults with or without ID.

**Older adults with ID**

Strydom et al. (2005) completed a cross-sectional community survey (N = 23) of adults aged 65+ years without Down syndrome. They reported that 33% screened positive for possible dementia on the Dementia Questionnaire for Persons with Mental Retardation and 13% for mental illness on the Psychiatric Assessment Schedule for Adults with Developmental Disabilities. Checklist.

**Gender and level of ID**

Bhaumik et al. (2008) analysed the register of service-users accessing specialist psychiatric services in Leicestershire from 2001-2006 (N = 1,244). They identified an overall prevalence rate for mental health problems of 33.8%, with males more likely to be diagnosed with ASD, challenging behaviour or be given a psychiatric diagnosis, psychiatric disorder and females more likely to be diagnosed with schizophrenia, depression or organic disorder such as dementia. Rates of psychiatric disorder also varied depending upon level of ID as follows: mild ID 24.2%; moderate ID 27.4%; severe LD 34.3% IDnd profound ID 44.8%.

**Significant life events**

Caution should be exercised in interpreting data on the impact of significant life events on people who have ID, as much of the research evidence is retrospective and the relationship may be spurious. However, Hulbert-Williams and Hastings (2008) reported that adverse life events result in a higher risk of a range of psychological disorders, particularly depression. Owen et al. (2004) found a correlation between life events and aggressive behaviour and psychological distress in a hospital-based sample (N = 93), and Hastings et al. (2004) found a significant increase in the numbers of people experiencing psychological distress in a community sample (N = 1,155).

Finally, Sequeria et al. (2003) found a significant increase in mental health problems, post-traumatic stress disorder, behavioural difficulties and self-
injury in a matched case-control study of adults with ID who experienced sexual abuse ($N = 54$).

**Relationship between mental health and challenging behaviour**

There are a number of theories regarding the relationship between mental health and challenging behaviour. These include:

- that challenging behaviour may represent an atypical presentation of mental health difficulties;
- that challenging behaviour may be a secondary feature of mental health difficulties;
- that mental health difficulties may act as establishing operations for operant-maintained challenging behaviour;
- that challenging behaviour and mental health difficulties co-occur due to an underlying biological pathology; and
- that the presence of challenging behaviour increases risk factors for the development of mental health difficulties.

Overall, review of the evidence base would indicate that challenging behaviour and mental health difficulties can occur separately or can co-occur. The incidence of co-occurring difficulties is particularly evidenced in people with severe and profound ID.

**Developments in provision of psychological therapies**

Current policy in the UK is for people with mental health needs to receive assessment and treatment in community settings. Documentation outlining this policy includes: *Valuing People Now*, Department of Health, 2009 – England; *Equal Lives*, Department of Health and Social Services, 2005 – Northern Ireland; *The Same as You*, Department of Health, 2000 – Scotland, and *Fulfilling the Promise*, Welsh Assembly, 2001 – Wales. Guidance indicates that treatment should be delivered within the context of a stepped-care or tiered model of service provision (see chapter 11).

Psychological therapies are an important aspect of such service provision, and recent years have witnessed a significant increase in emphasis on improving access to evidence-based psychological therapies. In the early 2000s, reviews of the literature on psychological therapies and people who have ID continued to report the domination of case studies, but a few research reports evaluating the effectiveness of cognitive behavioural therapy (CBT) and psychodynamic psychotherapy with people who have ID began to appear (Beail, 2003, Prout & Norwak-Drabik, 2003; Willner, 2005).
Reviews have now become more systematic and meta-analytic, demonstrating a growth in published research on the effectiveness of psychodynamic psychotherapy (James & Stacey, 2013), CBT for anger (Hamelin, Travis & Sturmey, 2013; Nicoll, Beail & Saxon, 2013), and psychological therapies (Vereenoghe & Langdon, 2013). Concurrently, chapters on psychological therapies have made their way into textbooks for professionals (Beail, 2015; Beail & Jackson, 2009; Beail & Jahoda, 2012; Willner, 2009). In addition, books on psychological therapies for people who have ID have now been published (Baum & Lynggarrd, 2006; Fletcher, 2011; Taylor & Novaco, 2005; Lindsay, 2009; Taylor et al, 2013).

It is clear from all of this information, that since the publication of the Royal College report in 2004, the range of psychological therapies being made available to people who have ID has expanded considerably. However, this expansion has largely come about in specialist services for people with ID.

Since 2006, substantial investment has been made in the IAPT programme for adults with mental health needs, although less attention has been paid to the provision of the IAPT programme for people with ID. Public policy is that people with ID should access mainstream services and that specialist service provision should be made available only for individuals who are unable to access mainstream services. In practice, however, there is a very low uptake of mainstream service provision. This is in part due to lack of professional training in dual diagnosis for staff in mainstream services, and territorial demarcation between services and variability in access criteria. Dodd (2011) identified that mainstream IAPT services would require significant modifications to facilitate access for people with ID. Modifications would include: attention to issues relating to informed consent; screening to assess suitability; staff training and supervision; and modification to service process issues and targets.

In spite of the above challenges, it is clear that public policy will remain focused upon achieving access to mainstream services. In order to achieve this goal, the Royal College of Psychiatrists (2012) produced a paper ‘Enabling people with ID and mental health problems to access health care services’. This paper advocates for the development of protocols jointly agreed among service-providers for people who have ID, mainstream mental health services and local authorities which facilitate patient care pathways, develop information-sharing protocols and deliver staff training placements and educational programmes. In order to evaluate achievement against these goals, the ‘Green Light for Mental Health in Learning Disability: a service improvement toolkit’ (National Development Team, 2004) outlines a framework for comprehensive, integrated services. The framework includes a self-assessment checklist and a service improvement toolkit, and can be used by service-providers to chart progress over time.
A significant policy development has followed the broadcast of an undercover documentary on the cruel and criminal acts taking place in a care home (Winterbourne View). The Department of Health (2014) has published guidance that replaces the 2002 guidance on the use of restrictive practices. The focus of this policy is on the reduction of the use of restraint, and improved care based on positive behavioural support. The definition and scope of positive behavioural support (PBS) can be found in Gore et al. (2013). Within the PBS model they describe 10 components. Of relevance to this report is level six which is the secondary use of other complimentary, evidence-based approaches to support behaviour change. These include the use of therapeutic approaches that work with the family, systems, such as systemic approaches, and also therapeutic approaches such as individual and group psychological therapies. This report is, therefore, timely in providing an overview of and evidence base for current models of psychological therapy that have been adapted and applied for use with people who have ID.

Despite developments in policy and provision, there are still some basic issues that continue to require consideration when psychological therapies are being provided for people who have ID. Beail and Jahoda (2012) have point out that a noteworthy difference between clients with ID and other clients receiving psychological therapies from mainstream mental health services, is that people who do not have ID usually seek help for themselves, whereas people with ID are generally referred by others. Further, many people with ID are dependent upon the support of professional carers or family members to get to and from outpatient appointments. They also point out that while clients should be involved in the referral process, we should not assume that they are, or are well informed about why they are attending. Therefore, it is important to establish from the outset whether it is the client or someone else who believes that treatment is needed. If the client appears to be uninformed, then the information in referral letters should be sensitively shared with them and they should be advised of treatment options before their consent is sought.

Providing consent for therapy does not mean that potential clients require a full grasp of the therapeutic model from the outset, as this can over-complicate the matter. The therapist needs to provide a brief description of what is involved and then provide information on the positives and negatives of therapy. This includes telling clients that the treatment may help reduce their symptoms and improve their quality of life but also explaining that it may be a difficult process involving talking about painful or upsetting things. The therapist needs to check that the client has retained and understood this, weighed the positives and negatives and made a choice. If the client cannot do this and the therapist believes that therapy is in their best interest and that they would assent, they should follow the legal procedures and guidance for
their state or country for providing treatment for adults who cannot consent. Wherever possible, clients should be enabled to make an active choice and enter the therapeutic relationship willingly (Beail & Jahoda, 2012).

All the therapies described in this report include adaptations to the method. These are necessary due to the possibility of cognitive deficits impacting on the therapeutic process. Beail (2013) and Lindsay et al. (2013) have described some of the key domains and specific cognitive processes that have implications for how psychological therapy is delivered and experienced. For example, difficulties with verbal understanding and reasoning are addressed through use of simple language and short sentences, and also supported by non-verbal techniques and the use of materials. Therapy may include some educational elements, such as helping labelling emotions, things or actions. People with ID may have good visual recall of a past event but lack the verbal ability to describe what they are visually recalling. Thus they may act out past experiences with the therapist. People who have ID have been shown to be able to assimilate their problematic experiences during psychological therapy (Newman & Beail, 2005), but Lindsay et al. (2013) suggest that assimilating new material may need frequent repetition within and between sessions. This could also be addressed through more frequent sessions. Information may also need to be broken down. For example, when making an interpretation in psychodynamic psychotherapy or working with a procedural sequence in cognitive analytic therapy (CAT), it may be more appropriate to deliver these in parts and then go over the parts to bring things together as a whole so that the client retains them. CBT commonly includes an element of homework, which many people with ID would struggle to complete. Lindsay et al. (2013) suggest involving carers to support clients in doing this. These are just some examples of the adaptions that have been suggested to facilitate the use of psychological therapies with people who have ID.

Pat Frankish, a pioneer in the provision of psychodynamic psychotherapy and a contributor to the 2004 report, has reflected on the last 30 years, and recognises an incremental shift towards paradigm change in the conceptualisation of psychotherapy and its provision for people who have disabilities. She draws attention again to the importance of identifying the emotional needs of people who have ID and meeting those needs to facilitate having an ordinary life (Frankish, 2013). Similarly, Taylor and Knapp (2013) reflect on the past therapeutic disdain identified by Bender (1993). They conclude that this can no longer be justified in the face of the emerging evidence base for the effectiveness of psychological interventions. Indeed, as new approaches develop, there seems to be much more willingness to make these approaches available to meet the emotional and mental health needs of people who have ID. This has been evidenced through a developing case study literature, and it is notable that such service provision is largely being developed in specialist ID services.
This chapter demonstrates that there is now a much clearer account of and evidence for the psychological and mental health needs of people who have ID. In some respects they are no different to the rest of the population, but it would seem that prevalence of need is higher. Thus services need to be in place to meet these needs. In the chapters that follow the range of psychological therapies that can meet those needs are described.

References


Chapter 2

Psychodynamic psychotherapy

Nigel Beail

Introducing psychodynamic psychotherapy

In psychodynamic psychotherapy, the therapist is concerned with the patient’s mental representation of themselves within the world. Therapy seeks to identify the origin and meaning of these representations, and to seek resolution of difficult feelings and inappropriate behaviours in doing so. It promotes the assimilation of painful and warded off experiences. The work entails making links between past life experiences and how these experiences influence unconscious and conscious expectations of relationships in the present day.

Typically, psychodynamic sessions begin with the therapist providing the client with space to free associate; this involves inviting the client to say whatever is in their mind and whatever comes to mind. However, people who have ID may struggle to understand this request. So, we prefer to focus on exploring the reason why they have been referred; thus taking a more problem-focused approach. The psychotherapist will be interested in anything that the client says, including information about their current circumstances, current and past relationships, dreams, and fantasies and so on. The therapist resists giving the client information about themselves. The therapist empathically engages with the client and develops a relationship with them which enables the therapist to experience the client as others also do. That is, the client transfers their way of being with other people into his or her relationship with the therapist. This enables their strengths and difficulties or conflicts in relationships to be observed.

The therapist uses a number of methods to enable the client to tell their story and then formulates interpretations aimed at helping the client to access and make sense of unconscious content. However, advice and instruction are not usually within the remit of psychodynamic model. The therapist will be carefully listening to the client’s verbal communications, and attends not only to what the person says in terms of the factual content and the words used but also to what is not said. The therapist also observes the client’s mood, as communicated through what they say, the way they say it and how they behave. The client may talk about a range of things and the therapist does not interrupt. At various times when the client is telling their story, the therapist may reflect back, paraphrase or précis what the client has been telling them or
acting out. The therapist may also use exploratory and information-seeking responses to attempt to draw out more information from the client. While listening to the client, the therapist monitors their own feelings, fantasies and reactions in response to the client’s material. These are accepted as meaningful elements in the communications between client and therapist and are referred to as the counter-transference. These feelings may help inform the therapist what impact the client has on other people in their life.

Information-seeking responses are aimed at clarification and help sort out what is happening by questioning and rephrasing. The psychodynamic psychotherapist may also use confrontation to draw the client’s attention to what they are doing or avoiding, apparently unaware. Theses are then generated from hypotheses - not only about what is actually said, but also about what the client may not be saying in words but hinting at through behaviour or tone of voice. The therapist also makes responses linking words and/or actions together as a tentative interpretation to try and understand the nature of the client’s anxiety in the session. These responses differ from the others in that they aim to elucidate unconscious feelings and ideas.

In seeking to understand with the client the latent or unconscious meaning of the client’s communications, psychodynamic therapists recontextualise the manifest content of the client’s communications as transference (Smith 1987). Freud (1912) described transference as occurring when psychological experiences are revived and instead of being located in the past are applied to dealings with a person in the present. This allows the therapist to identify interpersonal issues and deal with them as empirical data in the here-and-now. The process of transference allows traumatic experiences and empathic failures on the part of parents and other caregivers to be relived and corrected. The therapists understanding of what is being transferred enables them to communicate of this to the client (the interpretation) which helps with its resolution and this is considered to bring about an improvement in psychological wellbeing.

Psychodynamic psychotherapy also seeks to understand unconscious communications through models of the internal world. Most significantly, we all have an ego, which is the location of the anxiety caused by the tensions between the drives, unconscious material, the super-ego (internal parents, ideals and conscience) and reality. It is the ego that employs a range of defences to ward off anxiety. The therapist draws attention to these defences and links them to the anxiety they the client is attempting to manage. Newman and Beail (2010) have shown that people who have ID use the same range of defences in therapy as the general population. However, they noted a tendency for what are referred to as more primitive defences such as acting out and projection to be used more frequently than say repression.
There is also a range of psychodynamic theories relating to development, which the therapist may also employ to understand the origins or development of the client’s difficulties and conflicts, as well as coping styles. Hence, in the situation where the client’s original parenting or caring relationships were deficient, abusive or overprotective, the therapist provides a corrective, reparative or replenishing parental relationship or action (Clarkson, 2013). Such a relationship modality is a further facet of the therapist’s intervention and style.

In individual psychodynamic psychotherapy, the main approach to intervention is through the provision of interpretations. This poses particular problems in clients with ID, and Jackson and Beail (2013) have been critical of the literature on psychodynamic therapy for people who have ID because of a lack of description of how interpretations are formulated. However, in fairness, the aim of many writers is not to illustrate the process of formulating in psychotherapy but to illustrate different aspects of psychotherapy. None the less, some descriptions of this process have been given. Alim (2010), Beail and Newman (2005) and Beail and Jackson (2009, 2013) illustrate the process of formulation and interpretation through the application of the framework provided by Malan’s two triangles (1979) (see Fig. 1). The first of these triangles represents a framework for understanding conflict between hidden feelings (which are unconscious) and anxiety about their expression. The second triangle represents the person and their life stages.

Beail and Newman (2005) describe the process as follows: the therapist attempts to identify the hidden (unconscious) feelings which lead to the ego employing defence mechanisms to keep them out of consciousness; the therapist then notices defences and identifies anxieties; finally, they interpret potential meanings by triangulation of the information available (linking information together). This process involves making links between Malan’s
triangles: the stages of conflict and the person’s life stages.. The diagram thus depicts the entire picture: the origin of the information, the setting in therapy (the transference), the person’s present living environment, and the person’s past (usually with parents).

Simpson and others (Simpson, 2004 and Simpson & Millar, 2004) provide accounts reflecting the synthesis approach. For example, Simpson (2004) provides a detailed description of the client’s state of mind based on observations of their behaviour in relation to him (the therapist), its impact on him (counter-transference) which is understood in terms of a compulsion to engage in behaviours with the therapist that developed in early relationships with his parents.

Frankish (1989, 1992, 2013) has developed an approach to formulation and interpretation based on the work of Mahler et al. (1975). The focus here is more on stages in early development located at the apex of Malan’s triangle of the person, which Frankish argues are observable in distressed adults who have ID. The stages that Mahler et al. identified were: symbiosis, where there is no discernible separation between mother and child; differentiation, where the child engages in self-referenced behaviours and does not seek contact; practising where behaviour is repetitive and does not change until another behaviour becomes available; early rapprochement where there is the beginning of two-person activities and negotiation; late-rapprochement, where the child moves towards being more independent with manageable anxiety; and the final stage of individuation, where the person can tolerate separation with manageable anxiety. In addition to identifying stages of development through the transference relationship, Frankish (2013) also developed an observational tool to identify these stages. The aim of the therapy is to assist the client move towards individuation through the provision of a reparative and safe relationship. Frankish extended this approach to systems and services so that concurrently with psychodynamic psychotherapy, emotional care and stability are provided through individualised care packages with well-trained support staff.

**Adaptations to psychodynamic psychotherapy for clients with ID**

When providing psychodynamic psychotherapy to clients with ID, the therapist has to work within their client’s communication abilities. Therefore, the therapist must pay careful attention to the words used and attempt to identify problems from non-verbal communications, or acting out within the session. It may be appropriate to help clients communicate by suggesting words for actions or feelings. It may also help to use alternative means of communication such as drawing or using objects. The communication of
interpretations should be done in manageable parts using short sentences. Over years of working with people with ID, Ann Alvarez has developing the thinking around interpretation, and suggests that the therapist may need to consider different levels of interpretation (Alvarez, 2012). Consider, for instance, a client who has ID who is acting in an angry manner about how others are angry with him. Typically, the therapist might extend a reflective comment ‘you feel angry …’ into an interpretation by going on to say ‘you feel angry because…’. However, in the case of the person with ID, an interpretation with this location, i.e. ‘you’, may feel intolerable and so they will defend against it. It may be better to use a different level of interpretation and say ‘part of you feels angry’. This too may fail to be accepted, and in this case, Alvarez suggests using the ideas of Winnicott, and locating the feeling, behaviour or issue in others. Hence the therapist may say something like ‘isn’t it annoying when people get angry?’.

People who have ID also have a tendency to act out in therapy and sometimes the acting out may challenge boundaries. In such situations, the interpretation may have to be put on hold and the therapist needs to bring the client back into the reality of the relationship with the therapist rather than the transferred one they are acting into. Here Alvarez (2012) suggests methods of gaining the client’s attention, such as saying ‘hey’, or saying the person’s name clearly and firmly (Beail and Newman, 2005).

The evidence base for psychodynamic psychotherapy

Case studies/descriptions

The case study has been the main means of reporting psychodynamic practice and ideas (see Sinason, 2010 as an example, and Jackson & Beail, 2013 for a review). However, this literature does not report outcomes. In those cases where outcomes are provided, they are mentioned only anecdotally.

Case studies with outcome data and single-case experimental designs

Very few single-case outcome data reports have been published. Newman and Beail (2002) demonstrated change using the Assimilation of Problematic Experiences Scale. Kellett et al. (2009) demonstrated how a single-case experimental design can be used to evaluate psychodynamic psychotherapy with people who have ID. Alim (2010) has also demonstrated how Malan’s triangles can be used to show change and progression.

Case series reporting outcome data

The first attempt at reporting outcomes was a case series of seven people with whom Frankish worked (1987). She showed that improvements in behaviour occurred across the course of psychodynamic psychotherapy. The next case series was reported by Newman and Beail (2005). They demonstrated
progression using the Assimilation of Problematic Experiences Scale across eight participants in eight sessions of psychodynamic psychotherapy.

**Open trials, i.e. group studies, reporting pre/post data**

Beail (1998) published the first open trial of psychodynamic psychotherapy with people who have ID. He looked at changes in presenting behaviour pre-therapy to post-therapy and at six months follow-up. The study showed reductions in problem behaviour for most recipients and this was maintained at six months follow-up. Beail (2001) reported a study on the outcomes of psychodynamic psychotherapy for offenders who have ID. Eighteen men who had offended were offered therapy. Of the 13 who accepted, all but two men remained offence-free at the end of therapy and at four years follow-up. The five men who refused treatment had all re-offended within two years. Beail et al. (2005) published a pre/post and three-month follow-up study of open-ended psychodynamic psychotherapy. They found that participants reported statistically significant reductions in psychological distress, and improvements in interpersonal functioning and self-esteem. In a further analysis, the same researchers examined the impact of different lengths of therapy – the dose effect (Beail, et al. 2007). This study showed that positive effects were found across therapy lengths but that all participants made rapid gains in the first eight sessions. This provides preliminary evidence for the dose effect relationship. However, the group who participated in therapy for longer were the ones who had greater psychological distress at the beginning of the programme.

**Controlled trials, i.e. group studies reporting comparison of intervention with a waiting list or routine therapy control group**

Controlled trials are somewhat lacking in the literature. Bichard et al. (1996) evaluated the outcome of two years of psychodynamic psychotherapy for seven adults and children who were matched with a waiting list group. The outcome measure was the draw-a-person test: a projective technique which simply involves asking the participant to draw a person. The drawing is then scored for it’s level of emotional development. They showed scores for emotional development significantly increased in the therapy group whereas those for the control group did not.

The literature does not report any meta-analyses of single-case data or randomised controlled trials.

**User views**

Two studies reporting participants’ views of individual psychodynamic psychotherapy have been published. Merriman and Beail (2009) evaluated the views of participants in long-term, individual psychodynamic psychotherapy. Participants were interviewed about their experiences and
views. Interview transcripts were analysed using the qualitative methodology called interpretative phenomenological analysis (IPA). The outcomes indicated that service-users reported feeling positive towards their therapist and therapy in general. They felt that positive changes had been made in both behaviour and emotions. Areas of difficulties which could be improved included a perception of dependency.

Khan and Beail (2002) adapted the Experience of Service Questionnaire (ESQ) and the Satisfaction with Therapy and Therapist Scale (STTS-R)(Oei & Green, 2008) to meet the needs of people with ID by adapting the question wording for ease of understanding. For example, the STTS-R question ‘My needs were met by the program’ was adapted to ‘I got what I wanted from the sessions’. All participants reported a high level of satisfaction with the psychological therapy they received. The average total scores for all participants for the ESQ was 4.32 out of 5 and for the STTS-R it was 4.27 out of 5. Fifteen of the 20 participants, received psychodynamic psychotherapy and 19 reported that psychotherapy had made things a bit or a lot better. One service-user reported that things stayed the same.

**References**


Introducing cognitive behavioural therapy

In the general population, cognitive behavioural therapy (CBT) is the psychological treatment of choice for a range of clinically significant problems, which include depression, anxiety and anger. There has also been a burgeoning interest in the application of CBT with people who have psychosis and personality disorder. The growing application of CBT across a range of difficulties has led to the development of more specialist theories and interventions to target specific problem areas. For example, interventions for anxiety have become increasingly specialised as more elaborate cognitive models of such problems have developed (Clark & Wells, 1995).

Cognitive behavioural therapy for emotional problems is an approach that works with the meaning that people attach to events, or the nature of their self-evaluations (Beck et al., 1979; Ellis, 1962). In other words, it starts from the premise that people’s perceptions of events influences their affect and behaviour. Therefore, beliefs and thinking styles can contribute to significant emotional problems and maladaptive patterns of behaviour. For example, people who are depressed may hold negative beliefs about their past, present and future, and they are also likely to interpret events negatively even where there is little reason to do so. Low mood might also mean that people are unable to concentrate or gain pleasure from pastimes that they previously enjoyed, leading to withdrawal and an increasing sense of hopelessness. Therefore, interventions usually consist of a package of approaches that work at a cognitive, emotional and behavioural level.

Adaptations to cognitive behavioural therapy for clients with ID

Deficits and distortions

There is a growing body of literature about working with people who have ID using CBT, cognitive restructuring and working with distorted perceptions of event. ID However, it has been pointed out that many interventions with people who have ID adopt a ‘deficit’ model. In other words, it is assumed that people’s cognitive deficits play a major role in their emotional difficulties and so these deficits are addressed through educational or self-instruction type approaches, such as problem-solving, assertiveness or anger management.
Cognitive challenges

CBT is a talking therapy, and people with ID may have difficulty discussing abstract thoughts and feelings. It is extremely important to recognise the limits of the approach and the fact that people require the ability to hold and articulate their views of events. Moreover, they need to be able to enter into a dialogue with another person and to realise that they may hold a different perspective from their own. Willner (2009) and Whitehouse et al (2006) have identified strategies for dealing with particular cognitive and communicative difficulties that might be barriers to engaging in CBT. Arising from poor memory, concentration or difficulty with planning in therapy sessions, these might include the use of flip-charts to set out agendas and using visual aids to bring points to life. For example, thought bubbles might be used to represent different possible interpretations of the same events. Role-plays can provide an excellent way of exploring what happens in particular situations and how different interpretations can lead to different emotions and outcomes.

Another key adaptation relates to the number of sessions required and the fact that problems with understanding and learning mean that the pace of therapeutic change is slower. The other factor to bear in mind is the individual’s ability to generalise what they learn in sessions to their everyday lives.

Agency

The basic premise of working with people using a cognitive behavioural framework is that there is a collaborative relationship between the therapist and client, and that they work towards explicit goals. If the therapist adopts an educational or self-instructional type approach there may be less emphasis on a collaborative therapeutic relationship. Nevertheless, there remains an assumption that clients will have sufficient agency or sense of self-efficacy to be able to use the information they obtain to change the way they think, feel and behave. Findings from studies in the general population have shown that clients’ level of motivation on starting CBT is the best predictor of positive outcome (Keisjers et al., 2000). In contrast, people with ID rarely refer themselves for psychological help and remain dependent upon others for support in their daily lives. Therefore, extra care has to be taken when using CBT with people who have ID to take account of the wider context of their lives and to address explicitly their sense of self-efficacy in relation to therapeutic change (Jahoda et al, 2009, Willner, 2006;).

Therapeutic bond

Another element likely to have an impact upon the success of CBT is the nature of the relationship or ‘bond’ between the client and therapist (Keisjers et al., 2000). People with ID may have little experience of collaborative working with professionals. Therefore, a particular effort may have to be made
to establish a therapeutic bond and to ensure that the client trusts and feels respected by the therapist. This helps clients deal with therapists challenging the views and beliefs they hold - an aspect of CBT Willner (2006) has suggested may be particularly uncomfortable for clients with ID. As an interpersonal process, it has been argued that one of the main routes of change in therapy sessions is through social influence (Safran & Segal, 1990). Consequently, the therapist’s contributions will have greater impact if the client values their contribution.

**Facing real challenges**

The main goal of CBT is to challenge or attempt to shift patterns of thinking or underlying beliefs that are maladaptive (Beck *et al.*, 1979; Ellis, 1962). Nonetheless, challenging people with ID to open up to different interpretations of their world does not mean that the therapist necessarily holds a more accurate or objective view of events. People with ID are likely to face stigmatising treatment and experience more failure in their lives than people in the general population., hence, the aim may be to work with the clients’ self- and inter-personal beliefs that stem from such experience. Therefore, for example, someone may be right to believe that she is socially excluded but be wrong to deduce that she is a dislikeable person.

**Self-monitoring**

CBT places considerable emphasis on the self-monitoring of thoughts feelings and behaviour. However, many of the materials used in CBT for recording thoughts, feelings or behaviour require some level of literacy skills. Once again, this means that existing materials need to be adapted or new and more accessible approaches developed. For example, tape recorders or dictaphones can be given to people to use as personal diaries or simplified diaries with stickers can be adapted for recording purposes.

**Real life change**

The other key process issue concerns the ‘outward’ focus of CBT. In other words, CBT is about helping clients to make positive changes in their lives and not just in their heads. Hence, a key part of CBT interventions is the process of linking the work in sessions to clients’ wider lives. This is achieved through the use of homework tasks where clients are asked to seek empirical evidence to support the work being done in sessions. These homework tasks play a crucial role in both generalising the interventions to clients’ everyday lives and in supporting the rationale for the work carried out in sessions. The difficulty for people with ID is that they may lack sufficient independence or confidence to follow through on these homework tasks. For example, someone might be unable to complete a graded exposure exercise or schedule pleasurable events without the support of staff or significant others in their lives. One way of
tackling this issue has been to ask significant others in the person’s life to assist with homework tasks.

Involving significant others in the therapeutic process is consistent with a tradition of working both at an individual and systemic level when using psycho-social approaches with people who have ID (Clements, 1997). Safran and Segal (1990) point out that people learn and change through experience in life rather than just in therapy. Therefore, someone’s employment status, social opportunities and relationships, and the level of autonomy that they are afforded, might all be crucial components of an intervention. Rose et al. (2005) have also found that including staff alongside clients in cognitive-behavioural anger management groups leads to better outcomes than working with clients alone. It could be hypothesised that changing staff perceptions contributes to a shift in their relationships with the individuals concerned, which in turn reduces the level of conflict.

However, involving other people in the process raises ethical concerns about confidentiality, and care has to be taken to ensure that efforts to achieve change are balanced with a respect for clients’ need or wish for their own therapeutic space.

**Evidence base for cognitive behavioural therapy**

There is evidence for the use of CBT for a variety of emotional and interpersonal problems but the strongest body of work concerns the use of CBT for people with anger management problems.

**Case studies and series**

Initially published accounts of CBT with people who have ID were in the form of case studies and case series and new developments continue to be reported this way. Wright, (2013) as an example, has reported using CBT with a man with autism and social phobia.

Haddock et al. (2004) reported findings of CBT intervention for a case series of five people with mild ID and psychosis. There were positive improvements on measures of psychotic symptoms and behaviour.

**Controlled trials**

Most research on CBT with people who have ID has concerned the outcomes for people who experience difficulties in managing feeling of anger. Nicoll et al. (2013) carried out meta-analyses of the effects of anger management interventions on participants’ pre- and post-intervention reported levels of anger. Six group anger management studies and three studies examining individual therapeutic approaches were included. They examined uncontrolled effect sizes and found strong overall effect sizes of 0.84 for
group anger management and 1.01 for individual therapeutic work. Despite the small number of participants taking part in these studies, the review provides consistent evidence for the positive impact of anger management interventions on reported levels of anger.

Hamelin et al.’s (2013) systematic review of anger management studies included an important critique of the existing research in this area. They argued for the need to establish whether reports of angry behaviour are reliable and to determine whether positive improvements are clinically significant. However, their analysis of effect sizes was compromised. In two instances, they reported the effect sizes from different studies as if they were independent when, in fact, the data were from the same cohorts.

Outcomes for depression have been the only other area of research. Two small scale studies by McCabe et al. (2006) and McGillivray et al. (2007), compared the outcomes for individuals receiving an adapted group CBT intervention for depression with waiting list controls. The outcomes showed clinically significant improvements for the intervention group at post-intervention and three-month follow-up on self-reports of depression. Comparable improvements were not found for the control group. While these studies are not definitive, the results are very promising.

**Randomised controlled trials**

Although the term randomised control trial has been used in other reports reviewed by Nicoll et al (2013) and Hamelin et al (2013) only one published study had enough participants to be truly called this. Willner et al (2013) completed a large-scale, cluster randomised control trial but failed to find a significant reduction of reported anger using the Provocation Inventory, a general measure of self-reported anger, compared with service users who were in receipt of day services who did not attend the anger groups. However, positive effects were found for those who attended the anger groups in the use of anger coping skills to deal with personally salient situations of anger.

**User views**

Pert et al. (2012) used interpretative phenomenological analysis to explore 15 clients’ experiences of CBT. The individuals had mild ID to borderline intellectual functioning and the problems they presented with included anxiety, depression and anger-related difficulties. The themes that emerged reflected the value the interviewees attached to having a confidential space to talk about their problems. They appreciated being listened to and having their views taken seriously. The therapeutic relationship was perhaps the most important aspect of the experience but the individuals also described ways in which CBT had proved helpful, and valued the therapists’ expertise. Yet they were only cautiously optimistic about the outcome of therapy, believing positive change would be gradual or that that therapeutic gains were fragile.
and might not be maintained once therapy finished. Such sceptical views may be related to these individuals’ limited sense of self-efficacy or the difficulties they face in achieving real-life change.

References


Introducing cognitive analytic therapy

Cognitive analytic therapy (CAT) is an integrative, time-limited, relational therapy, typically involving 16 or 24 sessions. The CAT theoretical approach is that the client’s difficulties arise from patterns in the way they relate to others, the way they experience others relating to them, and the way they relate to themselves. Understanding these relational patterns is described as reformulating the client’s difficulties. The first four sessions involve the therapist and client working collaboratively to map out the client’s interpersonal patterns and work out which are causing difficulties. In the initial session, the psychotherapy file, a self-report tool, is used to begin the process of understanding the client’s interpersonal patterns. Reciprocal roles are described in a personal letter, the ‘reformulation letter’, from the therapist to the client, which the therapist reads out during a session. The letter acknowledges the client’s sense of what their difficulties are, how these difficulties arose from the client’s early life, and how these problematic patterns continue to be played out in the client’s life in the present. The therapist also describes how these same problems have appeared between them both in the therapy room during the sessions. The focus will be to target a couple of problematic relational patterns.

In addition, from the first session onwards, the therapist and client begin sketching a pictorial reformulation in a flow diagram, mapping out the essential features of the client’s reciprocal roles and tracking how he or she moves from one set of roles to another. This is known as the sequential diagrammatic reformulation (SDR). This might map out, for example, how the roles the person longs for are transient, how they avoid those roles they dread, and how they may end up chronically enduring a role which is self-defeating.

This narrative and pictorial reformulation process sets the basis for the next eight sessions, in which client and therapist learn to recognise when the problematic relational patterns they have identified are played out. Such recognition may develop from the client’s descriptions of events in their everyday life, but also from what happens in the room during therapy. The client and therapist concentrate on finding new ways of approaching one to three
target problems and understanding the interpersonal procedures associated with those target problems.

During these eight sessions, the active stage of therapy involves revision and explorations of ‘exits’ - different and hopefully more useful ways of relating. The new ideas and approaches that may be tried out are built on the positive, useful actions and ideas that clients already have to some extent in their relational repertoire, and ways forward which build on their healthy relationship roles. The therapist does not try to impose new roles; the aim is a collaborative, open-minded exploration of what might be useful, holding in mind what may be realistically possible. Client and therapist discuss their own relationship, which aims to provide space for the client to experience these new, more useful relational approaches. By trying out these ideas between sessions, through 'homework' experiments, the client can discover what is useful in practice. Therapist and client develop rating scales to track how target problems are being recognised and evaluate whether revision has occurred through trying one of the new approaches they have explored together.

The final four sessions involve the client and therapist saying ‘goodbye’ to each other; which may be particularly hard for clients who wish that therapy was not ending. Therapist and client write goodbye letters to each other, describing what happened in therapy, what was achieved, what the limitations and disappointments were and how they both see the future.

As CAT works specifically on difficult relationships and was developed to help clients with a range of emotional, psychotic and social problems.

The central organising body for CAT is a charity, the Association for Cognitive Analytic Therapy (ACAT). Primarily a training body, ACAT offers a range of courses from brief, introductory courses to accredited, advanced psychotherapy training. Practitioner training, accredited with Sheffield Hallam University, is a two-year, part-time course. The organisation also hosts regional groups and special interest groups for clinicians working in specific services, such as with older adults, forensics, and those with physical disability and ID. The ID group includes people working in community teams and in specialist forensic settings and frequently publishes in the ACAT journal. They meet four times a year (which they have been doing since 2004), offer two-day introductory courses into CAT in ID services, and hold conferences.

**Adaptations of CAT for clients with ID**

The CAT approach has been adapted to facilitate its use by people with ID (Lloyd & Clayton, 2014). These adaptations include:

a) adaptations to the CAT tools,
b) adaptations to the process of therapy, and
c) adaptations to the focus of therapeutic intervention. Each of these will be outlined in turn.

Adaptations to CAT tools for people with ID

Ryle and Kerr (2002) and King (2005) suggest the tools of CAT can be modified and used successfully with clients with moderate intellectual disabilities, who may not be able to read or write. Many of the changes required are relatively superficial and fit within the flexible approach of CAT. Kirkland (2010) highlights how the use of abstract language can be a barrier to engaging people who have ID and discusses how creative adaptation of tools in CAT encourages the use of metaphor, which, broadly defined, can enhance the therapeutic relationship.

The psychotherapy file

The psychotherapy file has been simplified verbally, and symbols of dilemmas and traps have been developed (Bancroft, 2010, Clayton, 1999). An example of an adapted verbal statement might be ‘I must keep my feelings inside me. If I don’t, other people will not like me’ (Clayton, 1999). A symbolic representation of a ‘snag’, a particular kind of self-defeating procedure, is represented in Anne Bancroft’s version of the Psychotherapy File in figure 2 below.

Fig. 2: Adapted ‘snag’ diagram for PWLD (Bancroft, 2009).

The sequential diagrammatic formulation

People with ID may have better recall of diagrammatic reformulations than written letters (Wells, 2009). Reciprocal roles and interpersonal patterns can be shown symbolically using drawings on the SDR (King, 2000) to convey complex relational information in an understandable way (Wills and Smith, 2010). Diagrams can be adapted creatively and made easier to follow by using
a different colour to show each target problem and procedure, or by using separate diagrams for each target problem (King, 2000). Images can be used to support any part of the therapeutic process and may be incorporated into the SDR through using ‘off-the-shelf’ images (for example the ‘Blob People’; Wilson, 2004) or through painting, modelling with clay or plasticine, or cutting out pictures. ‘Draw on Your Emotions’ (Sunderland & Engleheart, 1997) contains useful pictures of dyads in different relationships and roles which can be included in SDRs.

Fig. 3. Using diagrams in CAT to support the therapeutic process.

Collins (2006) discusses the usefulness of adapting CAT diagrams with young people with physical and intellectual disabilities, through the use of comic strips. Wills and Smith (2010) also suggest further adaptations such as use of talking mats, drawings, feeling boards and story characters.

Reformulation and goodbye letters

King (2000) advises that the letters between client and therapist in CAT can be made accessible through use of clear language, preferably the client’s own. Where clients have limited literacy, audio or DVD recording may provide useful alternatives (King, 2000; Wills and Smith, 2010). Pictures from service users may be used as the goodbye letter in themselves as have pictures developed through using the six-part story method.
**The six-part story method**

The six-part story method is a projective technique using structured instructions to help the client create a new, fictional story which can be used in psychotherapy assessment or treatment. The themes, conflicts, world view, and problem solving displayed in the story communicate something meaningful about the client’s own experience, but in a non-threatening way.

**Working through objects and the body**

Moss (2006) argues that not only verbal dialogue but ‘gesture, drawing and other non-verbal signs’ can be understood ‘as a ‘way in’ to the individual’s subjective experience’ and that these may be particularly helpful strategies for working with PWLD. Non-verbal signs can be negotiated between client and therapist through the body, for example lying sitting or standing in the position that describes a dilemma ‘either I’m a doormat or one of the furies’ (Wilde McCormick, 2012). Signs and meaning may also be developed and shared through objects, for example picking objects from a box (toys, stones, beads, shells) to represent self, others, a trap, or a dilemma and through placing objects on the floor to show scenes, noticing closeness and distance, and inter-relationships (Wilde McCormick, 2012). Different sizes of buttons may be used to represent how the patient experiences themselves and the therapist (King, 2000)

**Adaptations to the process of CAT for people with ID**

**Engagement and pre-therapy**

Therapy with PWLD may need to begin with a ‘pre-formulation’ phase in which client and therapist establish a relationship (Bancroft and Murphy, 2009). During this initial phase, the tasks of the therapist are to socialise the client to the model, clarifying their expectations of therapy and the therapeutic relationship. CAT features in the DVD developed by Ogi and colleagues (2007), in which people with ID ask questions of therapists and can be used to help clients develop a clearer understanding of what to expect.

**Pace and length of therapy**

Ryle and Kerr (2004) note that clients with ID:

> may require a rather longer experience of therapy than people in the general population, usually around 24 sessions, or up to 32 for those with additional features of personality disorder.

The length and frequency of sessions may also need to be varied to meet the client’s needs (Bancroft and Murphy, 2009) but should remain within mutually agreed boundaries.
Psychotherapy file

This may be filled in collaboratively with the client during the session. The psychotherapy file may also be used selectively where it is outside the client’s understanding. In this circumstance, therapists often select a couple of examples of unhelpful relational patterns that they have encountered in the therapy room, and inquire if this bit of the file describes what is happening.

Emphasis on recognition

When working with someone with ID the goals of the therapy may also need to be carefully considered; sometimes ‘Recognition’ may be a more appropriate goal than revision (Bancroft and Murphy, 2009).

Reciprocal roles

Ryle and Kerr (2002) observed that people with ID appear to have fewer reciprocal roles that the general population, cautioning that this can create a more intense pressure to reciprocate. Psaila & Crowley (2006) investigated the common reciprocal roles found within people with ID, many in contrast to the most dominant reciprocal roles found within society (Ahmadi, 2011). Roles may reflect the person’s increased dependence on others, limited life experiences and roles, or the person not having a strong sense of self. The roles they found to be common for people with ID are:

- Abusing in relation to Abused;
- Rejecting to Rejected;
- Rescuing/Caring to Rescued/Cared for;
- Damaging to Damaged;
- Abandoning to Abandoned (Unloving to Unloved);
- Special/Perfect to Learning Disabled;
- Controlling to Controlled/Fragile;
- Blaming to Blamed;
- Overwhelming to Overwhelmed.

Several reports (Frain, 2011; Murphy, 2008) suggest focusing on one problematic reciprocal role in therapy and in the reformulation letter (King, 2000). Willis and Smith (2010) reported the need to make the concept of reciprocal roles accessible through linking them to everyday situations. This raises the question of how accessible this concept is to people with ID. Lloyd (2010) investigated this further and found that the ability to recognise reciprocal roles is dependent on the capacity to observe and synthesise image patterns and not language ability, supporting the notion that diagrams are more meaningful to PWID. Focussing on one problematic reciprocal role in
therapy is also a useful way of remaining within the client’s zone of proximal development (ZPD).

**Zone of proximal development**

A key concept in working with people with ID from a CAT perspective is Vygotsky’s (1978) ZPD. The ZPD describes the distance between the learning a person can achieve independently, and the potential learning they can attain when they are helped by a ‘more capable’ peer, in this case the therapist. A well-pitched therapeutic process will aim to stretch the person emotionally to see just a little more than they can currently, using the CAT tools to internalise the therapist during the collaborative sessions. It is particularly important in work with people with ID to consider the person’s ZPD both in a cognitive sense and in an emotional sense. Where the client has experienced significant trauma there may be a complex relationship between their cognitive and emotional functioning.

**Transference and counter-transference**

King (2005) suggests that creative adaptation for the individual needs of the person serve to maintain the working alliance but that there are particular issues in the therapeutic relationship which need to be addressed, including a need for therapists to overcome personal counter-transference to disability. King argues that therapists may be drawn into procedures with powerful feelings of guilt & intense compassion (Sinason, 1992), contempt (Symington, 1992) or a desire to deny disability through avoidance, distancing and rejection. She states that what is needed is a ‘developmentally needed or reparative relationship’ addressing three types of injury or deficit; trauma (e.g. abuse); strain (e.g. negative societal attitudes) and extra-familial limitations or tragedies (e.g. genetic conditions). A therapeutic emphasis on witness, containment, care and deliberate use of positive reciprocal roles in therapy may allow a therapeutic process whereby any experiences of neglect can be met with careful attention and responsiveness and where smothering and overprotection have dominated, the therapist can provide an experience of respect and space. King (2005) notes that ‘getting stuck’ in the reparative relationship may foster dependency and infantilisation requiring movement from the ‘reparative’ towards a deeper ‘person to person’ relationship as the therapeutic relationship develops.

**Ending therapy**

Given that some people with ID may have difficulties with understanding time, and the increased likelihood of experiences of rejection or abandonment; sensitive and active use of the ending of therapy with people with ID can be particularly important. King (2000) recommends the use of a
visual, concrete ‘session tracker’ in the form of a pie chart divided into the
total number of sessions; a section of which is shaded in at the end of each
session.

Adaptations to the focus of CAT for people with ID

A more central development of the CAT model with people with ID has been
the use of contextual reformulation when working with staff teams and the
stakeholders supporting a client. The use of CAT tools to increase staff morale
and facilitate change has been described in working with borderline
personality disorder (Ryle, 1997). The intense pressure to reciprocate (Ryle &
Kerr, 2002) and possibility of staff being attracted to work in challenging
behaviour services because they may fit with their own reciprocal roles,
increases the likelihood of conflict between people with ID and the people who
support them. The experience of abuse within the lives of many people with
ID may also increase borderline presentations with consequential increased
risk of splitting within staff teams.

CAT has also been used to provide an alternative framework for
understanding behaviours which challenge (Bancroft, 2008; Greenhill, 2011).
Lloyd & Williams (2003) found that service settings, particularly forensic
settings, may inadvertently reinforce ‘challenging behaviour’ because of a lack
of awareness of the reciprocal relational influence on the person’s behaviour.
They found that through sharing a client’s diagram with their staff team or
developing a diagram from the team’s perspective and talking about the roles
invited by client’s behaviour, there were changes in staff attitudes and that
staff made previously withheld resources available. Therefore, CAT may
explain some mechanisms through which the actions of staff maintain
challenging behaviour (see also Fisher and Harding, 2009). Moss (2007)
recommends the use of Carradice’s model (2004) of staff consultation within a
CAT framework. Case-studies attest to the benefit of using contextual
reformulation with the stakeholders around a client with behaviours which
challenge to enable positive change (Murphy, 2008; Fisher & Harding, 2009).

Evidence base for CAT

Case studies

CAT is proving popular as a psychotherapeutic modality within the
intellectual disability field because of the perceived strength of its flexible
methods, focus on issues of disability and relational approach including
transference phenomena. As in any new development, observation and
description of the process and effects of therapy precede large scale formal
studies. Over 25 papers have been published; many in the form of single case
reports (Clayton, 2000; 2001; King, 2000; Collins, 2006; Lloyd, 2007;
Murphy, 2008; David, 2009; Smith and Wills, 2010; Frain, 2011) and reflective essays (Crowley, 2002; Lloyd & Williams, 2003; King, 2005; Clayton, 2006; Collins, 2006; Moss, 2007; Bancroft, 2008; Fisher & Harding, 2009; Kirkland, 2010; Greenhill, 2011). Only a few of these case studies contain outcome data on standardised measures (Lloyd, 2007) and none of those reviewed contain pre and post intervention data, but some contain evidence of change in client’s abilities to recognise and revise interpersonal patterns (King, 2005; Murphy, 2008; David, 2009; Smith and Wills, 2010; Frain, 2011).

There are also papers reporting the utility of some of the basic ideas of CAT as applied with people with ID. Several researchers have looked at the notion of reciprocal roles in relation to people with ID. Psaila & Crowley (2006) retrospectively content analysed the therapy notes of 16 participants, finding 22 different reciprocal roles within the client group and formally endorsing those originally suggested by Ryle (2002). Well’s (2009) qualitative study on people with ID’s experience of CAT suggests that diagrammatic formulations were substantially more memorable than when in letter form. Ryle and Kerr (2002) suggest that it is perhaps inherent in the nature of pictures that complex information can be described in an eloquent and memorable form.

Researchers have also explored the utility of particular methods in CAT for people with ID. Pettit (2012) explored whether the ‘Six part story method’ (6PSM; Dent-Brown, 2009) could discriminate ‘victims’ of bullying from ‘non-victims’. The study aimed to see if the detail and accuracy of pictures (as evidenced by the ‘Draw-A-Person Test: Quantitative Scoring System; Goodenough, 1926) drawn by six participants with ID was influenced by prior experience of bullying. Participants were asked to draw both a ‘non-bullying’ (happy) and a ‘bullying’ story using the 6PSM. Although findings were not significant, victims of bullying performed worse on their bullying story in comparison with their non-bullying story, whereas victims described as bullies were the opposite, and performed better on their bullying story in comparison with their non-bullying story. The author interprets this as evidence that past trauma impacts on present pictorial ability and notes the congruence of the picture content with reciprocal roles which might be expected if a participant had been bullied in the past.

Much of the available evidence has been gathered by the CAT ID special interest group, working in community and forensic settings, and published in ACAT’s own publication, ‘Reformulation’. To date, all studies have been carried out in routine clinical practice and therefore represent an emerging base of practice-based evidence. Failure to offer more RCT-based evidence has a number of explanations both specific to conducting research with the ID population and more generally to the rapid develop of CAT, without a centralised academic base.
User views

Wells’ (2009) qualitative study of CAT as experienced by five clients with learning disabilities in a community setting, suggested participants with ID viewed CAT positively. This study provides preliminary evidence that CAT can be used effectively to produce outcomes which are valued by people with learning disabilities. Participants felt they were engaged in a collaborative process, evidenced that they had incorporated CAT into their own conceptualisations of their problems and that these conceptualisations and resulting strategies continued to be applied independently by clients after ending therapy.

Service examples

A number of services in the UK offer CAT for PWLD. They can be contacted via the CAT and LD Special Interest Group (see ACAT web site for details).

References


Greenhill, B (2011). ‘They have behaviour; we have relationships? Using CAT to understand why the ‘un-offered Chair’ remains un-offered to people with Learning Disabilities’. Reformulation, 37, 10-15.


Introducing mindfulness and acceptance-based therapies

Mindfulness and acceptance-based approaches have been described as a third wave of behavioural therapies. Unlike traditional cognitive and behavioural therapies, these approaches are not concerned primarily with changing particular thoughts or emotions, and do not focus on direct manipulation of the social or physical environment. Rather, they aim to change the way people relate to mental events and experience the world through cultivating a non-judgemental awareness of the present moment.

Mindfulness and acceptance-based approaches draw heavily upon meditations and other ancient practices developed predominantly through Buddhism and systems of yoga. While these practices have their routes in spiritual traditions, when used therapeutically they are applied through a psychological framework, in combination with other aspects of cognitive and behavioural science (Baer, 2003; Chiesa & Malinowski, 2011).

Mindfulness as both a process and as a state has been the subject of multiple definitions. These include the act of ‘paying attention in a particular way, on purpose, in the present moment and non-judgementally’ (Kabat-Zinn, 1994, p.4) and the ‘awareness and non-judgmental acceptance by a clear, calm mind of one’s moment-to-moment experience without either pursuing the experience or pushing it away’ (Singh et al., 2003). A dimensional approach has also been adopted by some in an attempt to assess mindfulness as a trait. Most notably, Baer et al. (2006) proposed that five key elements (observing; describing; acting with awareness non-judging of inner experience and non-reactivity to inner experience) characterise what it means to be mindful.

Psychological acceptance is closely related to the concept of mindfulness, overlapping in part with the non-judgmental stance to experience highlighted in the definitions above. Acceptance is seen as an alternative to automatic attempts to alter events, thoughts or feelings in response to negative evaluations made by the mind and as central to fostering ‘bare awareness’ (Nyanaponika Thera, 1996) of the present moment as part of mindfulness meditation. Acceptance is typically viewed as an active process, distinct from defeat or tolerance and is suggested by some models to be a major mechanism by which cycles of suffering may be broken (Hayes et al., 1999).
The various mindfulness and acceptance models differ in terms of their emphasis on cognitive (Segal et al., 2002) or behavioural (Hayes et al., 1999) underpinnings and the extent to which regular and ongoing meditation practice is (Kabat-Zinn, 1990; Segal et al., 2002) and is not (Hayes et al., 1999) considered as an essential component for generating mindful awareness and therapeutic change. Despite these differences, each model recognises that psychological suffering is the product of an unquiet mind that may be experienced by both client and therapist. Personal commitment to developing a mindful and accepting way of life is, therefore, considered fundamental to professional practice. A basic description and clinical use of each major mindfulness and acceptance approach is provided below.

**Mindfulness-based stress reduction (MBSR)**

The development of MBSR marked the first attempt to use mindfulness meditation within a therapeutic/clinical framework (Kabat-Zinn, 1990; 1994). While the initial focus of MBSR was on chronic pain and other stress-related conditions, the model has now been applied to a variety of physical and mental health conditions (for a review of randomly controlled trials see Fjorback et al., 2011).

The standard MBSR intervention is an eight-week programme delivered via 2.5-3 hour sessions to groups of up to 30 people. The programme places considerable emphasis on regular and lengthy meditation (45-minute exercises) with home practice required for six out of seven days. During early sessions, clients are introduced to a ‘body scan’ exercise in which attention is systematically focussed on different areas of the body in turn. While this exercise may result in a state of relaxation, the aim of the exercise is simply to experience bodily sensations however they are.

In later sessions, clients are taught: a seated and walking meditation; Hatha (breath-based) yoga movements; and exercises to promote mindful awareness in daily activities (including mindful eating). Behaviour-change strategies are not promoted in sessions. Rather, group discussions focus on describing the qualities and nature of momentary experiences in detail, with a curious, non-judgmental attitude. A final, day-long session is completed by group members to consolidate and refine all practices.

**Mindfulness-based cognitive therapy (MBCT)**

MBCT (Segal et al., 2002; Teasdale et al., 1995) has an established evidence base as an intervention for recurrent depression (NICE, 2009) and has been used effectively to alleviate a variety of other psychological difficulties (Chiesa & Serretti, 2011; Fjorback et al., 2011). The model is typically delivered as an eight-week programme and draws heavily on several of the key exercises
developed in MBSR. While routine home practice is a critical requirement of MBCT, briefer meditations are also taught, including the ‘three-minute breathing space’ that offers group members a way to break cycles of automatic thinking and behaving in stressful or problematic daily situations. Again, this is not intended as a relaxation exercise but as a time to reflect on opportunities that are available in the present moment to allow a more skilful course of action to be taken.

While traditional cognitive restructuring (for instance challenging of automatic thoughts) is not consistent with a mindfulness approach, MBCT does incorporate other cognitive strategies that promote increased awareness of thoughts and how these may function to influence mood and behaviour. From this standpoint, MBCT emphasises a decentred approach to internal experience, whereby thoughts are recognised as momentary experiences, rather than facts that must be acted upon or responded to directly. In addition to these cognitive elements, MBCT explicitly promotes some behaviour-change strategies through encouraging increased participation in pleasure and mastery activities for group members, and by developing individual relapse-prevention plans.

Acceptance commitment therapy (ACT)

ACT-based interventions (Hayes et al., 1999), in individual, group and brief formats, have been applied to a broad spectrum of physical and mental health difficulties (for a review see Ruiz, 2010). ACT is based on relational frame theory, an account that attempts to extend the behavioural tradition to understand human language and cognition (Hayes et al., 2001). Within the ACT model, difficult thoughts and emotions are considered to be the natural product of a highly developed language system, and so a common and integral part of human experience.

Whilst contact with unpleasant mental states is, therefore, not considered to be problematic in and of itself, ACT suggests that psychological suffering may be generated by attempts to avoid or control such experiences and a tendency for cognitions to connect together or fuse. These processes appear to have the paradoxical effect of increasing the occurrence of negative thoughts and feelings, while simultaneously reducing an individual’s ability to behave in accordance with their personal values.

ACT incorporates mindfulness meditations (such as the body scan) and some degree of home practice is often recommended to increase contact with the present moment. Mindfulness is, however, only one component of ACT which also uses exercises, metaphors and discussions to promote ‘diffusion’ from thoughts and the development of self-observations, or what is called an ‘observer-self’. Ultimately, ACT attempts to increase psychological flexibility
by fostering acceptance as an alternative to unhelpful agendas of control, and by increasing commitment to live in line with personal values.

**Mindfulness adaptations and developments for people with ID**

Accounts of mindfulness and the proposed benefits of mindfulness meditation are suggested to be universal, and so applicable to all people regardless of level of ID. While mindfulness and acceptance-based approaches encompass some quite abstract concepts, there is emerging evidence that adaptations can be made to increase accessibility and engagement with key practices for people with ID. Particular promise lies in the possibility that experiential exercises are less reliant on the use of verbal reasoning skills than some traditional cognitive behavioural approaches. Furthermore, the minimisation of power differences between therapist and client in mindfulness and acceptance-based approaches would seem to have particular relevance for a group that has historically been stigmatised and discriminated against.

**Adaptations to the therapy**

The following recommendations for adapting mindfulness and acceptance-based approaches for use with adults who have ID are drawn from academic and research studies that have provided useful detail about modification of interventions (Brown & Hooper, 2009; Chapman & Mitchell, 2013; Miodraget al., 2012; Robertson, 2011; Singh et al., 2013), together with the research and clinical experience of the authors.

1. Initial preparation sessions should be used to orientate clients to the programme structure and to support attendance of sessions (for instance, by using visual time tables). Robertson (2011) also suggests initial sessions may be used to help clients develop some foundational skills in identifying and labelling bodily sensations, feelings and thoughts and to be able to record these on simple rating scales. In some instances, it may be helpful for clients to be supported to record examples in a mindfulness journal of when they experience emotional and/or behavioural difficulties in daily life.

2. Time needs to be taken at the beginning of a programme to create a safe and supportive context. The nature of experiential exercises and delivery of mindfulness and acceptance-based approaches is likely to be quite different from other more didactic therapeutic processes or support groups that clients may have encountered. The power of helping clients recognise that we are ‘all in the same boat’ and can work together to develop mindfulness and increased emotional well-being, should not be underestimated.
3. Additional session time should be built into all programmes to allow processing of ideas and increased support for practising and refining exercises. Clients are likely to require breaks during sessions. Brown and Hooper (2009), for instance, describe how a woman attending an ACT-based intervention requested to take a walk midway through one session. The need for breaks should, therefore, be anticipated and scheduled in advance.

4. Simple, brief and clear language should be used to explain all exercises, and abstract language should be minimised during discussions. For instance, the body scan exercise may be adapted to focus on a smaller number of primary body regions (feet, legs, arms, etc) with avoidance of more specific areas that may be more difficult to identify and discriminate (eyelids, ankles). Facilitator guidance during the exercise should also use concrete phrases such as ‘focus on your feet’ rather than more poetic descriptions (‘become aware of how sensations arise and dissolve from moment to moment’). Frequent checks should be made to confirm clients’ understanding throughout sessions.

5. Graded physical prompts and supports may be needed to facilitate movement-based meditations (as used by Miodrag et al, 2013 to teach Qigong) and mindful breathing (Roberston, 2011 suggests blowing bubbles may be a useful strategy). A range of visual methods should also be developed and individualised to support understanding, for example Miodrag et al., (2012) describe using a ‘glitter ball’ when discussing feelings. Such strategies help to make concepts concrete and act as an enduring physical reference point for later exercises and discussions.

6. A range of strategies should be employed to support and encourage mindfulness practice during and outside of sessions. This may include provision of carefully adapted leaflets and CDs (as reported by Chapman & Mitchell, 2013) but may also incorporate support from family carers and paid staff. It may be useful for carers to attend mindfulness sessions with people they support, not only to facilitate client engagement and understanding but also to develop their own understanding and personal practice of mindfulness. Carers will then be well placed to model mindful awareness and promote this outside of treatment through rehearsal of exercises for clients.
‘Soles of the feet’ meditation

The above strategies have been used to modify mindfulness and acceptance models from the general mental health field (predominantly ACT and MBSR) but are also incorporated into a mindfulness intervention that has been developed specifically for people with intellectual disability. The Soles of the Feet (SOF) meditation (Singh et al, 2003; Singh, Singh et al, 2011) is a self-management approach that has been employed both as a standalone intervention and in combination with other mindfulness strategies to support people ID. Effectiveness of the SOF approach for self-management of behavioural and emotional functioning has been demonstrated for adults who have mild to moderate ID.

‘Soles of the Feet meditation is described in a manual (Singh, Singh et al., 2011) which includes examples of appropriate language to use when explaining and guiding the exercise. Three major steps are required to teach the exercise across sessions. Firstly, clients are supported to increase awareness of the soles of their feet and helped to develop their ability to maintain focus on this area. In practice, some clients require individualised prompts to identify and directly experience this bodily area. Singh et al. (2007) describe one such study where participants were found to benefit from having a sticker placed on the soles of their feet as a physical prompt.

During subsequent stages of the exercise, clients are instructed deliberately to bring to mind memories of events that induce both pleasant (happy) and, later, more difficult (anxious, angry) emotional states. Once the emotion has been experienced, clients are guided to direct their attention away from the events of the mind to the sensations in the soles of their feet as a way of regaining contact with the present moment. It is often necessary to support clients firstly to identify and record emotion-inducing events and then to have a physical reference point for these in sessions (for instance a photograph) to help recreate the scene. It may also be useful to create an hierarchy of events to work through so that clients build up some fluency in the exercise before applying it to memories of events and situations they find most difficult.

Following repeated practice of the SOF exercise in therapy sessions, a range of methods may be employed to support clients’ use and practice of the SOF strategy in everyday life. Examples include video modelling, direct prompting from carers for in situ use, and supportive reflective conversations with staff following clients’ successful and less successful self-management of emotional and behavioural wellbeing.
Evidence base for mindfulness and acceptance-based therapies

Although there are several clinical sources discussing methods for adapting general mindfulness-based interventions for adults with ID, the research evidence is much less prolific. Two recent systematic reviews (Chapman et al., 2013; Hwang & Kearney, 2013) demonstrate that the bulk of the research evidence has been generated by Dr Nibhay Singh and colleagues and is based on the SOF mindfulness intervention. Given this, we will first review evidence for other approaches – evaluations of general mindfulness interventions, and ACT case reports – and then provide an overview of the evidence relating to the SOF method. We will focus only on evidence relating to adults with ID and not those with autism who do not have ID.

Group-based mindfulness interventions

We found two studies reporting outcomes from general group-based mindfulness interventions for adults with ID. Chilvers et al. (2011) implemented twice-weekly, 30-minute, optional mindfulness groups for 15 women with ID in a medium-secure unit over a six-month period (approximately 44 mindfulness mediation sessions in total). Over the six-month period, official records of aggressive incidents reduced substantially and to a statistically significant extent for this group of 15 women. However, there was no control group for this study and so interpretation is difficult. Miodrag et al. (2013) reported outcomes for 24 adults with Williams syndrome attending a five-day, residential music camp for adults with ID. The mindfulness intervention consisted of small group activities for two hours per day over the five-day period, informed by the MBSR protocol. Self-reported anxiety and cortisol levels were consistently lower following each mindfulness session. Again, no control group was included and the music camp setting is unlikely to be typical of participants’ daily life experience. However, both of these studies report encouraging outcomes and also provide some evidence that adults with ID can successfully participate in group-based mindfulness interventions over time.

Acceptance and commitment therapy evidence

The only evidence we could locate for the use of ACT with adults with ID comes from two case reports. Pankey and Hayes (2003) reported a brief case example of a four-session ACT protocol to treat psychosis in a 22-year-old woman with mild ID. Improvements were noted in eating, sleeping, taking medication and obsessive behaviours. Her reported distress in response to hallucinations also reduced over the course of the treatment. Brown and Hooper (2009) reported a case of a young woman with moderate to severe ID who had obsessive and anxious thoughts that prevented her attendance at college. An ACT intervention was delivered over 10 sessions, and some data
was presented in the case study to suggest that the young woman was less avoidant of her thoughts and emotions at the end of the intervention. She was also reported as being calmer, and successfully returned to her college course.

‘Soles of the feet’ mindfulness evidence

To date, the SOF mindfulness intervention has been used with adults with ID with a focus on four types of outcomes: weight management and healthy lifestyle, smoking cessation, deviant sexual arousal, and aggressive behaviour.

Single-case descriptions of SOF in combination with other healthy lifestyle factors (exercise and healthy eating) have shown reduced weight over time in four adults with Prader Willi Syndrome (Singh et al., 2008; Singh et al., 2011). These designs amend a (reduced) weight target once the participant has successfully kept their weight to a new reduced level for a few weeks. Therefore, these studies lack a no treatment phase to compare the intervention phase with; although detailed weight data are presented over the course of several months for each individual. Similar approaches have been used in reports of four adults with ID using SOF only to reduce the number of cigarettes smoked on a daily basis (Singh et al, 2011a; Singh et al., 2013). Again, detailed data are provided on the number of cigarettes smoked by each individual over a long period of time but these studies lack experimental control.

An improved evaluation approach used by Singh and colleagues is the multiple baseline design across participants design. This design relies on regular reports of relevant behaviour graphed for three or more participants where their no treatment baseline observation periods are increasingly longer for each participant. Thus, intervention is delayed for the second and third participant and some experimental control is offered by looking for positive change only when the intervention is implemented (and not during baseline phases) with this pattern replicated across all participants in the design. In Singh et al.’s (2011) report of three sex offenders with ID, deviant sexual arousal to images was measured regularly and found to reduce when a combination of the SOF intervention and a mindful exercise was used.

Following an initial case report with regularly repeated records of aggression data (Singh et al., 2003), Singh and colleagues have published three multiple baseline studies with a total of 12 participants showing reductions in aggression as a result of the use of the SOF intervention. These outcomes have been achieved with experienced mindfulness therapists, and by community support staff trained to deliver the intervention, and with adults with mild to moderate ID in community settings as well as those with a history of aggressive offending behaviour (Adkins et al., 2010; Singh et al., 2007; Singh et al., 2008). In the study with six offenders (Singh et al., 2008), data were also reported showing reduced economic costs of service support after the
mindfulness intervention. Financial savings were achieved by reduced staff absence and medical costs following reductions in their exposure to aggressive behaviours.

‘Soles of the feet’ mindfulness has also been evaluated as an intervention for aggressive behaviour using a randomised controlled trial (RCT) design. Singh et al. (2013) worked with 34 adults with mild ID who were living in community settings and were aggressive infrequently but to an extent that placed their employment placements in jeopardy. These participants were randomised to a 12-week SOF intervention or to a waiting-list control group. Data were gathered using self-reports of aggression and supporter/family reports. Physical aggression reduced with a large effect size and to zero levels at follow-up (6 months+), and verbal aggression also reduced over the intervention period with a large effect size and to near-zero levels at follow-up. As a pilot trial, these data are encouraging given the effects observed. However, outcome data were reported non-blinded and the developers of the SOF intervention carried out the study.

A mindfulness-based smoking cessation intervention which includes the SOF meditation has also been subject to RCT evaluation. Singh et al (2014) allocated 51 adult smokers with mild ID on an alternate basis (pseudo-randomisation) to the mindfulness intervention or ‘treatment as usual’. Statistically significant and large reductions in the number of cigarettes smoked daily were found at the end of the intervention period for the treatment group, and a one year follow-up still showed a significant advantage for the mindfulness intervention group. Again, we should note that data were reported non-blinded and the intervention developers carried out the study.

One small, multiple baseline study (Singhet al., 2011b) focused on a man with mild ID who had successfully used the SOF intervention and then taught three peers to use the technique to manage their aggression. The fidelity of the teaching was reported as good, although somewhat idiosyncratic. Reductions in aggressive behaviour also appeared to be achieved for the three peers.

Evidence summary

So far there have been only a small number of studies on the effectiveness of mindfulness and acceptance-based interventions with adults with ID . There are case reports only of the use of ACT, and uncontrolled studies of group mindfulness interventions. There is a need for evaluations of suitably adapted versions of MBSR and MBCT for adults with ID. There is RCT evidence that MBCT can be successfully adapted and lead to positive outcomes for adults with Asperger syndrome/high-functioning autism (Spek et al., 2013).

Controlled studies have been published on the SOF intervention, especially utilising multiple baseline designs for its use with adults with ID and aggressive behaviour. Results from pilot RCTs with a focus on aggressive
behaviour and smoking cessation are also encouraging. Intriguing data also suggest that the SOF method can be taught by people with ID to their peers with some fidelity and good outcomes. A significant limitation with the SOF evidence is that only the developers of the intervention have reported outcome data. There is an urgent need for stronger research designs overall, and also independent evaluation of the SOF intervention.

All of the adults involved as participants in the studies reviewed above are reported to have mild, moderate or borderline levels of ID. Therefore, there is an open question about whether mindfulness-based approaches could be adapted successfully for adults with more severe ID. It is also worth noting in relation to this point that Singh and colleagues have provided evidence of positive outcomes for people with ID from studies with support staff who attend a mindfulness intervention similar to MBSR. Using multiple baseline designs, training staff in mindfulness has been shown to be associated with improved success of positive behaviour support interventions, increased happiness amongst people with profound ID, and improved social skills and other skill learning (Singh et al., 2004; Singh et al., 2006). This raises the intriguing possibility that therapeutic outcomes for adults with ID might be achieved indirectly by helping support staff to be generally more mindful. In contrast, when ACT-based interventions have been used with support staff (Bethay et al., 2013; Noone & Hastings, 2009, 2010; Smith & Gore, 2012), the outcomes measured have to date been primarily reductions in staff stress rather than changes in the adults with ID supported by the staff.

**User views**

There are some data on the perspective of people with ID about mindfulness interventions. In terms of the SOF intervention, some comments about participants’ experience were reported in the sex offender study (Singh et al., 2011). Participants found the transfer of using SOF from managing anger to managing deviant sexual arousal a considerable challenge, and the addition of the mindful observation of thoughts procedure was also challenging because the instruction to ‘observe your thoughts’ was initially difficult to understand. There was also a perception that relationships with staff had improved when the participants had learned to control their aggression.

In Singh et al.’s peer teaching study (2011b), informal interviews were conducted alongside the main research study. The participant taking the role of therapist found the role rewarding because it gave him a positive sense of contributing to the community. His ‘clients’ reported that they valued the chance to learn a technique that gave them control over their own behaviour, so that they did not have to respond to other people telling them to ‘calm down’.
Chapman and Mitchell (2013) carried out a survey (N = 76) and detailed qualitative interviews (N = 6) with adults with ID who attended mindfulness introductory workshops of 1 to 1.5 hours in length. The workshops involved a description of mindfulness, a meditation practice and group discussion. Most people had attended the workshops to learn how to relax or because it was part of another meeting they were attending. Of survey respondents, 88% rated the workshops as very good or good. The most commonly reported positive aspect of the workshop was that it helped people to relax. There were less positive observations about the complexity of the language used in the meditation instructions. In the interviews, participants were clear that they were looking for ways to deal with a wide variety of problems including how other people responded to them in the community, suggesting a need for a broad, wellbeing-focused intervention like mindfulness. Although they may have been anxious about attending in the first place, it was clear that the interviewees found the workshops enjoyable and relaxing.

References


Introducing dialectical behaviour therapy

Dialectical behaviour therapy (DBT) was devised by Marsha Linehan (1993) in the United States in the early 1990s as a psychotherapeutic approach for working with suicidal women with a diagnosis of borderline personality disorder (BPD). DBT is a comprehensive treatment approach that assumes that people with BPD lack essential skills in managing distress, interacting with others and regulating emotions. It further assumes that there are personal and environmental factors that prevent an individual acting in the most effective (or skilful) way or serve to reinforce the individual’s maladaptive behaviour. Dialectical behaviour therapy helps people to decrease unhelpful behaviours and to learn new skills, and to ensure those skills become part of their behavioural repertoire and generalise across different settings. It has been found to be effective in reducing self-harm, decreasing inappropriate anger and improving general functioning in people with BPD (Cochrane review: Stoffers et al, 2012). In addition, DBT has been modified and developed for people with co-morbid disorders, such as eating disorders, across the lifespan, including with suicidal adolescents, and in a range of different clinical settings (Feigenbaum, 2008).

Dialectical behaviour therapy is underpinned by a dialectical philosophy which relates to the tension of holding on to opposing ideas or truths at the same time; in DBT a key dialectic is balancing “acceptance” and “change”. DBT can be described as a 3rd wave CBT approach because it uses many of the principles and techniques of cognitive behavioural theory (such as cognitive restructuring, exposure and contingency management) and also draws on Eastern traditions such as Zen Buddhism in promoting mindful awareness.

The DBT model (Linehan, 1993) holds that BPD is a product of an invalidating environment during development and a biological emotional vulnerability. This emotional vulnerability is characterised by the person with BPD having both a heightened sensitivity and a rapid and intense response to emotional stimuli, which is then slower to return to baseline levels of arousal. Extreme emotional arousal can lead to the typical impulsive behaviours, chaotic relationships, dysregulated thinking and lack of sense of self seen in people...
with BPD. The combination of biological vulnerability and growing up in an invalidating environment leads people with BPD to distrust their own emotional reaction to events. Engaging in problematic, impulsive behaviour becomes a way of reducing the overwhelming feelings of distress.

The structured therapeutic package which forms the foundation of DBT consists not only of individual therapy but also of group skills teaching and telephone skills coaching. Hence, in standard DBT, the client has weekly individual therapy alongside participating in a weekly skills training group for 2 to 2½ hours and can contact their therapist for skills coaching over the telephone.

The structure imposed by the DBT model helps the therapist to determine which symptom or behaviour to target and at what point. This is particularly beneficial when presented with people whose lives are typically chaotic and characterised by numerous issues such as problems sleeping, extremes of anxiety or low mood, intense relationship difficulties, deliberate self-harm and suicidal urges, and concerns over benefits or housing. Individual therapy uses a range of strategies to focus on specific, individualised targets according to a hierarchy with the first target being to reduce life-threatening behaviour, then to reduce therapy-interfering behaviour (such as missing sessions, not filling in diary sheets, falling asleep or refusing to speak in therapy), and then to target reducing quality-of-life interfering behaviours.

In individual therapy, the therapist encourages the individual to complete a daily diary to monitor strong emotions and unhelpful behaviours such as use of alcohol, self-harm or urges to engage in self-harm or suicide. Identified (maladaptive) target behaviours from the diary card are then the focus of an in-depth discussion using behavioural chain analysis to determine in great detail what happens in terms of the actual behaviour and the associated thoughts, emotions, bodily sensations and consequences. More helpful solutions employing existing skills or identifying those that need to be learned for each of the steps in the chain can then be developed and agreed.

Throughout therapy, the therapist is aware of and assessing the risks that the individual’s behaviours present; in particular, behaviours that could be life threatening. The therapist works with the individual to find support within their usual environment to help manage risk and to reduce access to the means of suicide. Through consultation with the client the therapist helps to empower the them to self-advocate rather than expect professional to consult with another professional on their behalf. The approach is collaborative, but it can also be challenging both for the individual and for the therapist. Along the way, the therapist is encouraged to use humour, be irreverent at times and to self-disclose as appropriate.
Group skills training aims to increase the client’s ability to be aware and in the moment, get on with other people, manage emotions and cope at times of crisis. The skills are taught by pairs of facilitators as four distinct modules: Mindfulness, Interpersonal Effectiveness, Emotional Regulation and Distress Tolerance. Mindfulness is taught at the start of each of the other modules and is a thread running throughout the process. In standard DBT, Mindfulness will be taught for two weeks, and the remaining modules for six to eight weeks each. Completion of all the modules would usually take about six months, although typically participants are invited to complete the cycle a second time in order to consolidate learning. The group in DBT is not strictly closed – new participants can join at the start of any Mindfulness module and then complete the remaining modules in any order. Treatment compliance and attendance at the group are enhanced by having a period of pre-treatment lasting several weeks before an individual is fully accepted on to a DBT programme. In this pre-treatment phase, the DBT approach is introduced, the process of the group and individual therapy is explained and the individual’s commitment is tested using a variety of strategies.

The third element of the therapeutic package is telephone skills coaching. The therapist agrees to receive telephone calls during which the client is coached to use the skills they have learned so far to help them act more skilfully and less impulsively. The therapist and the client mutually agree the limits to these calls – one therapist may be happy to receive calls in the evenings or at weekends, others may limit calls to office hours. These limits may change during the course of therapy and may be ‘stretched’ to meet needs, for example accepting calls out of hours when an individual is facing a particularly difficult time.

An essential part of the DBT therapeutic package is the support and opportunity for reflection provided to therapists through consultation team meetings. This provides an opportunity for therapists and group facilitators to meet, review their effectiveness, build capabilities and increase motivation. The consultation session lasts up to two hours, begins with a mindfulness exercise and is followed by a reminder of dialectical principles, for example reviewing the statement: ‘there is no absolute truth, and when caught between two conflicting positions, the team will acknowledge the truth in each position and attempt to arrive at a synthesis’. Consultation team meetings have been described as ‘therapy for the therapists’.

Adaptions to dialectical behaviour therapy for People with ID

The NICE guidance (2009) on BPD states that:

When a person with a mild intellectual disability has a diagnosis of borderline personality disorder, they should have access to the same services as other people with borderline personality disorder.
However, in practice, DBT can be intellectually demanding, the terminology used is unfamiliar and the style of presentation culturally ‘American’. Furthermore, skills teaching groups rely on wordy hand-outs, there are mnemonics for key concepts and there is a requirement for the individual to keep written diaries of behaviour and emotions. Despite these apparent barriers to delivering DBT in services for people with ID, there are valid reasons for choosing to do so. As Lew et al. (2006) point out, people with ID are particularly likely to have the biological predisposition coupled with an invalidating upbringing that is described in the DBT approach. DBT has a strong behavioural foundation; it is also an empowering approach that gives control and responsibility back to the individual.

For DBT to be accessible for people with ID, some adaptations are necessary. While the overall structure of the therapeutic package (individual therapy, skills group, telephone coaching and consultation group) and the hierarchy of targets (focusing first on life-threatening behaviour) are still applicable, the language used in both verbal and written communication and the format of the skills training need to be significantly modified to accommodate the needs of people with ID. Care needs to be taken to check that people fully understand the basic concepts such as what is a thought, emotion or behaviour and to take into account cognitive deficits such as poor memory, lack of a concept of time and limited capacity for abstract thinking.

Adaptations include:
- re-naming skills training modules (for example Managing our Feelings instead of Emotional Regulation),
- shortening the length of skills group from 2 ½ hours to 2 hours or less,
- simplifying and breaking information down into chunks,
- using pictures in diary cards,
- greater use of role play,
- more emphasis on practical mindfulness exercises (mindful walking, blowing bubbles, listening to music etc.),
- presenting material visually, and
- repeatedly checking for understanding.

Evidence base for dialectical behavioural therapy

There are examples in the literature of adapting DBT for people with ID, although the evidence base in this client group is limited. Also it is notable that applications with people who have ID have extended beyond BPD to working with people who present with behaviours that challenge or offend.
Case studies

Dunn and Bolton (2004) report a case study of a man with ID in a medium secure unit who was threatening to stab people. The DBT formulation assisted in understanding his emotional distress and underlying difficulties in regulating emotions.

Case series reporting outcome data

Lew et al. (2006) describe an adapted DBT programme for eight women with ID ranging in age from 25 to 61, five of whom also had a diagnosis of personality disorder. All of the women had been identified as ‘multi-problem’ individuals presenting with risks in the community. Data was collected using 22 relevant items from the Youth Risk Behaviour Survey which included questions about safety and violence, self-harm, substance misuse, eating disorders and risky sexual behaviour. Seven of the eight women completed the DBT programme. Data was collected by a consensus of team members at the centre where the DBT was provided at four data points: baseline, 6 months, 12 months and 18 months. Although at the 6-month point there was some indication that risky behaviours had worsened (30% of the 22 items rated at baseline had improved, 22% stayed the same and 54% got worse), improvements were noted at 12 months (60% of the items improved, 22% stayed the same and 18% got worse) with this pattern being maintained at 18 months. Lew et al. (2006) particularly noted the ‘slow but gradual reduction’ in self-harm, with six of the women engaging in self-harm in the 6 months prior to baseline decreasing to two at 18 months of treatment.

Sakdalan et al. (2010) conducted a pilot study evaluating the effectiveness of a DBT group skills training programme adapted for offenders with ID. Five men and one woman completed at least nine sessions of a 13-week programme. The group aimed to address the emotional and behavioural difficulties associated with offending and challenging behaviours, and focused on quality of life and therapy-interfering behaviours rather than self-harm or suicidal behaviours. Measures used included the Short-term Assessment of Risk and Treatability Scale (START), the Vineland Adaptive Behaviour Scale, the Health of the Nation Outcome Scale for People with Learning Difficulties (HONOS-LD), and incident reports. Significant improvements were reported from a few weeks before the group started to a few weeks after individuals finished the programme on the HONOS-LD and on both the risk and strength domains of the START. Sakdalan et al. (2010) describe the results as promising, while acknowledging the small scale of the pilot study.

Open trials i.e group studies reporting pre post data

Morrissey and Ingamells (2011) have been running a DBT programme since 2004 for male offenders with ID in the National High Security Learning
Disability Service. The programme includes weekly adapted group skills training (consisting of about 60 sessions) and weekly individual therapy. Telephone skills coaching and ‘consultation to the patient’ are necessarily excluded from the treatment programme because of the nature of the setting. Morrissey and Ingamells (2011) reported that 25 men had completed all skills modules at least once and most had also received individual therapy. There were no drop outs from individual therapy in six years. Outcome data including a variety of self-report and informant measures were collected but were reported to be difficult to analyse because of the varied treatment doses and difficulty of separating out effects of DBT as opposed to other treatments occurring at the same time (such as medication and offence-focused programmes). Preliminary outcomes based on data for six men found significant reductions on the Global Severity of Distress Scale of the Brief Symptoms Inventory but no significant differences in incidents of aggressive behaviour (although rates were already low at the outset for most of the men). Compared with a waiting list control group (n=5), participants in the treatment condition were more likely to be moved to provisions with lower levels of security.

Brown et al. (2013) devised an adapted DBT skills training programme which they called the Skills System or DBT-SS for individuals with ID and a history of severe problem behaviours such as aggression, fire-setting, sexual offences and self-harm. They reported pilot study data on 35 men and five women, 82.5% of whom had an IQ of 70 or below, who took part in the treatment (no comparison group was used). Many of the participants had been hospitalised or in secure services in the two years before joining the DBT-SS programme. Data were collected over several years and included behavioural data categorised according to intensity as ‘red flags’ (behaviour such as yelling and swearing), ‘dangerous situations’ (verbal outbursts, slamming doors and threats) and ‘lapses’ (violent and illegal behaviours such as aggression and self-injury). Large reductions were found in problem behaviours during treatment with statistically significant reductions reported for all three categories in the first year and improvements being maintained over four years. Results suggested that DBT-SS would be more helpful in reducing behaviours that challenge, for those who were younger and who had BPD, engaged in self-harm or aggression. The authors note the dramatic reduction in admission to psychiatric hospital, secure settings and out-of-state residential treatment during the course of the DBT-SS programme.
User views

Qualitative data from five people with intellectual disabilities who were accessing an adapted DBT programme (Hall et al., 2013) suggested a number of positive outcomes including positive change, enjoyment and continued use of DBT skills following the end of the group programme.

References


Chapter 7

Solution-focused brief therapy

*Helen F. Lloyd, Alasdair Macdonald and Lauren Wilson*

**Introduction to solution-focused brief therapy**

Solution-focused brief therapy (SFBT) covers the terms solution-oriented work, solution-focused practice, thinking, consultation and coaching. SFBT is described by Sundman (2012) on behalf of the European Brief Therapy Association (EBTA) as:

- client-centred and -directed

- interactional because therapists use language carefully to help clients re-construct problems and solutions

- competency-based - meaning that SFBT focuses on resources, strengths, abilities and successes and then aims to transform them into skills and competencies

- future-oriented because it helps the client describe a detailed vision of their preferred future.

- Goal-directed.

Developed largely by de Shazer, (1985, 1988), de Shazer et al. (1986), O’Hanlon & Weiner-Davis, (1989) their colleagues and their clients at the Milwaukee Brief Family Therapy Centre in the USA in the early 1980s, SFBT is a relatively new and pragmatic therapeutic approach. The developers recorded and observed substantial amounts of therapy, examined the questions asked and clients’ responses. The questions that most often led to clients thinking, talking about or reporting solutions and progress were incorporated into the approach. Those that did not were excluded. Hence, the therapists and their clients identified the elements of therapy they thought most useful to the client. The therapists did more of ‘what worked’ and less of ‘what didn’t work’ to develop the approach. This development work continues (e.g. Miller & de Shazer, 2000 and Piercy, Lipchick & Kiser, 2000, De Shazer & Dolan, 2007). Each session is designed so that it can stand-alone and be of some value to the client even if he or she attends only once.
Inevitably, the original therapists' theoretical and clinical backgrounds influenced the development of SFBT; these included the philosophical ideas of Wittgenstein, the work of Milton Erickson, therapists from The Mental Research Institute in Palo Alto, strategic and systemic family therapy and brief narrative therapies. SFBT is considered post-modernist in that it does not try to replace previous models or theories but integrates and builds on them. The SFBT approach makes some assumptions, as outlined in Table 1.

<table>
<thead>
<tr>
<th>Table 1. SFBT assumptions.</th>
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<tbody>
<tr>
<td><strong>Problems and solutions are subject to an individual client’s perception and interpretation.</strong></td>
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<tr>
<td><strong>Language constructs and re-constructs both problems and solutions.</strong></td>
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<td><strong>The solution is not necessarily related to the problem.</strong></td>
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<td><strong>The client’s goals are central.</strong></td>
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<td><strong>An emphasis on the past, diagnosis and details of the problem are not essential.</strong></td>
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<td><strong>There are occasions when problems are less or absent (exceptions).</strong></td>
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<tr>
<td><strong>Practitioners believe that clients can make changes.</strong></td>
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<td><strong>Small changes can have an important impact.</strong></td>
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<td><strong>Resistance is not a useful concept, clients co-operate in different ways. The clients have expertise on what is helpful and unhelpful.</strong></td>
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The EBTA (Sundman, 2012) has created a practice definition of SFBT that captures the elements of the intervention and the evolving nature of the approach. It states ‘we make no claim of ownership or copyright.... Solution Focus should remain open for all. We also believe that the Solution Focused Practices will develop further.’ To enable research and meaningful comparisons across outcome studies, the EBTA (Beyebach, 2000) also created a research definition or protocol. This is prescriptive, to a point, as it has minimal requirements and some questions must be asked in a specified format or verbatim. It advocates that a specific therapy model must be used (de Shazer, 1988,).

**Common features of SFBT interventions**

**Language**

The client’s language is used by the therapist. In SFBT, language also reflects two important ideas:
a) problems and solutions are subject to individual’s perceptions of them, and
b) there are times when problems are less intense.

In this way, ideas of hope, that problems are transient or have potential to be different or perceived differently, are introduced. For example, ‘I am depressed’ may be paraphrased as ‘You say you feel depressed at the moment’ or ‘How does depression show itself?’

Exceptions, pre-treatment change and problem-free talk

The therapist enquires about areas of the person’s life that illustrate competence, strength and resources. An interest is taken in steps the client has already taken to address their situation and the therapist is curious about times the problem is absent or less intense. The approach does not ignore problems, adversity or difficulty if the client raises them. An empathic stance is combined with curiosity about resources, coping and resilience, e.g. if a client describes adversity the therapist may respond with ‘That sounds tough. How have you coped?’

Hypothetical future

SFBT aims to shift attention to the life the client would like to lead. The client is asked to imagine a desired hypothetical future, to imagine a time beyond their immediate problems. de Shazer (1988) designed the ‘miracle question’ for this purpose, and it is this form of words that is recommended in the EBTA research protocol.

‘Suppose that one night when you were asleep there was a miracle and this problem was solved. The miracle occurs while you are sleeping, so you do not immediately know that it has happened. When you wake up what are the first things you will notice that will let you know there has been a miracle?’

In the practice definition, the client’s vision of his or her preferred future may be elicited in a variety of ways, often capitalising on the language the client is already using. The therapist then asks what the client will notice is different and what others might notice about the client. The client then describes a future in which the perception of problems or the problems themselves are less intense. Hypothetical futures sometimes involve others changing and clients are reminded that the miracle happened to them alone.

Rating scales

Rating scales from 0-10 are created where 10 is the day after the miracle/preferred future. The client positions the present on the scale. Questions follow and the client describes different parts of the scale. The therapist is curious about how the client got so far, what is preventing him or her sliding backwards on the scale and if there are any times when he or she is
at a different point on the scale. Another strategy might be to explore what a 0.5 move forward on the scale would look like. Scales may also be used to indicate how confident the client feels in working towards the goal.

**Goals**

Goals are elicited from the clients. The goals are small, observable and positive, i.e. the presence of behaviour rather than the absence of something.

**Breaks, tasks and compliment**

The therapist may take a break to consult with a reflecting team. Compliments are given; usually observations or reflections about exceptions, strengths, resources and motivation. Inter-session tasks often include observing exceptions, experimenting with doing more of what works or doing something different from usual when the problem arises. If the client has not completed the inter-session task, the therapist may suggest that the client perhaps wisely prioritised other things in life or that perhaps the client judged that the task or the time were not right.

**Closing the session**

The therapist seeks the client’s opinion on whether there should be another session, if so how distant in time, where and when.

**Adaptations to SFBT in services for people with ID**

SFBT is used in a variety of ways in services for people who have ID. There is face-to-face work with a therapist and a person who may engage alone or with a parent, paid carer or teacher involved to varying degrees as a supporter. There are also those, often with little or no language, who receive therapy ‘by proxy’, when a parent or carer seeks help on their behalf or seeks help for themselves as the carer to manage a situation. This is often called solution-focused consultation. Finally, there is solution-focused coaching in which SFBT is taught to staff to change interaction styles and thinking within an organisation, e.g. a care home. The core assumptions of SFBT and adaptations to the approach for each of these groups are considered below along with some notes of caution.

The core assumptions of SFBT described in Table 1 do not need to be changed when working with people with ID. However, some beliefs about people who have ID may be challenged by the model. Bliss (2012) reflects on how humbling it is to realise that a client who was previously seen as institutionalised, limited and problematic can be seen as having huge resources and strengths; the resilience to have survived the trauma of long-stay institutions while remaining cheerful, determined and kind. It raises the question ‘how did that happen?’ which leads to conversations about resilience. Acknowledging the client’s expertise when that client has an ID may also be a
challenge to therapists and support staff but once it is acknowledged, true collaboration can occur. Sometimes a therapist can think it is unethical to withhold expertise or wishes the client to make an informed choice. Bliss (2012) advises taking a ‘one down’ position of curiosity; collaborating rather than directing. Suggestions may be framed with ‘your story reminds me of a client who did x. I don’t know if this would work for you but maybe you’d like to experiment with this and tell me about it?’ Or ‘The books say x helps a lot of people, I wonder if this would be helpful or unhelpful for you?’

**Face-to-face therapeutic work**

Adaptations to the approach for people with mild ID, who use spoken language, mostly focus on simplifying language and using visual aids in ways that will be familiar to most practitioners in the field. The area that requires most consideration is the hypothetical future or the ‘miracle question’.

It is generally helpful to use short sentences, commonly used words, and visual material or signs to back up speech or to use items such as a sand timer to show the passage of time. Some people, often individuals with Autism Spectrum Disorder, have expressive language that exceeds receptive language skills, which can result in an over-estimation of their comprehension. A speech and language assessment can helpfully inform the therapist, so that the therapy is pitched to the client’s receptive and expressive language skills. Focusing on the present rather than the past can be helpful to those with poor memory recall. In addition, focusing on concrete, observable details of everyday life can be helpful for individuals who find abstract concepts difficult to understand.

Raffensperger (2009) discusses factors associated with good outcome in therapy for people with ID. He suggests that using the client’s resources, e.g. tenacity, is more important to therapy than technique. The SFBT focus on strengths, resilience, exceptions to the problem and compliments, draws attention to competencies. This may be quite alien but helpful to people with ID who have had years of ‘problem-focused’ narratives about their lives. An adolescent with Autism Spectrum Disorder described in Lloyd and Dallos (2006) literally voted with his feet, joining the room and conversation as compliments and exceptions were discussed but wandering out at other times.

The hypothetical future is perhaps the most challenging part of SFBT when working with people with ID and Autism Spectrum Disorder. Individuals who are very literal have difficulty with abstract concepts and imagining the future, and can have a single-channel attentional style in which one small detail is focused on rather than the whole picture.

Despite these apparent difficulties, Bliss & Edmonds (2007) demonstrate in a book on SFBT and Asperger syndrome that the approach can be used with
individuals with Autism Spectrum Disorder although alternatives to the miracle question tend to be used. Indeed, the majority of articles which deal with using SFBT with people with ID, report asking alternatives to the ‘miracle question’. Roeden et al. (2009) suggest asking ‘What will it be like when the problem is solved?’; ‘What are you wishing for?’; ‘What will you be doing on a really good day?’.

Clients may choose to draw pictures or bring pictures of people to sessions who may represent their difficulties or preferred outcomes.

Rating scales and goals can readily be adapted for people with ID and will be familiar to therapists working in the field. Stoddart et al. (2001) and others have simplified the 10-point scale to a 3-point scale, and used line drawings of facial expressions, building bricks, pictures of ladders, thermometers, stepping stones or circles divided into portions, and collages of preferred futures or self-portraits (Roeden et al 2009, Roeden & Bannink 2007).

The inter-session task is probably best not referred to as ‘homework’ which is likely to have negative connotations for people with ID. There may also be issues with remembering the assignment or practicalities in carrying it out.

Stoddart et al. (2001) suggested that modified SFBT was most successful for those who were more able, self-referred and were supported in the therapeutic process by others. Clients with fewer presenting problems and whose problems were related to self-esteem, family and loss were perceived to have better outcomes by their clinicians. When people with ID access SFBT with the assistance of a trusted supporter or carer, some adaptations are necessary to engage the carer constructively. Bliss, in Raghavan and Patel (2005), reflects on how this can be complex when what the client wants contradicts what the referrer or carer thinks ‘would be best’. As long as the client’s goals and carer’s goals are not mutually exclusive, it is possible for both parties to have their own goals. If the goals are incompatible, the client’s goal remains paramount and the carer’s task becomes finding ways of accepting and valuing this. Sometimes a parallel joint goal or an agreed quid pro quo can be negotiated.

**SFBT with support staff or parents**

Therapeutic work can be carried out with the carers, e.g. Rhodes (2000) or parents (Lloyd & Dallos, 2006, 2008). Little or no adaptation is required to the approach for this, although the ‘miracle question’ remains controversial. Overall, SFBT contains many elements that the literature suggests are helpful to parents caring for a people with ID. Knox et al. (2000) report that parents find it helpful when professionals acknowledge that caring can be a positive, gratifying and personally enhancing experience. They also indicate that for
parents a vision of a promising future helps to create a sense of control over family life.

**SFBT with people with ID who have little or no language**

For this group, the adaptations to the approach are so great that it is better described as an intervention informed by solution-oriented thinking. Behavioural observations can focus on exceptions to a problem or after a functional analysis has been conducted. Observations can focus on naturally occurring, adaptive behaviours that the client uses to meet his or her needs (e.g. Bliss, 2012). Behavioural records can be used to better understand exceptions to the problem by examining setting events, interactional styles, antecedents and consequences or posing the question ‘what helps this client be so good?’.

Murphy and Davies (2005) used ‘self-modelling’, a competency-based intervention in which the client, a boy with ID, watched videotape of himself engaged in desired behaviours, and used sign language, rather than acting out, to communicate.

**The evidence base for using SFBT in services for people with ID**

Because SFBT is a relatively new therapeutic approach which has only very recently been adapted for people with ID, the evidence base for its use is still emerging. Exploratory studies have been cautious and have excluded high-risk individuals. For example, Stoddart *et al.* (2001) and Roeden *et al.* (2014) excluded people with ID who required more than psychotherapy, had ongoing serious mental health concerns or a risk of suicide or homicide, and cases in which a long-term intervention was indicated or where there were multiple problems. Therefore, the evidence base, where it exists, is not robust enough to generalise findings to complex situations with people with ID. Situations in which the approach may be contra-indicated will become more evident as more outcome studies are published about SFBT and people with and without ID.

The evidence for using SFBT is presented for a) face-to-face therapeutic work with people with ID with verbal skills; b) face-to-face work for people with ID who have little or no language; c) use as a consultation tool with carers, and d) for use as a training tool with carers.

**Case studies /descriptions/qualitative research on process**

for anger management. He was seen, together with his support worker, by a clinical psychologist for five sessions of SFBT lasting between 60 and 90 minutes each over an 11-month period. Much of the first two sessions was spent in ‘problem-free talk’. Some time was spent identifying characteristics of problem situation so that exceptions could be explored, i.e. high-risk times when the client had not become angry. The client looked at his preferred future and scaling questions were used. Between sessions, ‘Dave’ spoke to significant others about what he found helpful and unhelpful in controlling his anger. He also reported how he had dealt with new, provoking incidents, and received positive feedback. The author noted that for this particular client, the most helpful technique was finding exceptions to the problem behaviour and doing more of what helped to create those exceptions. He also noted that spending time discussing the client’s strengths, and the present and future helped ‘Dave’ to remain engaged. In this case, Smith sensed that a discussion about problems may have embarrassed the client to the point that he would not return.

Case studies of direct SFBT work with those people with ID with little or no language are emerging. Bliss (2012) describes using SFBT principles with ‘Beth’, a resident in a home for people with Autism Spectrum Disorder. She self-injured, engaged in flicking, rocking, screaming and playing with saliva. As ‘Beth’ did not speak, staff voiced the preferred future for ‘Beth’ and gave examples of times when she responded positively. Exception-seeking was combined with behavioural observations of ‘exceptions’ and intensive interaction techniques as described by Firth (2006).

For those with little or no language, solution-focused consultation can be carried out with their carers or family members. Lloyd and Dallos, (2006, 2008) described the use of SFBT as a first session tool with mothers who consulted a clinical psychologist about their children with moderate to severe ID and behavioural or emotional difficulties. A thematic analysis of seven initial sessions was conducted. Pre-treatment change, exception and coping questions led to pictures of remarkable, skilled, committed parents who were proud and stoical. The mothers discussed problems alongside strengths and solutions. The ‘miracle question’ led to a change of pace. Six of the mothers described a miracle in which the child would no longer have the disability. It seemed that ‘wishful thinking’ allowed the mothers to reveal covert hope and this was accepted as a part of their thinking and coping. Alternatives to the ‘miracle question’ yielded fuller replies and details of a desired future. Initially, these were vague but became more specific and concrete with prompting. The mothers integrated the scale and numbers into their conversation. The scale seemed to hold the hope of the miracle, and more realistic possibilities, as well as capturing the present reality. The mothers began to put ‘wishful thinking’ aside and created a narrative in which they made change happen. They began to problem solve, identifying more
exceptions and building on them. They also began to identify strategies that worked. Goals about managing the children’s difficulties were set. Some of the mothers revisited exceptions at this point in the session; they seemed to need to do this before moving on to the inter-session task. It was as if the mothers’ self-efficacy needed to be underlined. Compliments were given to the mothers and inter-session tasks were generated collaboratively. Often, the mothers complimented themselves and their children at the end of the session without prompting from the therapist. It seemed to the researchers that SFBT created a collaborative working alliance in which the mothers perceived themselves as resourceful agents of change. Future research could usefully look at locus of control as an outcome measure.

The reader is invited to judge whether the approach might be useful in their own practice from the detail provided. This seems to mirror the development and practice of the SFBT approach, in which there is exploration of what works and an invitation to others to try and find what works for them and their clients.

**Case studies with outcome data and single case experimental designs**

As we have described, in the SFBT model, self-rating scales are used at the initial and subsequent sessions. Despite this in-built data, there are few published case studies with outcome data. Murphy and Davis (2005) presented an empirical case study of a nine-year-old boy with moderate ID who had a repertoire of 12 sign language signs but tended to communicate by pointing, grunting, shouting or hitting. The intervention aimed to increase expressive communication by more signing. In the intervention, the boy was shown video clips of himself when he did use signs, i.e. self-modelling the exceptions. The context in which these exceptions occurred was explored. The mean percentage of 10-second intervals during 10-minute observation periods in which he signed increased from 23% in the baseline to 71% during the intervention, and at one-month follow-up, signing was still evident in 64% of the intervals.

Rhodes (2000) described SFBT as a consultation tool in eight sessions over six months with care staff who consulted a clinical psychologist about a 36-year-old female client with severe ID who engaged in severe regurgitation. The ‘miracle question’ was not asked; instead staff were asked ‘What arrangements would be ideal?’ for the client. At the outset, regurgitation occurred with a frequency of 1.34 episodes per day with only three days with no regurgitation. By the eighth session there had been no regurgitation for four weeks. The author found SFBT a useful approach to help carers generate solutions which built on their competencies.
The nature of these two studies means that factors other than SFBT could be at work and account for the successes.

**Case series reporting outcome data**

Roeden *et al.* (2011a) undertook a series of case studies with outcome data for 10 people assessed as having mild ID who lived semi-independently and received individual support from paid support staff. The issues leading to engaging in SFBT included alcohol abuse, anger, bereavement, depression, sleeplessness, low self-esteem and avoidance/anxiety. Each participant participated in five sessions of SFBT over a 12-week period. A member of support staff was always present in sessions. Measures were taken of: a) quality of life, b) maladaptive behaviour, c) goal attainment according to the client with ID and goal attainment according to the carers. Measures were taken before SFBT began, after SFBT and at a 6-week follow-up. Statistically significant improvements were found on the composite measure of quality of life and behaviour (and this was maintained at follow-up). Clients’ own ratings of goal attainment and that of their carers indicated that seven of the ten clients attained their goal, and this was sustained at follow-up. For the remainder, progress towards goal was made.

In a similarly constructed case series study, Roeden *et al.* (2012) looked at solution-focused coaching of care staff who worked with people with ID in the severe and moderate range. Thirteen teams of care staff, comprising 42 female staff members, took part. They provided care in residential or vocational settings; 95% had undergone three years professional training, e.g. in nursing or occupational therapy. The staff received solution-focused coaching with up to three sessions over a nine-week period. The ‘miracle question’ was asked on occasion but at other times alternative means of eliciting a vision of a positive future were used, e.g. ‘Suppose we make a video showing the most desirable support situation. What do we see and hear on this video?’. Measures were taken directly before and after SFBT and six weeks afterwards. Measures were: a) progression towards the goal (Bannink 2010); b) proactive thinking using the staff-client interactive behaviour inventory (Willems *et al.* 2010); and c) the Student-Teacher Relationship Scale (Koomen *et al.* 2012).

Progression towards the goal was shown to be substantial for seven teams, smaller for four teams and hardly perceptible for two teams. The mean increases on the progression towards the goal scale, proactively thinking and student teacher relationship were statistically significant. The authors concluded that SFBT can be a useful tool to build relationships between carers and people with ID.
Controlled trials

Roeden et al. (2014) conducted a controlled trial in which they provided SFBT to 20 people with mild ID. A control group of 18 people with mild ID received care as usual. The two groups were similar in terms of IQ, age and scores on the Reiss maladaptive behaviour scale (Reiss, 1988). People with severe psychiatric conditions were excluded from the study. Care as usual involved staff support in semi-independent living accommodation. Staff provided practical help, e.g. with cooking and problem-solving social and emotional issues. The SFBT group received the same support but in addition received six sessions of SFBT with a therapist. The clients were supported by a member of staff. Measures were taken prior to therapy, at the end and at six weeks’ follow-up for both groups.

Eighteen individuals in the SFBT groups completed therapy, of which 13 made clinically relevant progress towards their goals, measured by more than two points progression on the rating scales used in the therapy. At follow-up, this figure had increased to 14. Immediately after therapy, the SFBT group scored significantly better than the care-as-usual group on measures of psychological functioning, social functioning, maladaptive behaviour, and this was maintained at six-weeks’ follow-up.

In a similarly constructed study, Roeden et al. (submitted for publication) provided solution-focused coaching (SFC) for 18 teams of direct support staff (n = 45) who were experiencing a problem with a client with ID, e.g. aggression. Twenty six control teams (n = 59) received coaching as usual from a psychologist adopting an expert model approach, suggesting solutions and problem-solving. The SFC and control group were similar in terms of age, experience and clients supported. Measures were taken before, after and at six-weeks’ follow-up for both groups. The SFC group showed statistically significant improvement on the scales measuring proactive thinking and quality of relationships compared with the control group.

User views

A number of the studies described above consider user views. Roeden, (2011a) sought participants’ views using the Session Rating Scale (Miller, Hubble and Duncan, 1996) adapted for people with ID. Feedback from the clients was generally positive.

Stoddart et al. (2001) asked clients with mild ID and their carers to take part in a satisfaction survey by telephone six months after therapy was completed.
This in itself raises questions about the reliability and validity of the results if the people with ID had difficulties with memory or abstract concepts. The mean scores for SFBT clients was compared to two groups: a) mental health patients who provided the norms for this measure; and b) people with ID receiving long-term psychotherapy from the same service. The three groups expressed similar levels of satisfaction.

Lloyd and Dallos (2008) sought the views of seven mothers who participated in SFBT initial sessions regarding their child with ID. Two weeks after their session, mothers were interviewed using the helpful aspects of therapy questionnaire (Llewelyn, 1988) and structured recall (Elliot & Shapiro, 1988), i.e. parts of the session identified by the mothers was located on an audio tape of the session, and listened to in order to prompt recall and discussion by the mothers. The interview was recorded and transcribed, and a thematic analysis was conducted using interpretative phenomenological analysis (Smith, 2003).

Three themes emerged from the mothers’ accounts:

1) SFBT amplified or brought to mind a stance of ‘making the best of it’. This involved choosing how to appraise the situation - taking the position either of a victim or of someone who would ‘make the best of it’. ‘Making the best of it’ also involved looking to the future, hope, self-efficacy and self-worth.

2) The SFBT sessions led them to examine ‘wishful thinking’. This was complex - the ‘miracle question’ was reported to be the least helpful aspect of the session. While some revealed that they held covert hopes for a miracle ‘cure’, they went on to explain that change happened because of them and their efforts. In other word, a narrative which reinforced their sense of self-efficacy emerged. The ‘miracle question’ was distinguished from the vision of the future and scaling which were perceived by all mothers to be the most helpful aspect of the intervention.

3) The third theme in the mothers’ accounts was the therapeutic relationship. They valued time to think and feel hopeful. There was some disappointment that the therapist was not a directive expert, echoing the covert hope for a miracle ‘cure’. Yet alongside this, they valued the collaborative nature of the therapeutic alliance in which their expertise and ability to create change were amplified.

Some authors have noted that SFBT components are similar to those that are associated with good outcomes in therapy or are helpful for people with ID. Roeden et al. (2011 b) sought the views of 17 people with ID on factors that contributed to a successful working relationship with their support staff. The nominal group technique was used to generate individual ideas, and then list, clarify and rank the ideas. The highest ranking ideas included: 1) listens well,
takes me seriously, or asks questions; 2) makes time for me; 3) is reliable; and 4) lets me do things myself or solve them myself. Once ideas had been generated, the question was asked: ‘To what extent do the opinions... correspond with the core assumptions of SFBT?’ The authors concluded that the views of the people with ID did correspond with the core assumptions of SFBT, although these ideas are also relevant to a number of other counseling and psychotherapeutic interventions.

**Conclusions**

SFBT is emerging as a way of working therapeutically with people with ID. A key piece of feedback from clinicians, clients and parents is a preference for alternatives to the ‘miracle question’ to elicit a vision of a preferred future. The approach, because it is derived from helpful aspects of therapy, has high face validity and corresponds with factors identified as helpful in therapy for people with ID. Whether SFBT increases self-efficacy or locus of control is an interesting question and is worth considering in future research. The clinical studies, evaluations, outcome studies and controlled studies, while limited in number, do seem to suggest that SFBT is as effective as other approaches but may be briefer than some psychological therapies, therefore providing outcomes more efficiently. However, clinical studies with outcome data and more controlled trials are needed before SFBT can be used with confidence with people with ID.

**References**


Introducing systemic psychotherapy

We live our lives in relationship. Our identities, and our resources for responding to life events, are shaped and sustained by those we are close to. When we experience a crisis, significant people in our lives are affected too; and their responses in turn, affect us (Bownas, 2014). When a family have a son or daughter with disabilities or ID, this will have a very significant effect on all, and their responses and actions in turn will affect and shape the life of the person with ID. This creates a ‘human system’, and so, when we use the word systemic, we refer to the fact that our living is always in relation to others. We may define or punctuate a human system in different ways. For example, we may focus on a couple, a family, a network of professionals, an individual and his or her significant relationships, and so on. It is precisely because of this broader scope that the term ‘systemic therapy’ has increasingly been used in preference to ‘family therapy’ with which it shares a common history.

There have been many developments within the systemic field and different traditions of systemic practice since its inception in the 1950s. It is outside the scope of this chapter to provide a comprehensive overview of the development of systemic approaches. However, Vetere and Dallos (2003) provide a good introduction. Suffice perhaps to emphasise that the systemic approach developed out of dissatisfaction with the limitations inherent in psychological models where there was a predominant or exclusive focus on the individual, with little or no reference to the wider system of which he or she was part. For example, it is well known that people with ID can be particularly vulnerable to an assumption that problems are located within them, and the contributions of the wider networks or systems of which they are a part are frequently ignored. What we particularly appreciate about the systemic approach is its focus on context, relationships, communication and interaction: that is, what is happening between people rather than within people, since this moves us away from pathologising individuals and towards viewing concerns and predicaments as interpersonal (Fredman, 2010).
Systemic therapy approaches seek to explore the network of significant relationships of which each individual is part. In doing so, they consider the beliefs that give meaning to people’s actions, and the communication patterns between people as they interact both with each other and with each others’ ideas. Systemic therapists have highlighted that family transitions sometimes create challenges, which can, but need not, have long-term repercussions (Carter & McGoldrick, 1989, and Hedges, 2005). Carter and McGoldrick (1989) describe a sequence of life-cycle transitions that may create stressors within a given system or family as individuals reorganise and negotiate change, such as birth of a child, going to school, leaving home, family illness and death. How families/people cope at different stages will depend on what life-cycle issues each member faces at that time. For example, an adult with ID may want to move home to become more independent at the very time that a parent wants companionship, perhaps because of widowhood. A family member may experience and present with difficulties if the family cannot adapt or negotiate this new transition. A particular challenge for many families with a member who has ID, is that transitions are often out of synchrony, e.g. they often happen at a later time than for their similarly aged peers (Vetere, 1993). This, in turn, means that many aspects of normative developmental frameworks provide relatively little relevant guidance to family carers and can result in an increased sense of isolation or bewilderment. It is at times like this that systemic therapy with a family may be particularly useful.

One key aspect that specifically distinguishes systemic psychotherapy from other therapeutic models, is the engagement in therapeutic conversations with more than one person (often with many people in the room). This requires particular skills and expertise by the therapist in being able to facilitate and conduct conversations that are useful and include all of the people in the room. While talking with the family, the therapist often uses circular questioning, a form of questioning intended to generate information about relationships: relationships between people; relationships between people and contexts; and relationships between meaning and action (Tomm, 1984). Through circular questioning, family members are invited to consider their relationships and dilemmas in new ways. It is intended that clients become observers of their own thinking, actions and contexts in the process of considering their answers to systemic questions (Fredman, 2010).

A second distinguishing feature of systemic psychotherapy is the use of a team to assist in the development of multiple perspectives; this may lead to more ideas being generated that may be of use to the system in focus. Before meeting with the family or staff team who have been referred, the therapy
team come together to develop some initial hypotheses about the referral and the family or teams attitudes and feelings to help being offerred (Reder & Fredman, 1996). Hypothesising is intended to generate a repertoire of ideas that the therapist can use to facilitate the therapeutic relationship. The therapist will then interview or talk with the family or people in the room, while the rest of the team (usually one to three people) will be listening to the conversation. After a while, the therapist will take a break and the team will offer their ideas and reflections while the family or staff teamisten. Thus this team play a different role to the therapists (this method is referred to as the ‘reflecting team’). Families and staff teams often comment that they like to hear the ideas of many people as this offers more possibilities for change. (For more information on reflecting teams, see Andersen 1991; 1992.)

The use of the systemic approach where a member has ID, has evolved gradually over the last 20 years. It has wide applicability in a context where clients are part of large systems of concern, and it has been amply demonstrated that the systemic approach and its associated methods and techniques can be used in shaping many aspects of clinical practice. For example, it can be used to inform conversations and interactions with individuals (e.g. McFarlane & Lynggaard, 2009), with families (e.g. Baum, 2007) with staff teams (e.g. Haydon-Laurelet, 2009) and other networks (e.g. Jenkins & Parry, 2006). It can also be used in supervision and training (e.g. Haydon-Laurelet et al., 2012) and in thinking about referrals in multidisciplinary teams (e.g. Donati et al., 2000).

**Specific adaptations**

People with ID are an heterogeneous group who have varied abilities and needs. The practice guidance that follows consists, therefore, of a number of suggestions that may or may not have a useful fit with the specific circumstances that practitioners will encounter. In what follows, we have concentrated on offering a few suggestions that can be used when a person with ID is directly present in the therapeutic conversations, such as systemic family therapy. Several of these suggestions are further elaborated with specific examples in the book edited by Baum and Lynggaard (2006a). A systemic approach tries to create a space where all of the voices of the people involved including the person with ID, can be heard. It does this by ensuring that everyone has an opportunity to speak in sessions. For a few
people with ID who have relatively good communication skills, only minor adaptations are required. But if we consider that problems with communicating (to various degrees) are inherent in the definition of ID, then particular attention needs to be given to ensuring people can participate in a meaningful way. Standard recommendations include using simplified language and concepts, avoiding jargon, slowing the pace, using pictures and objects to augment understanding, being ever alert to and acting on feedback, regularly checking out that communication has been understood, and enlisting the support or advice of people who know the person well. In addition, Booth and Booth (1996) describe a process of occasionally offering and giving people words in order for them to be able to participate in conversations. This process is akin to the method employed by Hayward (2006) which involves a process that goes from ‘mis-naming to naming’; that is, offering a choice of words as close to what the therapist thinks the person is referring to in order to enable the person’s own description to emerge more readily. For example, the therapist might ask: ‘Would you call that "upset" or "sad" or what?’ That is, questions are used that begin to discern what something is by clarifying what it is not. We should, of course, also bear in mind that people with ID can often say a lot with just a few words, and when they do, we try to pick them up, use them and honour them.

Iveson (1990) has suggested a way of inviting and imagining the voice of a person with no speaking voice that can often be useful when people with severe or profound ID are included in sessions. He does this by asking a series of questions that invite someone to adopt, or to speak from, a different position. As a starting point, he suggests, for example: ‘If Saleha could speak, and if I were to ask her to choose someone to speak for her at this meeting, who do you think she would choose?’ The therapeutic intent in such an approach is to invite people to stand in, and relate to a different position - a position that may otherwise become marginalised. This can open up new understanding and opportunities for action. Anderson (1997) also describes a similar method, known as ‘as if’, where people are asked to listen as if they were a person central to the issue of concern and then after a while they are invited to speak from that position (see Haydon-Laurelet et al., 2012, for a description of this technique in an ID setting).

Other methods and strategies to facilitate conversations and make things more concrete and accessible include: drawing a picture of all the important people in someone’s life, or of all the things that are going well; showing or drawing the size of a worry/problem, which can often be easier to deal with in its externalised form; and writing down and taking notes of important events. Photographs of people and places can greatly enhance and facilitate conversations and understanding.
Finally, enabling the ideas expressed by a reflecting team to be accessible for the people at the centre of the work can present a challenge for all systemic psychotherapists. However, there are a number of practical ways that have can be used to aid understanding. These include: offering just a few comments and prefacing the reflection or comment by the name of the person for whom it is intended (Cardone & Hilton, 2006); writing keywords from the reflections on a flipchart (Haydon, 2008); explaining the process of the team in easily accessible words, and summarising in a letter (Petrie, 2011). When we bear the pertinent question, ‘Who needs to change?’, in mind (Rikberg Smyly, 2006), we may also lessen our concern as to whether the person with ID has understood all that is communicated in the family therapy session as the aim is to change the family system or the staff teams system.

The evidence base for systemic psychotherapy

The systemic approach has been proven to work with many clients group (see Stratton (2010)). However, the use of systemic approaches in working with people with ID has a relatively short history. So far, it has involved few practitioners working with a relatively small group of people and often in isolation from each other. What follows summarises some of the recent evidence for the usefulness and effectiveness of the systemic approach in relation to people with ID and their families; the use of systemic network meetings; and systemic consultations to staff teams.

Case studies

There have been many case studies which describe the use of the systemic approach in practice with people with ID and their families. See for example Goldberg et al., 1995; Fidell, 2000; Cardone and Hilton, 2006; Baum and Lynggaard 2006b; Scior and Lynggaard, 2006; Baum, 2007; mAlso see the special issue on Systemic therapy of Clinical Psychology and People who have intelectual Disabilities, 2012, Volume 10, part 2. In relation to using the model in network meetings or with multidisciplinary teams, descriptions include Donati et al., 2000; Lynggaard et al., 2001; Jenkins and Parry, 2006. Case studies that describe the use of systemic consultation to staff teams include Rikberg Smyly, 2006; Haydon-Laurelut, Bissmire, and Hall, 2009; and Haydon-Laurelut and Numkoosing, 2010.

Case series

In addition to case studies there is one case series by Baum (2006). There are no published group designs or controlled studies so far. Some of the reasons for this are the difficulties in assessing changes in families, as most measures cannot tap the subtle shifts in perceptions and attitudes that are brought about by systemic therapy techniques and interventions. In ID services, the systemic therapy evaluation questionnaire (STEQ) has been developed to help evaluate systemic work (Baum, Scior & Walden, 2007). This measure has not
been formally validated but has been useful clinically in the relative absence of other standardised tools. The STEQ is user-friendly and has been found to be sensitive enough to record changes post-therapy and has elements of the systemic clinical outcomes in routine evaluation (SCORE) tool, which has been developed to be used in everyday practice (Stratton, Bland, Janes & Lask, 2010).

It is important to bear in mind that although little process or outcome research exists, it does not follow that this approach is ineffectual. Lynggaard and Baum (2006) remind us that there is ‘a need to adopt research paradigms that are commensurate with the paradigm informing systemic practice’ (p.19) and talk about the idea of building up ‘archives’ of this practice-based evidence by approaching the process of therapy as co-research with clients. They suggest that this can be done using a number of different media such as letters, poems, videotaped conversations and so on (Speedy 2004). This co-created research should then be made available to others facing similar difficulties in producing cumulative, practice-based evidence of the experiences of working systemically with people with ID.

**User views**

Several research studies have sought to examine views about using qualitative methods of investigation with people who have ID. Arkless (2005) discovered a range of views when she interviewed 10 families who had been invited to participate in systemic family therapy. Some family members saw the therapy as having a positive impact on their views about and ways of approaching the difficulties they were facing. For the participants with ID, there was a general sense that the opportunity to talk about difficulties was seen as valuable. This study has important implications for how the practitioners explain and conduct their sessions. Pote (2004; 2006) and Baum (2010) investigated therapists’ accounts of systemic family therapy with this client group. Rikberg Smyly et al. (2008) asked what colleagues and carers thought about working systemically in community services, and Petrie (2011) asked people with ID about their experience of the reflecting team. Feedback has been positive.
References


A range of models and methods are used in group interventions with people who have ID (e.g. CBT, psychodynamic therapy, systemic therapy and so on). Readers are referred to the descriptions of these models in the relevant sections in this publication.

This section aims to outline the landscape and literature on group interventions with people who have ID, and provide some examples of different types of group interventions. Particular attention is given to group process issues which underlie and enhance the effectiveness of groups.

Introduction to group interventions

The Groups Mind Map in figure 1 (Heneage, Rossiter, Phillips and Gregory, 2012) lists the wide variety of group interventions for people with ID. The content of groups will vary according to their purpose and theoretical orientation. Some group interventions focus on enhancing specific skills and knowledge areas (e.g. social skills groups and educational groups), and some focus on specific life events or target issues (e.g. anger, anxiety, loss and bereavement, or sexual offending). Group interventions are also based on a range of therapeutic models, such as psychodynamic, narrative and cognitive behavioural therapies. Pfadt (1991) notes that in practice many practitioners use ‘pragmatic blending’ (Halgin, 1985) of behavioural/structured interventions with psychodynamic ideas.
Issues of power and group dynamics (e.g. Yalom, 2005) are present in all groups, so they require explicit attention from the start of the planning process, and throughout the running and review of the group. Yalom (2005) and others have identified ‘therapeutic factors’ - processes which can act as powerful influences in the group context, if harnessed appropriately. These include imparting information, developing socialising techniques, instillation of hope, universality, catharsis, altruism, group cohesiveness and existential factors.

A very accessible and helpful text for considering group process issues across different populations is Using Groups to Help People by Stock Whitaker (2001). Some of the key general issues she and others identify include:

the importance of establishing clear boundaries for groups

defining their purposes and remits

selecting group members with care
managing interpersonal conflicts

taking account of general therapeutic factors and processes

making use of supervision

remaining vigilant in relation to the need to manage potentially difficult group processes, such as scapegoating, people who monopolise groups and silent group members.

A number of authors have mentioned key themes that have emerged when working in groups with people with ID. Facilitators need to be aware of and work with these themes. For Hollins and Evered (1990), there were four recurrent themes: death and loss, sexuality, handicap, and independence, with Hollins (1992) also noting an additional theme of trusting others. For Fletcher and Duffy (1993), other common themes were problem-solving, social skills and interpersonal relationships. Gravestock and McGauley (1994) noticed that envy and hostility towards normality surfaced when discussing the painful reality of secondary handicap; a dynamic which needs to be carefully managed. Respondents to Heneage and Neilson’s (2012) survey of (mostly) clinical psychologists who provided examples of group interventions with people with ID highlighted the group interaction as one of the most useful aspects. Razza and Tomasulo’s (2005) interactive behavioural therapy groups make use of psychodrama to promote group processes. They note that these can counteract the isolation and competition for the attention of carers which often operates in settings for people with ID.

In group interventions, particular attention needs to be given to each of the following areas which are dealt with in more detail below:

practical organisation of groups

the role of the group facilitator

confidentiality and the need to involve significant others

addressing the meaning of ID for individuals.
Practical organisation of groups

Recruitment and preparation

Sheppard (2003) notes the need to gain the authority to set up a group from key players in the lives of the potential group members (given their dependence on others). Initial assessments should keep in mind a sense of the group as a whole, trying to ensure that no one person is markedly different in skills and abilities from others. Razza and Tomasulo (2005) highlight the need to screen out people for whom groups may not be suitable, such as those with paranoid or sociopathic tendencies. They favour groups with participants who have a moderate degree of heterogeneity with regard to intellectual functioning and personality, and with similar character styles (Razza & Tomasulo, 2005).

Whittall and Courtney-Brisbane (2012) note that groups which include members with greater impairments may require more facilitators. They recommend having a clear knowledge of the client’s history, needs, risk factors and social context when assessing group members. Hollins (1992) emphasises the need to ensure that people can make clear decisions about whether or not they wish to take part in groups. Therefore, clear, accessible information and consent procedures are needed.

Establishing group ‘structures’

The clinical psychologist groups’ survey (Heneage and Neilson 2012) identified a number of ‘structural’ aspects of groups found to be contributors to their positive functioning. These included:

- an appropriate location (e.g. accessible and with sufficient space)
- having clear and shared group aims and rules
- reminding group members to attend groups
- providing transport for those who need it.

Some survey respondents commented on the value of keeping groups small, echoing Schneider (1986) who found it helpful to reduce group sizes from eight to five people to allow all members to contribute.
The role of the group facilitator

From a psychodynamic perspective, Sheppard (2003) points out the need for facilitators to bear, survive and help make sense of painful projections from group members, feeling that supervision is essential for this. Gravestock and McGauley (1994) note the importance of avoiding the adoption of rescue dynamics, which they say is helped by working with a co-facilitator. Razza and Tomasulo (2005) recommend that facilitators should: be careful not to be too central to the group; work in the here and now; actively work to promote group processes and balance self-disclosure; ensure experiences spoken about/examples given are relevant to the lives of people with ID; and be flexible in their approach. Desnoyers Hurley et al. (1998) note that such flexibility might be needed in relation to a number of areas, such as adjustment of approaches, length of sessions, communication around appointments, need for breaks and changes in routine. Gregory and Heneage (2012) suggest having a 'skeleton' structure for sessions which can be adapted according to the needs of given individuals in a given group session. Pfadt (1991) notes that it may be important to take a more directive stance with people who have more severe disabilities.

Confidentiality and the need to involve significant others

Hollins (1992) points out that issues of confidentiality are complicated, as people with ID may know one another in different contexts and are often supported by others. It would seem important to find ways of involving families and carers optimally in order to enable people to make their way to groups and be supported afterwards. Family and carers may also need to provide support in respect of potential emotional distress following groups, practical issues, and generalising learning from the group context. Noting that there will sometimes need to be communication with carers, Desnoyers Hurley et al. (1998) suggest that the information shared is openly conveyed in the presence of the client. In some groups, it has been found helpful to include members of staff (Rose et al. 2005), although other authors feel that this risks compromising therapeutic independence (Pfadt 1991).

Addressing the meaning of ID to individuals

Szivos and Griffiths (1992) highlight the importance of addressing the meaning of ID to individuals, and stress that this should always be client led. For Desnoyers Hurley et al. (1998), it is important to take an active pro-
disability stance in groups. It seems important to keep in mind the processes and learning taken from self-advocacy groups. Such groups can enable members with ID gain greater awareness of political issues relating to disability (Gilmartin and Slevin 2010, Beart, Hardy and Buchan 2004).

Specific adaptations for groups with people with ID

Groups of people who have ID will require general adaptations for engagement and intervention, which Desnoyers Hurley et al. (1998) summarised as: simplification, language, activities, developmental level, directive methods, flexible methods, involvement of caregivers, transference/countertransference and disability/rehabilitation approaches. Other recommendations and illustrations on adaptations to make groups accessible and effective for people with ID include techniques, materials and helpful ways of working, as illustrated in the suggestions which follow.

Razza and Tomasulo (2005) highlight the value of drama therapy techniques, including the use of role play, which is very frequently mentioned in the literature. They see such techniques as pivotal to enable optimum behavioural and emotional engagement in the light of the cognitive difficulties of participants. The value of visual materials (examples from the media, mindfulness exercises and enabling participants to create something to share with the group) were highlighted by respondents to the Heneage and Neilson’s (2012) survey. The use of concrete objects, props and/or prompts is described by Rossiter (2012) who shows how different objects can assist interaction, comprehension and the development of skills such as relaxation. The creation of materials, such as accessible books with key messages from group sessions, enables participants to remember the group experience and share it with others (Whittall and Courtney-Brisbane, 2012). Generally, there is endless scope for creativity in groups.

When running groups, it is also important to be prepared for, and work with potential challenges, such as those highlighted in the Heneage and Neilson (2012) survey. Some of these challenges include:

- difficulties accessing groups (due to transport considerations or staff shortages)
- group members dropping out
- financial considerations
• meeting the varying cognitive and other needs of group members, and maintaining an appropriate pace and balance to suit them all
• process issues such as scapegoating.

There appears to be little literature relating specifically to groups and people with severe ID.

**Evidence base for the use of group therapy with clients with ID**

Reviews of group interventions with people with ID (Brown, 1994; Desnoyers Hurley *et al.* 1998; Fletcher and Duffy, 1993; Pfadt, 1991) report studies of a wide range of groups, in a wide range of settings, with a wide range of participants (abilities, age, presenting issues), and using a wide range of evaluative methodologies across more than 60 years of service delivery and research. Fletcher and Duffy (1993) suggest that group therapy is an underestimated treatment modality for persons who have ID, and is ‘an effective intervention in work with persons who have a dual diagnosis’ (p. 398), i.e. people with ID and mental health problems. They report group studies over more than 45 years, starting with Cotzin (1948) reporting on behavioural improvement after ten group sessions in an institutional setting. These reviews and the Heneage and Neilson survey of current clinical psychological practice (2012) indicated that groups are evaluated by clinicians and researchers in a wide variety of ways, using a wide variety of measures with participants, carers and other staff before, during and after groups (sometimes with follow-up).

Measures included quantitative tools (34 formal measures are named in the Heneage and Neilson’s (2012) survey found that 34 formal outcome measures were being used including some ID-specific and some general population measures.

The variety of measures and approaches demonstrates flexible adaptation to the different foci of the groups, the number of different tools in existence, the differing abilities of participants, and the differing preferences of practitioners. However, variety also poses the challenge of a lack of commonality across assessment measures, making comparisons of the effectiveness of groups difficult. Because samples and populations, designs, interventions and measures are very heterogeneous, it can also be difficult to judge clinical utility. What works for whom, how group versus individual interventions compare for outcome or cost effectiveness are not easy to distinguish. Understanding other aspects of the published studies, such as
dose-effect factors and/or how to replicate interventions is not always straightforward.

**Case studies/descriptions of groups**

There are published case examples of group work, such as Leaning & Watson (2006) and Hollins & Evered (1990) who describe group therapy with people who have ID.

**Case studies with outcome data and single-case experimental designs**

Oliver-Brannon (2000) compared group-based interactive behaviour therapy (based on Razza and Tomasulo) with behaviour modification in a small sample with non-random assignment. Group participants evidenced greater reduction in target behaviours, increased problem solving skills and earlier return to the community.

Crowley et al. (2008) describe a psycho-education group for eight individuals with a dual diagnosis of mild to borderline ID and psychosis. Measures of knowledge and self-esteem showed an increase in knowledge from pre- to post-group. All participants completed the programme and were able to understand the concept of psychosis, the need for medication, the role of stress and early signs of relapse. Crowley et al. suggest such groups may help participants have a better understanding of their condition and prepare them to cope better.

Douglass et al. (2007) evaluated an uncontrolled CBT-based anxiety management group for six adults with ID with 12 two-hour sessions. Using structured clinical interviews with service users and carers, and the Glasgow Anxiety Scale and Reliable Change Index (RCI; Jacobson & Truax 1991) pre- and post-intervention, they found half of the participants showed improvements while half showed raised scores (i.e. worse post-intervention than pre-intervention).
Case series reporting outcome data (including descriptions of series of groups)

Bender et al. (1992a, 1992b) in two papers on ‘How should we measure the effect of group work with adults with learning disabilities?’ focus firstly on outcome variables and secondly on process variables in their description of a ‘life review’ group of eight sessions based loosely on reminiscence therapy. This group was based on five previous groups of four to nine sessions with 26 participants of whom ‘only 4 .... had verbal IQs of over 60, and 11 had verbal IQs below 50’ (Bender et al. 1992a, p. 2). These group sessions demonstrated sharing of powerful experiences, development of awareness of others having gone through similar experiences and many of the therapeutic factors listed by Yalom (1985) despite their brevity. For the ‘life review’ group, measures included attendance, self- and staff ratings (what was good, liked, learned), evaluation of others (on a scale from physical to more personal, psychological aspects), therapeutic factors, and process (amount of talk amongst participants rather than addressing leaders). Bender et al (1992b). reported the collective experience as more powerful than face-to-face individual therapy.

Stoddart, Burke and Temple (2002) reported a significant reduction in depression scores following a group bereavement intervention for people who have ID. Anxiety and knowledge scores did not change significantly. Those with highest need (higher depression scores, dual diagnosis) showed the most improvement.

Open trials, i.e. group studies reporting pre- and post-group data

Loumidis and Hill (2010) evaluated group social problem-solving skills training (SPSST). They proposed a five-stage, social problem-solving process and detailed outcome criteria for planning and evaluating programmes. They then compared an experimental group of 29 with 17 controls matched to the trained group on age, general intelligence, place of residence, adaptive and maladaptive behaviour. They found statistically significant improvement in the trained group (p < 0.01), but not in the control group, on degree of maladaptive behaviour as rated by independent judges. Improvement was reported only in participants who lived in community settings, but was not influenced by age or level of general intelligence.
Murphy et al. (2010) reported on a year-long group CBT-based intervention for 52 sex offenders with ID from England. Fifteen sets of therapists provided therapy to closed groups in two-hour sessions once a week for the year. Of the 52 participants, 46 remained free of sexually abusive behaviour during treatment with six men showing non-contact ‘offences’. In the six-month follow-up, 45 remained free of sexually abusive behaviour (five men showed non-contact ‘offences’ and two sexual touch through clothing). Re-offending showed no relationship with pre- or post-group scores, IQ, presence of mental health problems, personality disorder, living in a secure setting, being the victim of sexual abuse or having a history of offending. Poor prognosis showed some association with having a diagnosis of autism /Asperger syndrome.

**Controlled trials i.e. group studies reporting comparison of intervention with a waiting list or routine treatment control group**

Controlled studies from the 1950s are reported in Fletcher and Duffy’s 1993 review, where four out of five skills-based group studies demonstrated improvement in the experimental groups. Examples included Yonge and O’Connor (1954) and O’Connor and Yonge (1955) reporting improved communication and social skills, heightened self-esteem, self-control and responsibility, as well as relief from anxieties.

Nicoll et al. (2013) have reported a meta-analysis of six group interventions for anger. Unfortunately, the control groups differed considerably from study to study and so the analysis was limited to pre- and post-group results. However, these were good, with an overall effect size of 0.84. Hagiliassis et al. (2005) evaluated a similar small randomised control trial of a 12 x 2-hour session group CBT-based anger management intervention which also included problem-solving and assertiveness, co-facilitated by two psychologists. They used Novaco’s Anger Scale and the Outcome Rating Scale (Miller & Duncan, 2000) with 14 participants in the experimental intervention and 15 controls. Results showed a significant effect (p<.05) for intervention at completion and p<.01 at four-month follow-up, suggesting effects increase over time.

Willner et al. (2013) carried out a large-scale, cluster randomised control trial of manualised group CBT for anger. The intervention was carried out by support workers in day services. The authors did not find a significant reduction of reported anger on the Novaco Provocation Inventory compared
with a treatment-as-usual group. However, the treatment groups showed positive effects for the use of anger-management skills. Other useful aspects of the study included health economics and intervention fidelity.

McCabe et al., (2006) and McGillivray et al. (2008) compared the outcomes for people receiving an adapted group CBT intervention for depression with waiting list controls. They found significant improvements for the intervention group on self-reports of depression after therapy and at three months follow-up.

**User views**

Macdonald et al. (2003) explored through interview the experiences and satisfaction of people with ID with two psychodynamic therapy groups. Four participants from a sexual offenders' group and five from a women's group participated in interviews which were analysed using Interpretive Phenomenological Analysis. Results suggested participants valued the therapists and the group, and appreciated the opportunity to talk about painful experiences and be included and valued in the group. They also indicated that they found the group emotionally painful, on occasion found it hard to identify with other group members, and were often unaware of any positive change in themselves.

Wilner et al. (2013) also sought information of user views in their study. They found most participants could describe the purpose of the group and valued the opportunity to talk about their problems and share experiences. Participants talked about the coping strategies that they had learned and used successfully, particularly behavioural strategies such as ‘walking away’ or ‘asking for help’. They described improved relationships with peers and staff and expressed a sense of pride in what they had achieved.

**Summary**

This chapter on groups and people with ID has outlined the landscape, literature and evidence across a range of groups with varied models and methods. The vast range of types of groups (participants, models, settings,
foci) and limitations of studies and/or reporting make summarising difficult. The literature demonstrates a long history of group interventions using a range of models, and also integrating models. Positive changes in participants are reported for target problem or goal areas (such as anger, sexual offending, weight loss, knowledge of psychosis), skills learned (such as problem-solving), social interaction, and broader psychological concepts such as self-esteem as well as for processes (such as talking over each other, talking to/through co-facilitator). Some literature shows mixed outcomes, and some identifies the more difficult or painful aspects for participants. There is also some evidence that carer/staff attendance and support may enhance effectiveness. A key finding is that irrespective of the model, method or focus, user-feedback often identifies group process themes as key (Yalom 2005Particular attention to group process issues outlined in this chapter should enrich practice and enhance the effectiveness of all groups.

References


In the *Psychotherapy and People who have Learning Disabilities Report* (Royal College of Psychiatrists, 2004), it was pointed out that the difficulty of establishing a therapeutic dialogue in the presence of ID communication difficulties has often been seen as a barrier to people with intellectual disabilities having access to, or making effective use of, psychotherapy. The report also pointed out that Arts therapists and related disciplines have a long history of working through means of expression other than speech with people who have ID. We have, therefore, included a section on Art, Drama and Music therapies in this report.

**Art Psychotherapy**

Simon Hackett PhD, Art Psychotherapist

Kate Rothwell, Art Psychotherapist

Chris Lyle, Lead Art Psychotherapist

**Introduction to art therapy**

Art therapy is a form of psychotherapy that uses art media as its primary mode of communication for clients. Despite the use of art media, clients are not expected to have particular skills, proficiency or experience in art. Art therapy can offer the opportunity for expression and communication in the context of a psychological therapy to people who find it hard to express their thoughts and feelings verbally (*British Association of Art Therapists, 2012,*).

“In practice, art therapy involves both the process and products of image making (from crude scribbling through to sophisticated forms of symbolic expression) and the provision of a therapeutic relationship. It is within the supportive environment fostered by the therapist-client relationship that it becomes possible for individuals to create images and objects with the explicit aim of exploring and sharing the meaning these may have for them. It is by these means that the client may gain a better understanding of themselves and...
the nature of their difficulties or distress. This, in turn, may lead to positive and enduring change in the client’s sense of self, their current relationships and in the overall quality of their lives.’ (Edwards, 2004, p. 4)

Specific adaptations for people with ID

Art psychotherapists working with people who have ID often use a flexible, adapted and individualised approach in their work. When working with people who have limited verbal communication, adaptation can include using picture symbols and other communication aids within the therapy. Additional communicative techniques such as intensive interaction may also be used. In many settings, particularly in community work, art psychotherapists also pay particular attention to the support networks of the people they are working with. This might include inviting significant people such as family members, carers, support workers, and friends to participate in aspects of the therapy. Ashby (2011) conducted a survey of 60 art therapists working with people with severe ID and challenging behaviour in the UK. Findings indicated that the therapists worked flexibly and used a wide range of theory to underpin their practice, including psychodynamic, client-centred, and behavioural approaches. Despite identifying constraints in many service areas, therapists reported that they thought they had offered a wide range of benefits to people with severe ID and challenging behaviour. The therapists’ perceptions of their effectiveness included factors such as providing safety and containment, empowerment, a thinking space to reflect and process, and an opportunity to develop a meaningful and trusting relationship. Therapists also felt that they had a role in enhancing communication through the development of non-verbal skills by modifying and re-directing challenging behaviour into more positive outlets of expression. The inclusion of art has also been seen to support communication, thinking and self-reflection for people with mild ID. Clients who had undertaken six months of art psychotherapy reported that making a picture that they could then speak about with the therapist helped them to make sense of their own thoughts, feelings and behaviour towards others (Hackett, 2012).
Dramatherapy

Jane Bourne, Dramatherapist
And Lorna Downing, Dramatherapist

Introduction to dramatherapy

‘Dramatherapy is a form of psychological therapy in which all of the performance arts are utilised within the therapeutic relationship. Dramatherapists are both artists and clinicians and draw on their trainings in theatre/drama and therapy to create methods to engage clients in effecting psychological, emotional and social changes. The therapy gives equal validity to body and mind within the dramatic context; stories, myths, playtexts, puppetry, masks and improvisation are examples of the range of artistic interventions a Dramatherapist may employ. These will enable the client to explore difficult and painful life experiences through an indirect approach.’ (British Association of Dramatherapists (Badth) www.badth.org)

Dramatherapy begins with play and the dramatherapist will aim to encourage expression, playfulness, spontaneity and creativity within the safety of a contained space. As a degree of trust becomes established, the session develops according to the pace and needs of the patient to incorporate an embodied experience of metaphor and symbol, often using story and myth.

In a dramatherapy session, clients take on different roles and also witness other roles being played, as an audience might. This experience of ‘the other’ has the ability to promote empathic feeling. Participants are invited to experience emotions that the characters experience yet at the same time are positioned at a safe distance within the narrative.

Adaptions for people with ID

Dramatherapy is a person-centred, non-directive approach in that it works with what is brought into the therapy room and does not follow any specific, session-by-session manual. Its flexible nature makes it particularly suitable for working with people who present with different intellectual abilities. It is action-orientated and, therefore, does not rely exclusively on cognitive or verbal ability, and is often delivered in a series of inter-connected creative exercises which assist in the engagement of those people who may struggle to maintain focus on one thing for any length of time. Dramatherapy sessions work with what the client brings and will usually follow the pattern of: check-in, warm up, bridge in (to main event), main event, bridge out, reflection and grounding.
In dramatherapy sessions with people who have ID, the therapists will remind participants at the beginning of each session about expectations and boundaries. Sessions usually begin with some warm-up exercises, then each member is encouraged to show how they are feeling by indicating this on an imaginary thermometer. To facilitate concentration and to assess coordination, small beanbags are passed to each member of the group as they say their own names and other group members' names. This can be developed into creating a chain where more than one bean bag is passed in a structured sequence and further statements are introduced for finishing, such as: I am..., I want..., I feel..., I need..., or I wish... Each member of the group physically demonstrates how they are feeling at the start of the therapy session by creating a sound and movement to represent this and sharing it. This is then repeated by the group members who mirror back each individual's sound and movement. Group members can choose any costume and prop to aid in the improvisation of a character which they present to the rest of the group. A story is told (not usually read) by the facilitator, and then the whole group enacts the story using improvisation, masks, props and instruments to bring the story to life. Traditional stories from a variety of cultures, which contain specific characters and themes, obstacle and consequences, are often used. After the main event of the session, there is time to reflect on what has taken place. At the end of the session, group members take part in a series of verbal and non-verbal grounding activities to bring awareness back to themselves, and contain the imaginary parts explored in the session so that they are aware of reality, ensuring that they can leave the session safely.
Music therapy

Cindy-Jo Morison, Music Therapist

Introducing music therapy

Music therapy is a psychological therapy which uses the musical components of rhythm, melody and tonality to provide a means of relating within a therapeutic relationship. Musical improvisation is the medium through which a relationship between therapist and client is built.

Clients work with a wide range of accessible instruments and their voices to create a musical language which reflects their emotional and physical condition. The purpose is to enable clients to build connections with their inner selves and with others around them. It can help people of all ages and abilities but is often used when someone finds it difficult to engage with a purely verbal therapy. People with ID may find this approach helpful, as the therapist facilitates clients’ communications with an individually or group-designed combination of improvised or pre-composed music. This can be produced through voice as well as musical instruments. People can discover new ways of communicating through the music, and the therapeutic support allows them to gain confidence that people will listen. Music therapy aims to help people develop a clearer sense of identity and autonomy and increase self-esteem. It aims to reduce challenging behaviour and increase skills and abilities in more effective communication. It also aims to facilitate emotional development through supporting the expression of difficult emotions and the processing of these.

Sessions are planned by the music therapist and follow a similar format each week: warm-up activity, song-writing or sound production, finishing game. When the therapy is taking place in groups, participants may be encouraged to make a group composition or write a group song. With the help of the group and the therapist, participants are then encouraged to perform what they have produced.
Evidence base for Arts therapies

Case studies and series

The majority of literature on art, drama and music therapies with people who have ID has been general in nature. Clinical observations made by therapists led to theory development in relation to practice (Rees, 1998). Clinical vignettes and case description and series have been used primarily to explore applications of art, drama and music therapies (Margetts, 2010; Wigham, 1988). A variety of subjects have been addressed in the literature, such as transference, communication (Tipple, 1993, 1994), group therapy (Lomas & Hallas, 1998), and work with people who have severe and profound ID (Hooper, 2002; Oldfield & Adams, 1990; Rees, 1995; Tipple, 1992). There has also been a focus on clinical issues, such as bereavement (Kuczaj, 1998, Tyas, 2010), work with rape victims (Hughes, 1998), personality disorder (Willoughby-Booth & Pearce, 1998) and work with offenders (Hackett, Porter & Taylor, 20013; Rothwell, 2008).

Pounsett, et al. (2006), evaluated individual art therapy sessions that were recorded on video using an adapted version of the Play Observation Scheme and Emotion Rating (POSER) (Wolke, 1986). Three case studies are reported showing evidence of increased pro-social behaviour during the first 12 months of the intervention. White, et al. (2009) combined case description with a post-therapy interview of a service user, who is also included as an author of the paper under a pseudonym. The reported key outcome for the service user was a significant reduction in dependence on services. The client reported that the therapy involved processing emotionally painful material, particularly in relation to bereavement. Bull and O’Farrell (2012) identified common themes in case material arising from art therapy practice with people who have ID. These included loss and bereavement, issues of abuse, infantalisation, fear, powerlessness, and self-identity.

Randomised controlled trials (RCTs)

One RCT investigating art facilitation with adults who had developmental disabilities, found evidence that the treatment group made improvements in communication and social relationships (Got & Cheng, 2008). In another study, no subjective gains were found using the quality of life enjoyment and satisfaction questionnaire (Q-LES-Q) (Endicott, 1990). Parent and carer ratings using the scales of independent behaviour-revised (SIB-R), designed to
evaluate individuals’ functional independence and adaptive functioning, did show treatment effects (Got & Cheng, 2008).

References


People who have ID may be able to access mainstream services that provide psychological therapies, but many will need specialist services adapted to their needs. Mainstream services can make reasonable adjustments but are challenged by the variation in intellectual, communication and memory ability of people who have ID. Further, they may be challenged by acting out in therapy, dysynchronous development, physical and sensory disabilities and dependence on others. In addition, people who have ID may have experienced institutionalisation, social exclusion, and physical, emotional and sexual abuse.

As observed in *Psychotherapy and people who have ID* in 2004, most people who have ID who are recipients of psychological therapies still do so through specialist ID services. Therefore, the focus of this chapter is on provision of psychological therapies and how to develop pathways for psychological therapies in specialist ID health services for people who have ID. We describe how a service for adults with intellectual disabilities has made attempts to develop service delivery strategies and modernise referral routes, so that services which better meet the needs of our client group can be delivered by optimising accessibility and effectiveness. This chapter concerns referrals to the psychology service for psychological therapies and not those for other types of work or those referred to intensive assessment and support teams.

A common issue in the provision of psychological therapies to meet the needs of people who have ID, is that there is often a significant gap between supply and demand (Bower & Gilbody, 2005). Not all services provide psychological therapies, and in those that do, service users are often faced with difficulties accessing it, and long waiting times have been commonplace in recent years. Current thinking in the National Health Service and health-care commissioning has led to increased accountability and competition among health providers, and in response to this many providers of psychological services have made attempts to increase the accessibility, effectiveness and
efficiency of their service offer. There is now a wider range of psychological therapies being shown to be suitable and being made available to people who have ID and there has been some growth in data on their outcomes. Adaptations to the way people access services, in particular to referral pathways and service delivery models, are constantly being made. Accessible services and employing collaborative and stepped-care models, have been identified as effective in delivering services in ways which best meet the needs of individuals and maximise the efficient utilisation of resources (Bower & Gilbody, 2005).

Service example

The service is provided in a local authority borough area by a large mental health trust which provides services to another three boroughs. All health care staff are employed by the NHS trust and all social care staff by the local authority. The two services have a long-established working partnership and have in the past been managed by the local authority. The Psychology Service provides direct work with clients (psychological assessment and intervention) and indirect work through consultancy and training with colleagues, carers and organisations. The service consists of three whole-time equivalent clinical psychologists, a part-time counsellor and an assistant psychologist. The service also provides placements for trainee psychologists from the local training scheme. In addition, there is a multidisciplinary assessment and intensive support team which works with clients who engage in behaviour that challenge services, and the psychologists also work as part of this team.

Referral process

About 10 years ago, the services identified a need for a single point of access in order to aid accessibility, provide efficient and simplified referral routes, and improve communication throughout the service for clients, carers and professionals. An important aspect of the referral pathway is that there is a process for logging and managing referrals for all parts of the intellectual disabilities service, health or social care, and is able to keep track of referrals. It was agreed that all referrals for services for people who have ID come to a single point and are then discussed at a multi-disciplinary meeting, and each referral is allocated to the appropriate pathway. Each referral for services is discussed at a weekly multi-disciplinary referral meeting at which there is a representative of each professional group in the service.
The single point of access, joint referral pathways/documentation, and multidisciplinary referral meetings aim to improve access to services, ensure service users access the most appropriate service to meet their needs, reduce inappropriate referrals or duplication of referrals, and improve referral tracking and access to referral information (activity, waiting times, capacity and demand). Additional benefits include improved multi-disciplinary team working and knowledge of local services, and better intra-team collaboration, communication and information-sharing.

All referrals received to the service are separated into those needing intervention and those needing other work (assessment, consultation, etc.). Those referred for intervention are then offered an appointment to assess their needs.

Triage

An initial assessment or triage was introduced to the service in 2006 in response to long waiting lists for psychological interventions and high rates of non-attendance. It has become an important addition to the care pathway, as a process by which referrals are organised, allowing clients to be received into groups based on need and capacity to derive benefit from the services available. It also allows for consideration of the appropriate level of clinical expertise required to undertake the work. After a client is referred for psychological intervention, a clinical psychologist meets with them (and anyone else the client wishes to bring with them) to assess their needs and suitability for treatment (clinical assessment), and to determine which intervention will be most helpful and appropriate for them. At this time, clients’ awareness and understanding of the referral are also assessed, along with confirmation that they wish to proceed with the recommended intervention (consent). Practical issues, such as communication, timetabling of sessions and transport arrangements are also discussed, and a basic risk assessment is completed which informs prioritisation of need, and may trigger further action if required (recommendation of risk management strategies or signposting/referring on to other services). At the same time as the triage, routine audit and evaluation measures are also administered.

For those interventions where there is no capacity within the service to proceed immediately following triage, clients are placed on the appropriate waiting list for each intervention rather than a single waiting list for all services. This strategy alone has led to increased throughput, more predictable waiting times and expedited provision for service users.

Service delivery

Prior to recent developments, the model of service delivery in this service example, provided a range of psychological interventions to meet the diverse needs of the client group, with a predominant approach of individual
psychotherapeutic interventions provided by qualified clinical psychologists. While clinical outcomes for clients were good using this ‘traditional’ model of service provision (Beail et al., 2005; Beail et al., 2007), long waiting lists were commonplace. NICE have recommended the use of stepped care for the treatment of a number of psychological problems in order to deliver the least resource-intensive yet effective treatments to service users (NICE, 2004, 2004a). The stepped-care approach recommends delivering low intensity, minimal interventions to those clients for whom it is appropriate in the first instance, with the option of clients stepping up to more resource-intensive traditional treatments if required (Bower & Gilbody, 2005). Common minimal interventions are those that are accessible, brief, focused and less dependent on the availability of traditional therapists/psychologists. Minimal intervention is recommended as the method by which scarce resources should be efficiently delivered in order to provide accessible and effective treatments (NICE, 2004, 2004a).

Typical stepped-care models, such as those recommended by NICE for the treatment of anxiety and depression (NICE, 2004, 2004a), employ five steps of increasingly intensive and specialised clinical involvement within traditional healthcare settings, from primary care through to specialist mental health services. Other models cast their nets wider, incorporating naturally occurring support structures (e.g. family and friends) and frontline workers in the initial steps, community mental health services in the middle stages, and specialist in-patient provision and formal services provided under the Mental Health Act in the later steps.

While all of these resources are available to people with ID very little work was being had been done locally to meet the psychological needs of this client group outside of the specialist psychology service. Subsequently, when considering employing a stepped-care model to meet the needs of the local population, the service initially focused attention on incorporating stepped-care principles within the service, with a view to possibly extending the model to other sources of psychological help at a later date.

As part of the move towards a stepped-care approach, referrals received by the service over a year were reviewed and a range of presenting difficulties were identified. Most common were anger and anxiety, with depression, attachment/relationship difficulties, hoarding, bereavement/loss, trauma, challenging behaviour (including offending behaviours) and unspecified psychological difficulties/identity issues also represented. In addition, there were a significant number of referrals requesting psychological input around supporting people with specific needs such as those on the autistic spectrum or with other pervasive developmental disorders, and those with dementia/cognitive decline.
Thinking of how to meet these diverse needs within a stepped-care model prompted consideration of the evidence for effective psychological interventions in these areas, as well as debate about the resource implications and intensity of different types of provision. Arising from this, opportunities were identified whereby more ‘minimal interventions’ (accessible, brief, focused and less dependent on the availability of traditional therapists/psychologists) and group interventions could be offered alongside existing services. A psycho-education and arousal management package was therefore developed. This package is suitable for delivery to groups of six to eight service users by an assistant psychologist, who is trained to deliver basic behavioural and cognitive-behavioural interventions for clients presenting with simple phobias/anxiety, depression and anger. In response to a significant number of service requests following bereavement and loss, the service also employed a counsellor who works with clients who have experienced difficult life events. The service also began providing group therapies, both CBT (time limited) and psychodynamic (open-ended), in an attempt to increase the effectiveness of traditional approaches. However, attendance at groups was so poor as to render the approach unviable. This may be due to local factors, as others have found this approach to be successful (Rose et al, 2009; Willner et al 2014).

Staff in the service have become much more fastidious at setting clear boundaries around treatments and re-assessing the need for further work regularly.
The resulting stepped-care intervention model includes the following steps:

<table>
<thead>
<tr>
<th>Step</th>
<th>Intervention</th>
<th>Mode of Delivery</th>
<th>Maximum Duration</th>
<th>Staff Delivering Intervention¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Psycho-education and arousal management</td>
<td>Group of six to eight service users</td>
<td>16 sessions</td>
<td>Assistant psychologist</td>
</tr>
<tr>
<td>2</td>
<td>Basic behavioural therapy and CBT</td>
<td>Group of six to eight service users</td>
<td>16 sessions</td>
<td>Assistant psychologist</td>
</tr>
<tr>
<td>3</td>
<td>CBT, psychodynamic psychotherapy or counselling</td>
<td>Individual (1:1)</td>
<td>20 sessions</td>
<td>Trainee psychologist or counsellor</td>
</tr>
<tr>
<td>4</td>
<td>Psychodynamic psychotherapy</td>
<td>Group of six to eight service users</td>
<td>Open-ended</td>
<td>Clinical psychologist</td>
</tr>
<tr>
<td>5</td>
<td>CBT, psychodynamic psychotherapy</td>
<td>Individual (1:1)</td>
<td>Open-ended</td>
<td>Clinical psychologist</td>
</tr>
</tbody>
</table>

These options are from necessity limited by the availability of staff in this particular service. In other services, different options may be available if, for instance, there are also psychotherapists and/or psychiatrists who have completed psychotherapy training.

¹ All work is appropriately supervised by experienced clinical psychologists.
Accurate monitoring and assessment is paramount within stepped-care models, in order that clients access the most appropriate intervention to meet their needs. Within the service presented as an example here, this monitoring occurs during triage and through an end-of-treatment assessment with a clinical psychologist. This assessment considers clients’ previous experiences within the stepped-care pathway, both the client’s and the therapist’s opinions regarding further work, and data generated from the administration of outcome measures. Because of the cyclical element of the model, it is self-correcting in that if a person enters the model at a level of intensity which is insufficient to meet their needs, this will be corrected at the next assessment and they will ‘step-up’ to a more intensive intervention.

Direct psychological interventions are provided as part of the service offer. The amount of consultancy (including collaborative functional analysis) and training being done with non-psychological staff, families and carers have also been increased. Overall, this model of service delivery attempts to acknowledge and use the psychological knowledge and skills present in other members of staff who have completed different professional trainings, and to cascade existing psychological knowledge and skills through other non-psychological professions and other parts of a person’s care network, such as family and carers.

In summary, the introduction of a stepped-care model employing minimal interventions alongside traditional interventions and group treatments aims to:

- provide effective interventions for psychological difficulties
- improve the efficiency of psychological interventions (time)
- improve the efficiency of psychological interventions (cost)
- reduce waiting times for psychological interventions.

Quality and performance

During the service development process, there was an opportunity to consider a number of quality issues in relation to the work conducted by the Psychology Service. Key among the aims was to ensure clients and others were satisfied with the work of the service with regard to communication, waiting times and
effectiveness of interventions. A number of minimum standards for communicating with service users and sharing information with referrers, GPs and other professionals were introduced. As a matter of courtesy, receipts of service requests are acknowledged to both clients and referrers, and the service informs GPs that a referral has been received for one of their patients. Clients then receive letters inviting them to attend a triage appointment, with subsequent letters informing them of the outcome of the triage assessment and the anticipated waiting time until therapy can begin. An invitation to attend an initial contracting meeting is sent prior to participation in therapy, with a subsequent summary letter containing a brief description of the agreed intervention and why it is deemed appropriate for them, general costs and benefits of intervention, a record of commitments (regular attendance, starting and finishing on time) and that the client is consenting to this, and a description of practical arrangements (time, place, frequency, travel arrangements). On completion of the intervention, clients receive a letter containing a brief summary of the work they have done and a description of potential routes back into services in the future, should they require this. All letters are addressed to clients (with key letters copied to the referrer and GP) and made as accessible as possible using simplified language and diagrams as appropriate.

The Department of Health set a target of 18 weeks as the maximum waiting time for patients referred by their GP for consultant-led services (Department of Health, 2004, 2008) and this has become a key performance indicator. When developing service delivery goals, the service aimed to meet this target despite having a different referral process. As a result of the application of stepped care and other service developments, this has largely been achieved, with the only exceptions being in those cases where service users express a preference for a form of service delivery which is not readily available (for example, open-ended therapy with a therapist of a specific gender).

The service is now in the process of transformation and is continuing to review and develop its service offer. Demand for psychological therapies remains high, and the service aims to continue to meet that need, but is now required to attend to local commissioning requirements and adopt new ways of working, especially contributing to the enabling, person-centred recovery approach. This involves extending the notion of psychological care beyond the specialist psychology service, cascading psychological knowledge and skills more widely, and making use of naturally occurring supports (family and friends, communities) and frontline workers. It is hoped that this will facilitate more health promotion activity and early detection of psychological distress.
Summary

Motivated by the current agenda within the NHS and long waiting times for psychological interventions, the service presented here undertook to review its service for adults with ID and develop its model of service delivery with the aim of improving accessibility of psychological interventions and increasing efficiency, while ensuring the effectiveness of its services were maintained.

The referral routes for psychological input were simplified by developing a single point of access for all services within the wider ID service. Closer multi-disciplinary working was encouraged through the establishment of weekly multi-disciplinary and cross-service referral meetings. Within the psychology service, a triage stage was introduced which aimed to match service users with the least intrusive, least resource-intensive intervention suitable for their needs within a new stepped-care model of service delivery. Greater use of assistant and trainee psychologists within the team and an increased use of group interventions facilitated the provision of more minimal interventions which sought to reduce waiting times for clients accessing the service, and increase the efficiency of existing resources. This service development activity appears to have been successful at improving the accessibility and efficiency of provision without reducing its effectiveness, and data are currently being collected to support these perceptions. On the basis of their experience with this service, the authors feel able to recommend the use of collaborative, stepped care as an effective means of delivering psychological interventions to adults with ID.
Fig. 1 – Referral Routes to Direct Psychological Interventions in an Adult Learning Disabilities Service

Single Point of Access
Multi-Disciplinary Referral Meeting
Triage/End of Therapy Assessment

- Link service users with the most appropriate service to meet their needs
- Assessment of Clinical Needs
- Identification of appropriate intervention
- Ensure consent to treatment

Stepped Care Interventions

- Improved/Simplified access to services
- Standardised referral documentation
- Improved MDT working & knowledge of local services

- Level of Psychological Resource Used
- Centralised Referral Management

Anticipated Waiting Time

Waiting List 5
Waiting List 4
Waiting List 3
Waiting List 2
Waiting List 1

Basic CBT Group
Psycho-Education Group

Individual Psychotherapy (Open-Ended)
Group Psychotherapy (Open-ended)
Individual Therapy/Counselling

Discharge

Individual Psychotherapy (Open-Ended)
Group Psychotherapy (Open-ended)
Individual Therapy/Counselling

Basic CBT Group
Psycho-Education Group

Waiting List 5
Waiting List 4
Waiting List 3
Waiting List 2
Waiting List 1


Each contributor to this point has provided information on the current evidence base for their approach to psychological intervention for people with ID. The extent of the evidence varies from one approach to another. For example, CBT for anger now has sufficient studies for meta-analytic reviews to be carried out (Hamelin et al., 2013; Nicoll et al., 2013), and psychodynamic psychotherapy now has sufficient studies to warrant a review (James and Stacey, 2013). Because these approaches were first used in the 1980s, there has been more time for research to be carried out. Newer approaches, such as CAT and DBT, have become available more recently, and so it is not surprising that little evidence for efficacy or effectiveness has yet emerged.

The emphasis on practice-based evidence has meant that there is an increased expectation for services that provide psychological therapies to show some evidence for the effectiveness of what they do (Department of Health, 2010). It is interesting to note that most of the research on psychological therapies with people with ID to date has been carried out by clinicians in routine clinical practice. This includes attempts at controlled trials. While efficacy research is clearly needed, very little currently exists, and it is unlikely that clinicians will be in a position to take on such large scale, resource-intensive studies. However, everyone can contribute to the demonstration of effectiveness by routinely building outcomes into their service design and delivery.

**Routine assessment**

In services providing formal psychological interventions to people with ID, the routine assessment of outcome is considered to be best practice. and part of
clinical governance processes. However, despite the availability of measurement tools and their use is considered optimal by many practitioners, little in the way of application is evident. This may be because practitioners fear unfair evaluation and its implications for their service, there is little time allotted for research or clinical audit, or simply because within day-to-day practice the culture of research is less established. The lack of any clear, national steer has definitely contributed to the patchy use of outcome measurement.

**Defining outcome**

A clinical outcome indicator can be defined as a characteristic of the service recipient’s experience that can reasonably be expected to change as a result of the person receiving the service (Lyons et al., 1997). It is neither the service inputs (provider and recipient characteristics, plus environmental circumstances), nor the processes (type and amount of intervention, therapeutic orientation, financing), though these are definitely of interest in determining what causes the indicator to change. It follows that outcome measures should capture change in the outcome characteristic and should not be confused with processes or service inputs.

**Choosing best quality measures**

Outcome measures should be chosen not on the basis of widespread use, successful marketing or even face validity, but on their overall scientific merit. By scientific merit we refer to sensitivity, specificity, reliability and validity. Measures should clearly be sensitive to the change that one wishes to observe following a particular psychological intervention. For example, many interventions based on the theory of applied behaviour analysis are designed to reduce the frequency or severity of incidents of challenging behaviour (e.g. differential reinforcement programmes), whereas individual psychotherapies can variously target symptomatic change (e.g. a subjective experience of lowered anxiety, less avoidance of aversive stimuli) or improvement in relational functioning (e.g. lowered likelihood of relationship breakdown, lowered experience of extreme aversive emotional states). These differences, though often subtle and not publically known, may account for why psychological therapists can sometimes view alternative approaches as
somewhat misguided. There is no agreed or widely used concept of generic outcome, though attempts have begun to be made to develop and use generic outcome measures (e.g. Skelly et al., 2006). Specific measures used to date in outcome research with people who have ID are systematically reviewed in the next chapter. For a more extensive list of measures available, see McGurk and Skelly (2014).

**Significance and effect size**

Any attempt to measure outcomes should produce data from which it can be calculated whether a statistically significant amount of change has occurred between at least two time points, typically at assessment (Time 1) and at post-intervention (Time 2).

Effect sizes can also be an important indicator of change, not only in terms of determining whether a particular intervention has a sizeable effect on outcome, but also by way of benchmarking against previous years or by comparing the effect sizes achieved in a service providing psychological therapy with effect sizes reported for the same intervention in published research (e.g. Pearce et al., 2011). Effect size can be determined by comparing the degree of change following treatment to control participants assigned to ‘no treatment’ or ‘treatment as usual’, which is common in formal efficacy research into psychotherapy and the efficacy of pharmaceuticals (e.g. Shedler, 2010). However, assigning people who want psychological services to a ‘no-treatment’ condition cannot be done outside of ethically approved studies. In service evaluations and everyday practice, it is much more practical to compare the average amount of change during therapy against the standard deviation of the initial scores using a statistic like Cohen’s $d$.

The effect size achieved in a clinical service may be lower than that found in formal research studies, but the difference should be examined in relation to population characteristics in the service compared to those in formal research studies. These are often very different in terms of their social-economic status. Waiting lists do occur naturally in most services and so it is also possible to collect data from clients’ whilst they are waiting to start treatment. If the wait is a few weeks long, a waiting list comparison group can be developed. Data collected at the start end of the Waiting time can be compared with data then collected at the start and the end of the therapy. It can also be used in a more traditionally designed study to compare a group that receives therapy with a group that have not yet had therapy.
A methodology for service-level evaluation

It is relatively practical to introduce a simple methodology that both standardises routine clinical practice and offers clear advantages for the clinical governance of a service. If all clients are simply assessed in terms of Time 1 (assessment) and Time 2 (post-intervention), then a within-participants comparison using inferential statistics can be carried out (see Beail et al., 2005, and Rose et al., 2005 for examples). Real, amalgamated data from an unnamed psychological intervention service is shown in Table 1, to demonstrate how this system of service evaluation can be reported within a single table.

As mentioned above, a methodology can also be applied if a service has any significant waiting list, which creates the effect of a control condition. For example, using the Health of the Nation Outcome Scale – Learning Disabilities (HoNOS-LD), whilst waiting for treatment (Time 0 to Time 1) the clients did not show any significant change, compared to a significant improvement during community team interventions (Time 1 to Time 2) across the intervention period (Skelly et al. (2006). It has also been shown that follow-up measurement can detect whether benefits are maintained (Beail et al., 2005; Skelly et al., 2009; Taylor et al, 2005).

The process of outcome measurement for the actual example presented in Table 1 provided information which allowed the clinical governance of the psychological service to be addressed in new ways. The evaluation demonstrated that the practice within the service to support people struggling with anger leading to non-physical aggression, was not leading to significant improvements. This led to a reflective process and eventual further training within the team to bring this work to the level of other interventions. In addition, using effect sizes, it was demonstrated that the 21 people who remained on the waiting list experienced little or no improvement until they saw a psychological practitioner. Since waiting did not result in spontaneous improvement, it would seem likely that the psychological inputs during intervention played a part in improvements, although it is not possible to determine with absolute certainty that they alone were responsible. Such information may become important in the context of service commissioning. Finally, the culture of continuous routine outcome evaluation was embedded, with the possibility not only of benchmarking results within the same service
year on year, but also of benchmarking against other findings, e.g. on the chosen generic measure, the HoNOS-LD, the effect size of .39 is higher than that in a published evaluation of community teams (Skelly et al., 2006), and indeed than that of the HoNOS-LD standardisation data (Pearce et al., 2011).
Table 1. Specific and generic outcomes in a psychological service using data from people referred over a nine-month period.

<table>
<thead>
<tr>
<th>Clinical concern</th>
<th>Selected recommended measure</th>
<th>n</th>
<th>Effect size (Cohen’s d) from assessment to discharge</th>
<th>Statistical significance</th>
<th>Concern/comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Glasgow anxiety scale</td>
<td>37</td>
<td>.42</td>
<td>&lt;.01</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Glasgow depression scale</td>
<td>16</td>
<td>.57</td>
<td>&lt;.01</td>
<td></td>
</tr>
<tr>
<td>Anger (non-physical aggression)</td>
<td>Novaco modified provocation scale</td>
<td>20</td>
<td>.23</td>
<td>Not statistically significant</td>
<td>Requires review of current practice, using practice guidance to improve outcomes</td>
</tr>
<tr>
<td>Aggression</td>
<td>HoNOS-LD scale(^3)</td>
<td>23</td>
<td>.35</td>
<td>&lt;.02</td>
<td></td>
</tr>
<tr>
<td>Self-harm</td>
<td>HoNOS-LD BMR scale</td>
<td>9</td>
<td>.27</td>
<td>&lt;.05</td>
<td>Low n</td>
</tr>
<tr>
<td>Traumatic reaction</td>
<td>Life events scale-revised</td>
<td>12</td>
<td>.33</td>
<td>&lt;.01</td>
<td></td>
</tr>
<tr>
<td>Generic (HoNOS-LD)</td>
<td>HoNOS-LD total score</td>
<td>104</td>
<td>.39</td>
<td>&lt;.01</td>
<td>Suggests expected level of overall effectiveness based on national benchmarks</td>
</tr>
</tbody>
</table>

\(^3\) Wilcoxon signed-rank test, or 1-way ANOVA, depending on data normality.

\(^3\) See Skelly and D’Antonio (2008) for the method of constructing factor scores on the HoNOS-LD.
The future

There are frequent calls for more research on the use of psychological therapies with the general population, but also for people who have ID. Despite these calls, the volume of research has remained small and it has taken many years to accumulate sufficient data for small meta-analytic studies (e.g. Prout and Browning, 2011). However, close inspection of the published research shows that it is almost entirely practice-based.

Practice-based outcome research is useful, but its usefulness does not end with simply measuring whether outcomes have been successful or not. It is also possible to carry out other forms of practice based research, for example, exploration of the processes that are important in psychotherapy outcome. For example, many clinicians suspect that the interpersonal aspects of therapies contribute more to success than prescribed techniques. This has been reported in key reviews of psychotherapy research with other client groups. For example, Lambert et al. (1986) demonstrated that common factors in psychotherapy, mainly related to therapist-client relationship quality, accounted for 30% of the variance in outcome, whereas ‘techniques’ only accounted for 15% (about the same as placebo, with 40% due to ‘extra-therapeutic’ changes). Change in outcome measures offers an obvious dependent variable in such studies.

The ‘gold standard’ of the randomised controlled trial is not as easily attainable in psychotherapy research in the same way as it is in trials for new pharmaceuticals. There are also further difficulties with this approach when carry out studies with people who have ID (Beail, 2010). Randomisation raises some ethical problems due to the complexities of ensuring the person with ID fully understands and consents to the process, and ‘blind’ delivery of therapy is not possible. However, Willner et al (2014) have shown that there are creative ways of achieving randomisation when services come together to carry out a project. To date, that is an exception, and also was funded by a very large grant. But all services can incorporate, as shown here, a pre and post evaluation of their interventions.

Social outcomes were once popular with professionals in ID services, as evidenced in studies of quality of life (QoL) after institutionalisation came to an end (e.g. Ager, 1998). QoL needs further consideration and development with a realistic focus on what therapy can influence. Some aspects of QoL, such as home conditions or the services available in the locality, may be little affected by psychological therapy. However, psychological factors often have
a powerful influence on social outcomes, such as community use, employment, attendance at vocational activities, and limiting of social networks. Evidence is starting to emerge that some change during therapy can be expected on daily living skills and community engagement (e.g. Skelly et al., 2014; Skelly et al., submitted), in addition to the emotional and behavioural changes which follow psychotherapy.

Psychological services have, in the course of a set time period, such as a financial year, sufficient numbers of recipients to allow the detection of even small change in average scores, with more than 100 people being typical, something which is set only to increase over time. From previous research, and using Cohen’s standard, effect sizes of 0.3 to 0.6 could be expected to be reasonable evidence of effectiveness for a local team. If improvements are shown to be maintained until at least a few months following discharge (preferably longer), then it is not unreasonable for a service to be described as effective. However, it is good practice to assume that demonstrated change is only suggestive and temporary, and improvements are always possible.

Summary

Routine outcome measurement of psychological interventions for people with ID is becoming essential practice today. Studies of the use of psychological therapies with people who have ID suggest that these interventions are effective to a moderate degree, though the evidence continues to be limited. With little evidence of ineffectiveness of psychological therapies, there is no reason to assume that all psychological therapies will not find future research to be an important foundation for their inclusion in specialist ID services. As discussed here, a simple methodology for measuring both global and specific outcomes can easily be implemented using existing tools that have acceptable reliability and validity. Further research may specify the relationship of inputs and processes to outcome, but there is very little current evidence in relation to these at present.

Beail, N. (2010). The challenge of the randomised controlled trial to psychotherapy research with people who have intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities, 4*, 37-41


A systematic review of the outcome measures used in psychological therapies with adults with ID

Nik Vlissides, Laura Golding & Nigel Beall

When conducting service-based studies or clinical trials, we require high quality therapy outcome measures. Currently, there are no established benchmark measures in the field of ID (Hatton & Taylor, 2013). The aim of this chapter, therefore, is systematically to identify and review the quality of outcome measures that have been used in published reports of psychological therapies with adults with ID. This will be limited to self-report outcome measures as a result of increasing recognition of involving service users’ perspectives in healthcare interventions (Slevin et al., 1988) and measures that assess psychological well-being (i.e. positive well-being, psychological illness/distress) and social well-being (i.e. family and intimate relationships) (Fitzpatrick et al., 1998).

One of the first steps in assessing whether a measure is appropriate for use, is ensuring that it has sound psychometric properties (Kraus & Castonguay, 2010). Psychometric properties of a measure are usually assessed through its reliability and validity (Beck et al., 1988). Reliability refers to an outcome measure’s ability to produce similar results from the same respondents in consistent conditions (Field, 2013). The reliability of therapy outcome measures is often assessed through test re-test reliability (degree of which scores are consistent from one administration to the next) and internal consistency (consistency of results across items in a test) (Fitzpatrick et al., 1998). Validity refers to the ability of an outcome measure to measure what it is supposed to measure (Rose & Sullivan, 1996). For example, when people are experiencing psychological distress, is psychological distress what the measure is actually measuring.. Validity of therapy outcome measures can be assessed through:

- construct validity (refers to the extent that a measure actually measures the constructs it claims to);
• concurrent validity (when a measure is administered at the same time as a pre-existing one and they are correlated); and
• discriminant validity (when a measure has low levels of correspondence with another measure that represents another) (Cahill et al., 2008; Fitzpatrick et al., 1998).

There are a plethora of psychological therapy outcome measures available to researchers and clinicians (Barkham et al., 1998). They can be used to assess a number of possible outcomes, such as: psychological well-being, social well-being and quality of life (Fitzpatrick et al., 1998); the outcome of specific problems (e.g. depression, anxiety disorders); and general mental health (Green & Latchford, 2012). Outcome measures can also be model- and/or population-specific (Lueger & Barkham, 2010). For example, the Beck depression inventory – second edition (BDI-II) (Beck et al., 1996) is designed for use in CBT with adults who are experiencing depression, whereas the Beck depression inventory – youth (BDI-Y) (Beck Youth Inventories, Beck et al., 2005) is designed for use in CBT with young people aged 7-18 who are experiencing depression. These two measures provide examples of measures that are model-, problem- and population-specific. Therapy outcome measures can be completed by the client, clinician and/or third party (e.g. relative, carer). The Health of the Nation Outcome Scale (HoNOS) (Wing et al., 1996), for example, a 12-item measure assessing the health and social functioning of people, is completed by clinicians.

When the Department of Health (1996) reviewed psychological therapy services in the UK it emphasised the need for evidence from routine clinical settings (effectiveness data) to complement the outcomes of randomised controlled trials (efficacy data) to inform practice. This view still holds today. Coupled with this there is a need to assess service users’ perspectives when evaluating any healthcare interventions (Slevin et al., 1988). Therefore, good quality self-report outcome measures are required to assess therapy outcomes from both randomised controlled trials and routine clinical settings, and to provide service users with an opportunity to have their voices heard about interventions provided (Barkham et al., 2001).

There are limited reviews of psychological therapy outcome measures used with adults with ID. One such review was undertaken by Hatton and Taylor (2013) who found that measures varied in their design (e.g. for use with the general population or specifically for people with ID), target population (mild, moderate ID, etc.) and psychometric properties (e.g. reliability and validity).
McGurk and Skelly (2014) conducted a review of clinical outcome measures used with people with ID. Again, they found that there was a huge variation in the reliability and validity of the measures, and that there were limited measures assessing social outcomes.

Both of these recent reviews are important in highlighting the available outcome measures, and in identifying their strengths and weaknesses. However, neither review systematically identified outcome measures that have been used to assess individual psychological therapy with adults with ID. Nor did they use an identified quality appraisal tool to assess the quality of the outcome measures.

**Review process**

The quality of self-report outcomes was assessed using a three-stage process:

- Systematically identify outcome measures that have been used in published, peer-reviewed studies assessing the outcome of individual psychological therapies with adults with ID.
- Identify the key papers that report the development/psychometric assessment of the identified self-report therapy outcome measures
- Use Fitzpatrick et al.’s. (1998) criteria (see Box 1) to assess the quality of the self-report therapy outcome measures
Box 1 Fitzpatrick criteria taken from Cahill et al. (2008)

<table>
<thead>
<tr>
<th>Reliability</th>
<th>A reliable measure is one that produces consistent results from the same respondents at different times where there exists no evidence of change.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Validity</td>
<td>The extent to which a measure really measures the concept that it purports to measure.</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Addresses the question: does the instrument detect changes over time that matter to the patient? It can be discriminative (between individuals) or evaluative (within an individual across time).</td>
</tr>
<tr>
<td>Acceptability</td>
<td>Addresses the question: is the measure acceptable to users?</td>
</tr>
<tr>
<td>Feasibility</td>
<td>Is the measure easy to administer and process?</td>
</tr>
<tr>
<td>Precision</td>
<td>How precise is the measure?</td>
</tr>
<tr>
<td>Interpretability</td>
<td>How interpretable are the scores of the measure?</td>
</tr>
</tbody>
</table>

Method

Search strategy

The initial strategy involved searching three major electronic databases (PsycINFO, Scopus and MEDLINE) for research articles that had assessed the effectiveness of individual psychological therapy with adults with ID. This first step was used to ensure that any therapy outcome measures found had been used in individual psychological therapy with adults with ID.

Keywords anywhere (title, abstract, journal etc.) for the terms ‘psycho* therap*’ and ‘outcome*’, returned 390,164 and 3,428,084 references. To limit the search to the desired population, keywords anywhere for the terms ‘intellectual disabilit*’, ‘learning disabilit*’, ‘developmental disabilit*’ and
‘mental retardation’ returned 253,966 references. The population terms were then combined with ‘psycho* therap*’ and ‘outcome*’, yielding 522 references. References were then limited to those articles published in peer-reviewed journals in English, and which contained only adult populations (18+) with ID (i.e. studies which included children with ID were excluded from the review). This returned 212 studies.

The 212 studies were screened for content by applying relevant inclusion and exclusion criteria. Studies were included if: i) they used a self-report outcome measure to report change; ii) the outcome measure was concerned with psychological and/or social well-being; and iii) service-users presented with a mental health problem of a psychological nature (e.g. depression, anxiety, etc.).

Studies were excluded if: i) they reported interventions that did not use individual psychological therapy (e.g. pharmacological interventions, group therapy); ii) service users did not present with mental health problems; iii) they did not measure mental health as the primary dependent variable (e.g. offending behaviours, challenging behaviours); iv) they did not use a self-report outcome measure to assess change (i.e. no psychometric measures were used); and v) they were themselves reviews or other non-primary research.

Of the 212 studies, 201 did not meet the criteria and were removed from the review. The search strategy, therefore, yielded 11 relevant studies. The 11 studies that met the inclusion criteria were reviewed to identify the therapy outcome measures used (see Table 1).

The primary articles concerned with the development and validation of the measures within the target population were then identified. If these did not exist (i.e. the psychometric properties had not been assessed within the target population), the therapy outcome measure was excluded from the analysis. This was the case for the Posttraumatic Stress Diagnostic Scale (Foa et al., 1997) identified in Dilly (2014), and the Beck Anxiety Inventory – Youth (and the Beck Depression Inventory – Youth (Beck et al, 2005) identified in Hassiotis et al. (2013).

This meant that the quality appraisal consisted of 11 articles, reporting the development of 10 self-report therapy outcome measures that have been used in individual psychological therapy with people with ID (see Table 2).
Table 1: Studies that have used outcome measures in individual psychological therapy with adults with ID that met the inclusion criteria.

<table>
<thead>
<tr>
<th>Author and year</th>
<th>Design</th>
<th>Presenting difficulties</th>
<th>Setting</th>
<th>Sample</th>
<th>Outcome measure(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Provocation Inventory (PI)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Brief Symptom Inventory (BSI)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Inventory of Interpersonal Problems, 32&lt;sup&gt;nd&lt;/sup&gt; ed (IIP-32)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Rosenberg Self-Esteem Scale (RSES)</td>
</tr>
<tr>
<td>Atnas &amp; Lippold</td>
<td>Case study</td>
<td>Anxiety, psychogenic</td>
<td>Community</td>
<td>20 year-old female with mild ID</td>
<td>Glasgow Anxiety Scale – Intellectual Disabilities (GAS-ID)</td>
</tr>
<tr>
<td>(2013)</td>
<td></td>
<td>non-epileptic seizures</td>
<td></td>
<td></td>
<td>Glasgow Depression Scale – Intellectual Disabilities (GDS-ID)</td>
</tr>
<tr>
<td>Beail et al. (2005, Open trial)</td>
<td>Aggression,</td>
<td>Community</td>
<td>17 men</td>
<td></td>
<td>Symptom Checklist 90-Revised (SCL-90-R)</td>
</tr>
<tr>
<td>Study</td>
<td>Methodology</td>
<td>Diagnosis</td>
<td>Sample Size</td>
<td>Setting</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>-------------</td>
<td>----------------------</td>
<td>-------------</td>
<td>--------------------------------</td>
<td></td>
</tr>
<tr>
<td>Brooks et al. (2013)</td>
<td>Not reported</td>
<td>Not reported</td>
<td>272 clinical (110 men, 162 women)</td>
<td>Community, high-security NHS, other NHS</td>
<td></td>
</tr>
<tr>
<td>Dilly (2014)</td>
<td>Case study</td>
<td>Trauma, Inpatient</td>
<td>25-year-old man</td>
<td>Clinical Outcomes in Routine Evaluation – Learning Disability (CORE-LD)</td>
<td></td>
</tr>
</tbody>
</table>

- Sexually inappropriate behaviour, psychosis, depression, OCD, bulimia, self-injury

- Mild ID

- RSES

- IIP-32

- Not reported
<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Design</th>
<th>Condition</th>
<th>Sample Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hassiotis et al. (2013)</td>
<td>Randomised control trial</td>
<td>Severe ID</td>
<td>16 treatment (5 men, 11 women) Beck Depression Inventory-Youth (BDI-Y)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>16 control (7 men, 9 women) Beck Anxiety Inventory-Youth (BAI-Y)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mild-moderate ID</td>
</tr>
<tr>
<td>Kellett et al. (2009)</td>
<td>Three single-case designs</td>
<td>Mild-moderate ID</td>
<td>40-year old woman with moderate ID, BSI</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>43-year old man with ID, IIP-32</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>27-year old man with mild ID</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Condition</td>
<td>Level of disability</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------</td>
<td>----------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Rose (2013)</td>
<td>Not reported</td>
<td>Anger (25 men, 12 women)</td>
<td>Low- and medium-secure</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>not reported</td>
</tr>
<tr>
<td>Taylor et al. (2002)</td>
<td>Delayed waiting-list controlled trial</td>
<td>Low- and medium-secure inpatient hospitals</td>
<td>Mild to borderline ID</td>
</tr>
<tr>
<td></td>
<td>Anger</td>
<td>9 treatment (all male)</td>
<td>10 control (all male)</td>
</tr>
<tr>
<td>Taylor et al. (2005)</td>
<td>Delayed waiting-list controlled trial</td>
<td>Low- and medium-secure inpatient hospitals</td>
<td>16 treatment (all male)</td>
</tr>
<tr>
<td></td>
<td>Anger</td>
<td>16 treatment (all male)</td>
<td>20 control (all male)</td>
</tr>
</tbody>
</table>

* Removed from quality appraisal
This meant that the quality appraisal consisted of 11 articles, reporting the development of 10 self-report therapy outcome measures that have been used in individual psychological therapy with people with ID (see Table 2). The primary articles were then reviewed for data extraction. Additional information was taken from the articles reporting the use of the therapy outcome measures in Table 1 if needed.
Table 2 Psychological therapy outcome measures identified for quality appraisal

<table>
<thead>
<tr>
<th>Measure</th>
<th>Areas assessed</th>
<th>Number of items</th>
<th>Response scale</th>
<th>General population measure or specific for people with ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger Inventory (AI)</td>
<td>Anger: reactivity to a number of anger-provoking scenarios</td>
<td>35</td>
<td>4-point Likert scale: higher scores suggest higher anger levels</td>
<td>Specific</td>
</tr>
<tr>
<td>Rose &amp; Gerson (2009)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brief Symptom Inventory (BSI)</td>
<td>Global indices of psychological distress (GSI, PSDI, PST)</td>
<td>53</td>
<td>5-point Likert scale: higher scores suggest higher levels of distress</td>
<td>General (adapted)</td>
</tr>
<tr>
<td>Kellett et al. (2003; 2004)*</td>
<td>Somatisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obsessive-compulsive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Interpersonal sensitivity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hostility</td>
<td>Phobic anxiety</td>
<td>Paranoid ideation</td>
<td>Psychoticism</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>----------------</td>
<td>-------------------</td>
<td>--------------</td>
<td></td>
</tr>
</tbody>
</table>

### Clinical Outcome Routine Evaluation – LD (CORE-LD)

<table>
<thead>
<tr>
<th>Feelings</th>
<th>14</th>
<th>higher scores suggest feeling worse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brooks, Davies &amp; Twigg (2013)*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Specific

<table>
<thead>
<tr>
<th>Overall anxiety including indices of worries, specific fears and physiological symptoms</th>
<th>27</th>
<th>higher levels of anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mindham &amp; Espie (2003)*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Specific

<table>
<thead>
<tr>
<th>Depression</th>
<th>20</th>
<th>higher levels of anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cuthill, Espie &amp; Cooper</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Specific

<table>
<thead>
<tr>
<th>3-point Likert scale:</th>
</tr>
</thead>
<tbody>
<tr>
<td>higher scores suggest feeling worse</td>
</tr>
<tr>
<td>higher levels of anxiety</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>higher levels of anxiety</td>
</tr>
<tr>
<td>Instrument</td>
</tr>
<tr>
<td>------------------------------------</td>
</tr>
<tr>
<td><strong>Inventory of Interpersonal Problems – 32 (IIP-32)</strong></td>
</tr>
<tr>
<td><strong>Novaco Anger Scale (NAS)</strong></td>
</tr>
<tr>
<td><strong>Provocation Inventory (PI)</strong></td>
</tr>
<tr>
<td><strong>Rosenberg Self-Esteem Scale (RSES)</strong></td>
</tr>
</tbody>
</table>
**Symptom Checklist – 90R** (SCL-90-R)

<table>
<thead>
<tr>
<th>Kellett et al. (1999)*</th>
</tr>
</thead>
</table>

- Global indices of psychological distress (GSI, PSDI, PST)
- Somatisation
- Obsessive-compulsive
- Interpersonal sensitivity
- Depression
- Anxiety
- Hostility
- Phobic anxiety
- Paranoid ideation
- Psychoticism

5-point Likert scale: 90

* studies that report the psychometric properties of the outcome measures with adults with ID
Quality appraisal

As we have already noted, Fitzpatrick et al. (1998) identified a series of desirable attributes for patient-based outcome measures (Box 1). Cahill et al. (2008) identified a way of assessing the criteria and developed a rating tool to address this. An adapted version of this rating tool was used to assess the quality of the therapy outcome measures used; this is summarised in Table 3. The ‘interpretability’ criterion is incorporated into ‘precision’ in the assessment of the quality of the outcome measures. ‘Responsiveness’ was assessed from the research papers reporting the use of the therapy outcome measure found in the initial systematic literature search.

Table 3 Criteria to assess quality of the measures (based on Cahill et al., 2008)

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reliability</strong></td>
<td></td>
</tr>
<tr>
<td>Internal consistency</td>
<td>As measured by Cronbach’s alpha, split-half reliability estimates</td>
</tr>
<tr>
<td>Test-retest reliability</td>
<td></td>
</tr>
<tr>
<td><strong>Validity</strong></td>
<td></td>
</tr>
<tr>
<td>Construct validity</td>
<td>Hypotheses are generated and a measure tested to determine whether it actually reflects these prior hypotheses</td>
</tr>
<tr>
<td>Concurrent validity</td>
<td>Where a new measure is administered at the same time as a pre-existing one and the two are correlated</td>
</tr>
<tr>
<td>Convergent validity</td>
<td>A measure converges with other indications of the same concept</td>
</tr>
<tr>
<td>Discriminant validity</td>
<td>A measure demonstrates low levels of correspondence with a measure that represents another concept</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Responsiveness</strong></td>
<td>Addresses the question: does the instrument detect changes over time that matter to the patient?</td>
</tr>
<tr>
<td></td>
<td>It can be discriminative (between individuals) or evaluative (within individual across time)</td>
</tr>
<tr>
<td><strong>Acceptability</strong></td>
<td>Addresses the question: is the measure acceptable to users?</td>
</tr>
<tr>
<td></td>
<td>Practicality of administration</td>
</tr>
<tr>
<td></td>
<td>Time taken to complete</td>
</tr>
<tr>
<td></td>
<td>Length of instrument</td>
</tr>
<tr>
<td></td>
<td>Translations</td>
</tr>
<tr>
<td></td>
<td>Access by ethnic minorities</td>
</tr>
<tr>
<td></td>
<td>Reading age</td>
</tr>
<tr>
<td><strong>Feasibility</strong></td>
<td>Is the measure easy to administer and process?</td>
</tr>
<tr>
<td></td>
<td>Cost and burden to administrative staff</td>
</tr>
<tr>
<td></td>
<td>Electronic scanning options</td>
</tr>
<tr>
<td></td>
<td>Scoring systems</td>
</tr>
<tr>
<td></td>
<td>Training package</td>
</tr>
<tr>
<td></td>
<td>Training manual</td>
</tr>
<tr>
<td></td>
<td>Support from measure developers</td>
</tr>
<tr>
<td><strong>Precision</strong></td>
<td>Interpretability</td>
</tr>
<tr>
<td></td>
<td>Normative data</td>
</tr>
</tbody>
</table>
Analysis

Each measure was critically evaluated using data from the primary articles and research papers, and the coding instructions were applied to assess the quality of each measure (see Table 4). The codings provided an overall estimate for each of the six criteria, and the overall reliability score for each measure was used when possible. When there were multiple reliability estimates and/or only estimates for each subscale, the range of the reliability scores was reported.

The number of validity tests that had been used to analyse the measure were used to assess the quality of that criterion. The types of validity analyses that were considered are outlined in Table 3. Each type of validity analysis had to meet significant levels and have an appropriate sample size to be considered acceptable for inclusion. For example, Floyd and Widaman (1995) recommend a minimum of 1:5 items to cases ratio for factor analytic techniques. Hence, assessment of the construct validity of any measure would require this ratio to be considered as an acceptable validity test.

Table 4 Coding instructions for the quality assessment of the outcome measures

<table>
<thead>
<tr>
<th>Fitzpatrick Criteria</th>
<th>Coding</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adequate</td>
<td>&gt; 0.7</td>
</tr>
<tr>
<td>Reliability</td>
<td>Partial</td>
<td>&gt; 0.5 &lt; 0.7</td>
</tr>
<tr>
<td></td>
<td>Inadequate</td>
<td>&lt; 0.5</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>Reliability not supplied</td>
</tr>
<tr>
<td>Validity</td>
<td>Adequate</td>
<td>Reports more than three types of validity tests</td>
</tr>
<tr>
<td></td>
<td>Partial</td>
<td>Reports two types of validity tests</td>
</tr>
<tr>
<td></td>
<td>Inadequate</td>
<td>Reports one validity test</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>Validity estimates not supplied</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Adequate</td>
<td>Significant differences found between groups or within individuals</td>
</tr>
<tr>
<td>----------------</td>
<td>----------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Partial</td>
<td>Non-significant trends found between groups or within individuals</td>
</tr>
<tr>
<td></td>
<td>Inadequate</td>
<td>Not addressed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Acceptability</th>
<th>Adequate</th>
<th>All of the components described</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partially addressed</td>
<td>At least one of the components described</td>
</tr>
<tr>
<td></td>
<td>Not addressed</td>
<td>None of the components described</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feasibility</th>
<th>Adequate</th>
<th>All of the components described</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partially addressed</td>
<td>At least one of the components described</td>
</tr>
<tr>
<td></td>
<td>Not addressed</td>
<td>None of the components described</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Precision</th>
<th>Adequate</th>
<th>All of the components described</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Partially addressed</td>
<td>At least one of the components described</td>
</tr>
<tr>
<td></td>
<td>Not addressed</td>
<td>None of the components described</td>
</tr>
</tbody>
</table>

**Results**

Table 2 summarises each of the measures and the articles that assessed the psychometric properties with adults with ID. There were six single-trait measures: three assessed anger, one assessed depression, one assessed anxiety, and one assessed self-esteem. There were also four multi-trait measures: two assessed psychological distress and nine indices of symptoms, one assessed interpersonal difficulties, and one assessed feelings. The response scales varied, with studies using 2-, 3-, 4- and 5-point Likert scales. Half used a 3-point Likert scale. Five of the outcome measures were adapted from use with the general population, four were
designed specifically for use with people with ID, and one was designed for use with the general population.

Table 5 summarises the key psychometric properties and the quality of each measure in relation to the criteria described by Fitzpatrick et al. (1998). The findings of the quality appraisal in relation to each of the criteria are discussed below.

**Reliability**

All measures showed adequate levels of internal consistency ($\alpha > 0.7$) apart from the RSES, which displayed partial levels ($\alpha = 0.64$). The following measures showed very good test re-test reliability $R = .57 \text{ - .97}$; Clinical Outcome in Routine Evaluation - Learning Disabilities (CORE-LD) (Brooks & Davies, 2007; Brooks et al., 2013), the Glasgow Anxiety Scale – Intellectual Disabilities (GAS-ID; Mindham & Espie, 2003), the Glasgow Depression Scale – Learning Disabilities (GDS-LD; Cuthill et al., 2003), Inventory of Interpersonal Problems – 32 (IIP-32; Barkham et al., 1996), the Novaco Anger Scale (NAS; Novaco & Taylor, 2004), the Provocation Inventory (PI; Novaco & Taylor, 2004) and the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965) The GAS-ID and the GDS-LD displayed the best overall reliability, with a combination of excellent internal consistency and test re-test reliability scores. However, sample sizes used for a number of these tests were very small. For example, the internal consistency of the GAS-ID was based on 35 participants with mild to moderate ID (anxious group = 19, non-anxious = 16). The test-re-test reliability was assessed on a subsample of only 17 participants from the overall group. Such small sample sizes create difficulties in extrapolating findings to the wider population.

**Validity**

There was a large discrepancy in the number and quality of the various validity assessments. For example, no validity assessments have been conducted on the CORE-LD and two assessments of validity (concurrent and convergent) were carried out on the GAS-ID. The anger inventory (AI) (Rose & Gerson, 2009) was found to have no relationship with the staff measure (concurrent validity) at assessment or pre-treatment. Overall, no measure met the ‘adequate’ level of quality in line with the
quality appraisal criteria, and only the GAS-ID, IIP-32 and RSES met the partially evidenced criteria.

Construct validity analysis (factor analysis) was conducted only on the BSI (Derogatis, 1993), IIP-32 and RSES. Interestingly, the analysis of these measures found that they did not factor in the same way as they did in their analysis with the general population. The IIP-32, for example, has been found to consist of eight four-item subscales when used with the general adult population (Barkham et al., 1996). Kellett et al. (2005) found only four interpretable factors in their analysis with 255 adults with ID: three factors which mapped with those in the general population (hard to be assertive, hard to be supportive, and too aggressive) and one which was an amalgamation of two factors (hard to be involved and hard to be sociable) from Barkham et al.’s (1996) analysis. Davis et al. (2009) found that the RSES yielded two factors (self-worth and self-criticism) when used with 219 adults with ID, compared with the uni-dimensional structure found through its initial development with adolescents without ID (Rosenberg, 1965).
<table>
<thead>
<tr>
<th>Measure</th>
<th>Reliability</th>
<th>Validity</th>
<th>Responsiveness</th>
<th>Acceptability</th>
<th>Feasibility</th>
<th>Precision</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Internal</td>
<td>Test</td>
<td>Discriminant</td>
<td>Convergent</td>
<td>Construct</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consistency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>0.923</td>
<td>No relation</td>
<td>Adequate</td>
<td>Not addressed</td>
<td>How data is administrated</td>
<td>Describes</td>
</tr>
<tr>
<td></td>
<td>study 1</td>
<td>No details</td>
<td>No details</td>
<td>No details</td>
<td>evalutive</td>
<td>describes</td>
</tr>
<tr>
<td></td>
<td>No details</td>
<td>No details</td>
<td>No details</td>
<td>No details</td>
<td>administered</td>
<td>scored and</td>
</tr>
<tr>
<td></td>
<td>study 2</td>
<td>No details</td>
<td>No details</td>
<td>No details</td>
<td>ed</td>
<td>mean scores</td>
</tr>
<tr>
<td>Brief</td>
<td>0.63 –</td>
<td>No details</td>
<td>No details</td>
<td>8 factor</td>
<td>Adequate</td>
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<td></td>
<td></td>
<td>Adequate</td>
<td></td>
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<tr>
<td>Symptom</td>
<td>0.78 / r = 0.66 – 0.79</td>
<td>structure</td>
<td>evaluative</td>
<td>addressed</td>
<td>Differences</td>
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<tr>
<td>Inventory</td>
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<td>Describes</td>
<td>found</td>
<td>assisted</td>
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<td>n format</td>
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<td>training</td>
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<td>required</td>
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<tr>
<th>Clinical Outcome</th>
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<tr>
<td>in</td>
<td>0.80 / r = 0.64</td>
</tr>
<tr>
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<td>No details</td>
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<tr>
<td>Evaluatio n - LD</td>
<td>Adequate questions</td>
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<td></td>
<td>for</td>
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<tr>
<td></td>
<td>population,</td>
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<tr>
<td>Scale</td>
<td>Correlation</td>
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<tr>
<td>------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Glasgow Depression</td>
<td>0.96 / r = 0.93</td>
</tr>
<tr>
<td>Glasgow Anxiety Scale</td>
<td>0.90 / r = 0.97</td>
</tr>
<tr>
<td>Depression Scale</td>
<td>0.90 / r = 0.97</td>
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<tr>
<td>LD</td>
<td>( r = 0.94 )</td>
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<tr>
<td></td>
<td>and carer</td>
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<td></td>
<td>form</td>
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<tr>
<td></td>
<td>( r = 0.93 )</td>
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<tr>
<th>Inventory of Interpersonal Problems - 32</th>
<th>Significant correlation</th>
<th>Partially addressed</th>
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<tbody>
<tr>
<td>( r = 0.89 )</td>
<td>with Interpersonal</td>
<td>Adequate</td>
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<tr>
<td></td>
<td>Sensitivity subscale</td>
<td>Evaluative</td>
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<tr>
<td></td>
<td>on BSI ( r = 0.35 )</td>
<td>and discriminative</td>
</tr>
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<td>Not addressed</td>
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<td>required</td>
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<tr>
<td>Scale</td>
<td>r</td>
<td>Correlation</td>
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<tr>
<td>Novaco Anger</td>
<td>0.92</td>
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<td></td>
<td>0.52</td>
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<td>Provocation</td>
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<tr>
<td>Inventory</td>
<td>(no scores given) and discriminative</td>
<td>Adapted questions</td>
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</tr>
<tr>
<td><strong>Rosenberg Self-Esteem Scale</strong></td>
<td>0.64 ( r = 0.63 ) Negative correlation with IIP-32 (( r = -0.32 ))</td>
<td>Adequate Evaluative</td>
</tr>
<tr>
<td>Symptom Checklist</td>
<td>90R</td>
<td>No details</td>
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<td>0.86 / r =</td>
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<td>0.71 –</td>
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and training required to administer populations
One possible reason for the lack of concurrent validity studies using factor analysis is the small sample sizes which are used in many studies to assess the psychometric properties of the outcome measures.

**Responsiveness**

All measures showed either adequate or partial responsiveness as a result of the initial search criteria limiting the quality appraisal to measures that have been used in individual therapy with people with ID. Many of the studies reported changes within individuals over the course of therapy (evaluative) rather than between groups (descriptive). Only the NAS and PI have been used in controlled research designs (Taylor et al., 2002, 2005). In these studies, changes in mean NAS and PI scores over an 18-session intervention were compared with a waiting list control. This is consistent with literature regarding assessment of psychological therapies with people with ID, where there are still very few controlled trials (Veerenooghe & Langdon, 2013).

**Acceptability**

No measures reached adequate levels of acceptability for service users. This was often the result of a lack of information rather than lack of acceptability. Only the GAS-ID, GDS-LD and CORE-LD were developed specifically for use with people with ID, and with the help of service users to generate the item pool. The acceptability (e.g. reading age, length of instrument, etc.) of these measures for adults with ID may be implicit through their design, but no data on this were reported.

The psychometric properties of all of the measures were assessed on people with ‘mild’ to ‘moderate’ ID. Moreover, only the NAS and PI reported why people did not complete the measure. Without information like this it is difficult to know for whom or when the measures are not suitable for use. Taken together, this means that there is still some uncertainty about which populations the measures are appropriate for or under what circumstances the measures are unsuitable for use. For example, it is not clear whether the measures could be used with people with ‘severe’ ID.
Feasibility

No measures reached adequate levels of feasibility. Again, this was the result of a lack of information rather than poor feasibility per se. All of the measures except the CORE-LD described administration instructions. The measures were administered using an assisted completed method, whereby the administrator would read each question to the individual and then ask them to rate themselves using a pictorial version of the Likert scale. However, no administration manuals or training packages for the measures were described, and only the GAS-ID and GDS-LD reported time taken to administer the measures.

Other areas that could not be determined included: level of training required to administer the measures, cultural or language translations or adaptations, and details on scoring instructions or availability of scanning options.

Precision

Analysis of precision (the ability to detect differences between different populations), information on how the measure should be scored, and the ability to cite benchmarks to facilitate interpretation of the scores, yielded mixed results. Analysis to assess the ability to detect differences between different populations was conducted on the BSI, GAS-ID, GDS-LD, IIP-32, RSES and SCL-90R (Derogatis, 1983). This often consisted of comparing clinical (meeting diagnostic criteria, referred for mental health difficulties) and non-clinical (referred for diagnostic assessments, not in receipt of mental health services) participants. The GAS-ID and the GDS-LD also analysed data from the general population. The measures that were assessed in this way showed good psychometric properties within each of the specific populations and were able to detect differences between them. For example, Kellett et al. (2003) compared data on the BSI across non-clinical, clinical and forensic populations, and found that '[t]he reliability results...illustrate that the nine symptom dimensions remain broadly reliable according to context' (p. 130). They also found that there were significant differences in reported symptoms and overall psychopathology across the three groups. The non-clinical group were the least symptomatic, followed by the forensic group, and the clinical group reported the highest levels of symptoms and overall psychopathology. The CORE-LD, NAS and PI did not compare scores across different populations.
Research analysing the GDS-LD, GAS-ID and BSI reported how data can be scored into an overall score and dimension scores. For example, Kellett et al. (2004) reported that the BSI can be scored up into nine symptom dimensions and three global indices of psychopathology. They also reported various meaningful benchmarks in terms of normative or comparative data to facilitate interpretation. Similarly, Cuthill et al. (2003) identified clinical cut-off score of 13-15 on the GDS-LD to identify people with ‘possible depression’ (p. 350).

All of the other measures reviewed did not report scoring instructions or meaningful benchmarks. They alluded to higher scores suggesting higher levels of distress in the domains they were assessing (e.g. higher scores on the NAS suggest higher levels of anger), but did not report how the administrator would score it up. For example, it was not clear whether one should record total scores, mean scores or scores from only the positively rated items. For this reason, they were not rated as having met the criteria for scoring in the quality appraisal.

Discussion

The main aim of the review was to evaluate systematically the quality of outcome measures that have been used in individual psychological therapy with adults with ID. The number of measures available is quite large (McGurk & Skelly, 2014) but the number actually used in studies was small (n = 13). It is also interesting to note that in 10 of the 16 controlled studies of group interventions reviewed by Vereenoooghe and Langdon (2013) used the same measures used in individual psychotherapy reviewed here.

The review highlighted that assessment of the construct validity of the available measures is lacking. This is important when one considers the measures that had their construct validity assessed – BSI, IIP-32, RSES – were found to factor differently with adults with ID compared with the general population. Findings like this suggest that adults with ID may experience mental health difficulties in a different way from the general population. This means that outcome measures designed to assess specific mental health difficulties (e.g. depression, anxiety disorders) in adults with ID may not be assessing the constructs we believe they are.
In assessing the responsiveness of measures, the review revealed very few controlled studies. This is an often-reported problem in assessing the effectiveness of psychological therapies with adults with ID (Nicoll et al., 2013; James & Stacey, 2014). It also limits the quality of the available therapy outcome measures, as their discriminative responsiveness cannot be assessed.

The acceptability of outcome measures with the target population was another poorly addressed area identified by the review. The AI, GAS-ID, GDS-LD and CORE-LD had been developed specifically for use with adults with ID. The remaining measures had been adapted for use with this population. There were no reports on service user involvement in the adaptation of these measures and/or how they found completing the measures. Only the CORE-LD reported any service user feedback on what it was like to complete (Brooks et al., 2013). Given the current drive for greater service-user involvement in ID healthcare services (DoH, 2000; 2009b), and the fact that co-production of services, resources and assessment tools is seen as essential in delivering effective services (Greenhill & Whitehead, 2010; Roberts et al., 2011; 2013), service-user inclusion in the development and/or feedback of outcome measures is essential to ensure acceptability.

As mentioned earlier, the review has identified that the psychometric properties of all of the currently available measures have been assessed on people with ‘mild’ to ‘moderate’ ID. This raises issues as to whether the measures are acceptable for use with people with ‘severe’ or ‘specific’ ID. Further work assessing the psychometric properties in different populations needs to be done to improve the acceptability of the measures.

Limited information was provided on time taken to administer outcome measures and administration instructions. This may be less problematic for well-established measures such as the BSI, IIP-32, RSES and SCL-90R that have administration manuals and detailed ‘assisted completion format’ administration instructions (see Kellett et al., 1999). The combination of these sources of information may be enough to aid administration of these measures. However, without clear instructions clinicians may adapt items for service users. This may affect the meaning of the items and the overall validity of the outcome measure.

A number of the outcome measures assessed single mental health difficulties. For example, the NAS assesses anger. This can create difficulties in routine care for people who have ID, where co-morbidity of mental health difficulties is common. Trying to use a number of single-trait measures to capture the difficulties of a service
user experiencing multiple mental health difficulties would be time consuming and burdensome even if each measure was relatively short to complete on its own.

Finally, there was limited reporting of benchmarks and/or cut-offs in the reviewed outcome measures. These are important to facilitate assessment of the severity of a difficulty in relation to normative data. Similarly, there is the need to be able to identify clinically significant change to assess the effectiveness of an intervention (Evans et al., 2002; Jacobson & Traux, 1991).

**Limitations**

One of the major limitations of the current review was the quality of the research assessing the effectiveness of psychological therapies with adults with ID. A number of studies identified in the systematic search did not report the use of any outcome measures to assess change (despite this being one of the search terms), and out of the 212 identified, only two had used a comparative waiting-list control. This is a major issue, as ability to detect change is an essential criterion for a therapy outcome measure (Fitzpatrick et al., 1998). Historically, researchers have been interested in developing diagnostic and screening tools for use with adults with ID (Kellett et al., 2003). However, it is now imperative that they develop measures that can be used to assess therapy outcomes, and design studies where change can be quantified.

Another limitation was the lack of information about the outcome measures in the research papers. Quality-assessing the acceptability and feasibility of measures was particularly difficult because of this.

There was also limited information on how each measure was scored. All of the papers implied that higher scores equated to higher levels of that symptom or symptoms but did not report how to score them (i.e. mean score or total score), or whether to take scores from specific items or all of them. Equally, there was no information on whether items were reversed, or if clinicians needed to reverse them when they were scored up. A good example of this is from the development of the CORE-LD (Brooks et al., 2013), where they report ‘the mean pre-therapy scores are 0.9 and the mean post therapy score is 0.5’ (p. 327), but do not report what these mean scores are taken from.
Conclusions

Results from this review reveal that the number of single- and multi-trait outcome measures used in individual psychological therapies with adults with ID is quite small compared with the range available. The quality appraisal of these measures highlighted that the outcome measures currently used have good psychometric properties and therefore there is potential for future research and service evaluation. However, there is still work to be done to improve their overall quality.

The three key areas that need to be addressed are as follows:

The construct validity of the available outcome measures should be assessed.

More rigorous study designs (e.g. controlled trials) are required to assess the effectiveness of psychological therapies with adults with ID and the ability of therapy outcome measures to detect change through intervention.

There should be greater involvement of service users in all areas of measure development (for example, item pool generation, wording of questions, feedback on length, and administration procedure).
References


Conclusions

Innovation, adaptation and reasonable adjustments to ensure equality of access to psychological therapies

There was a time when the words psychotherapy and intellectual disability rarely appeared in the same sentence, and when they did it was to negate one in relation to the other. For a while, a few lone voices challenged this, and then those voices became a choir.

Proponents of the psychodynamic and cognitive behavioural therapies began to explore their use with people who have ID. This was followed by a presence at conferences and a literature began to emerge. Many of those involved in this process worked together through the 1990s to bring into being in 2000 the Institute for Psychotherapy and Disability to promote provision and training (Frankish, 2009). Following this, work began on the 2004 Royal College Report on psychotherapy and learning disability. Since then, there have been many changes at the societal and political levels. Increasing attention has been given to the issue of human rights and, in particular, the rights of people who have disabilities. This has led rights for equality and freedom from discrimination to rise in prominence. Health care workers now have equality and diversity training, and service providers and employers are now required to make reasonable adjustments. Alongside these developments has been a greater awareness of the value of psychological therapies in the alleviation of psychological distress in the whole population, including people who have ID.

In the research and clinical practice area, much has been done to provide a fuller understanding of the mental health needs of people who have ID. This has been promoted by the Faculties of the Royal College of Psychiatrists and British Psychological Society and also internationally through the work of the European Association for Mental Health in Intellectual Disability and the International Association for the Scientific Study of Intellectual Disabilities. We now have a much better understanding of the mental health needs of people who have ID. We now know these are at least the same as the rest of the population and many studies show them to be greater. Therefore, it is only logical that if the mental health needs of people who have ID are similar, the range of interventions available to them should
be similar. This report shows that the range of interventions available has grown and that this has been due to the pioneering work of individuals and teams who have made those reasonable adjustments. Past objections have been replaced by innovation to accommodate the needs of people who have ID. As Safran and Segal (1990) pointed out, innovating to accommodate individual needs in psychological therapy should not mean abandoning the therapeutic model. Instead, they argue, the therapist requires a deeper understanding of the model to ensure that innovative or creative strategies remain faithful to the underlying principles of the approach. In this report the invited contributors have outlined their approach and the adjustment they have found necessary to enable people who have ID to participate and gain benefit. It is for readers to decide whether these adjustments stay true to the model. However, it is hard to accept that modifications in technique for people who have ID should be considered as more or less of a violation as modifications made for children or any other groups in society.

In 1996 and again in 2005, Roth and Fonagy published critical reviews of psychotherapy research which they titled ‘What works for whom?’ This principle has been at the forefront of the culture of evidenced-based practice and then practice-based evidence. Bearing this question in mind has enabled clinicians to make more informed decisions with their clients as to what psychological therapy works for which problem. This process continues with the development of NICE guidelines in general, although as yet no such guidelines have been developed for psychological therapies for people who have ID. However, a positive developments are the forthcoming NICE guidelines for people with ID who present with behaviours that challenge, and the guidance on the mental health of people who have ID.

Unfortunately, ID continues to be given as an exclusion criterion for research on psychological therapies when the general population are involved. However, as we have seen, evidence is emerging from studies providing psychological therapies to people who have ID.

The contributors to this report were asked to provide an overview of the evidence base for their approach. You will see from their contributions that some have suggested what their model may be best indicated for. Unfortunately, the volume of available research is such that it is still difficult to use it to inform decision-making. Generally, most models have evidence for effectiveness; however, effectiveness for what exactly is not always clear. There is, for instance, in comparison with other models, a lot of evidence for CBT’s effectiveness with people who have ID who present with anger issues. In the general population, most of the evidence for CBT is for the treatment of anxiety and depression. So far, there are a couple of studies showing outcomes for CBT with people who have ID who also have depression. However, there is no evidence for anxiety, trauma and many other difficulties. None the less, this should not mean we should not use this approach with people who have
ID and anxiety. We also need to consider that if these approaches work effectively with the rest of the population, they may work equally well with people who have ID provided reasonable adjustments are made. What we do need to do is evaluate that work as we go along, and this report provides guidance on how to incorporate a routine monitoring approach into clinical practice, and on the reliability and validity of the measures that can be used. It cannot be said too often that most of the evidence we do have comes from research and evaluation in routine clinical practice. We need to continue to be aspirational and seek opportunities to expand our research efforts. It is hoped that the wealth of information in this report will encourage the availability of psychological therapies to people with ID, and further research and evaluation efforts.
References


