Psychological treatments in intellectual disability: the challenges of building a good evidence base†

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Summary
Psychological treatments are widely used for the management of mental health and behavioural problems in people with intellectual disabilities. The evidence base, including the cost-effectiveness of such interventions, is limited. This editorial explores the current evidence base and analyses its strengths and limitations. The editorial also highlights current problems in conducting randomised controlled trials in this area and suggests a way forward.

Declaration of interest
None.

The existing evidence for the clinical effectiveness of psychological treatments for people with intellectual disabilities is limited despite the high prevalence of mental health and behavioural problems in this population, and the resulting greater demand for psychological treatments.1 A significant proportion of people with intellectual disabilities present with maladaptive behaviours that often originate in childhood and persist into adulthood. Behavioural problems, especially those without any underlying mental illness, are usually multifactorial in origin, and hence the use of medications to manage these behaviours is controversial.2

In particular, the clinical fit between the needs of the person with an intellectual disability and the psychological therapy offered is seldom described in the literature. This editorial attempts to describe the strengths and limitations of the evidence base for the range of psychological treatments for people with intellectual disabilities.

Current evidence base

The psychotherapeutic approach in people with intellectual disabilities is controversial,3 and the evidence base for the effectiveness of psychological therapies is extremely limited.4 Hence, a degree of inference is drawn from the interventions applicable to the general population with mental health problems. This inference may be acceptable for those with borderline or mild intellectual disabilities, but is certainly less acceptable in those with moderate to profound intellectual disabilities as their abilities and communication skills are limited. Although a few available randomised controlled trials (RCTs) have provided some evidence for the efficacy of psychological interventions, generally the studies have been of poor quality for a number of reasons.5 Most studies lack adequate numbers of participants, are of poor design, lack control groups and have differing outcome measures. It is therefore very difficult to draw any meaningful conclusions from the findings.

Empowering approaches such as participatory research that allows the participant to make decisions throughout the research process makes the RCT methodology less rigorous. The existing literature indicates that low-quality RCTs in this area tend to overestimate the effectiveness of interventions. Moreover, with the exception of a few studies,6 the cost-effectiveness of such interventions has not been addressed in a systematic manner. The paucity and poor-quality evidence in intellectual disability therefore encourages opinion-based practice in this field.

In addition, ethical concerns such as mental capacity and consent make it difficult to carry out good research. There is not much available evidence regarding the assessment of motivating people with intellectual disabilities to engage in psychological therapies, and similarly there is virtually no research that determines the best-fit therapy based on the profile and the needs of people with intellectual disabilities.

Effectiveness of psychological interventions commonly used

It is not within the scope of this editorial to cover the full range of psychological interventions. We have therefore focused on common interventions such as behavioural approaches, cognitive–behavioural therapy (CBT) and psychodynamic psychotherapy. Nagel & Leiper,7 in their survey of interventions used by clinical psychologists in the UK, found that 80% of respondents stated that they used behavioural interventions through staff, 35% reported that they used CBT techniques and 17% reported that they were using psychodynamic methods. Prout & Nowak-Drabik,8 in their meta-analysis of a small number of studies covering a wide range of psychotherapeutic approaches, found that such interventions only result in a moderate amount of change, and are only moderately effective. Their conclusion was that a range of psychotherapeutic interventions should be considered as part of the overall treatment plan for people with intellectual disabilities.

Behavioural interventions

Most services for people with intellectual disabilities employ nurses or psychologists with specialised skills in behavioural
Interventions who are able to deliver such treatments. These models can be adapted and applied to the full range of people with intellectual disabilities. Some critics, however, question the benefits of the behavioural approach as it often fails to address the emotional context of the behaviour, and therefore its sustained benefit is questionable.

There have been efforts to assess the effectiveness of the different components of behavioural interventions. For example, a meta-analysis showed that pre-treatment functional analysis and respondent contingent procedures were significantly more effective than other procedures.\(^6\) Hsiottois et al.\(^6\) assessed both the efficacy and cost-effectiveness of a service-led intervention over a longer follow-up period. Overall, it appears that there is not much evidence on the cost-effectiveness of different components of intervention packages.

**Cognitive–behavioural therapy**

Cognitive–behavioural therapy is widely used in mainstream services and has a good evidence base in terms of both short- and long-term efficacy. In the intellectual disability population, much of the research on CBT has come from forensic secure units and has shown it to be effective for conditions such as depression, anxiety, anger management and sex offending,\(^5\) with literature on anger management appearing to have the strongest evidence base. There are two RCTs on the use of CBT in anger management. The first trial was conducted in secure settings\(^7\) and revealed a significant reduction in self-reported outcome measures. The second trial was conducted in the community\(^1\) and revealed a reduction in anger as reported by both the participant and the carer.

Despite a number of available research studies in this area, the quality of studies remains poor with the exception of a few. Additionally, most of the trials on CBT have multicomponent packages making it difficult to establish the effectiveness of each component.

The use of CBT relies significantly on language, which can limit its utility when there are communication difficulties. Although a number of initiatives have been taken to improve access, it has not been possible to develop standardised approaches to the application of CBT in the intellectual disability population. Sturley\(^12\) in a review paper, pointed out the fact that the extent to which CBT can be used in an intellectual disability population is not clear and therefore, unlike behavioural interventions, CBT has not yet become an integral part of service delivery in many areas. The question that still remains to be answered is whether CBT can be provided for people who have limited intellectual abilities.\(^4\)

**Psychodynamic therapies**

Psychodynamic therapy is still at an early stage of development in people with intellectual disabilities. The literature suggests that psychodynamic psychotherapy can lead to a reduction of psychological symptoms and result in improved self-esteem in this population.\(^13\) There have been efforts to use psychodynamic interpretations to explore the experiences of people with intellectual disabilities.\(^14\) However, research in this area is restricted to a few case reports and case series. In common with all of the interventions discussed here, use of psychodynamic therapy is limited by any co-existing communication deficits, which makes it difficult to understand the dynamic constructs of the individuals concerned. Furthermore, assessing the effectiveness of the intervention may be difficult to differentiate if the individuals may have had from the humanistic element of the contact.

In order to prioritise research into psychological treatments for people with intellectual disabilities, the interventions need to be divided into three distinct categories: interventions with no evidence; interventions with limited but promising evidence; and those with adequate evidence.

Where there is no available evidence, the development of effective collaboration between health professionals from different disciplines is paramount to building an evidence base, as single-discipline perspectives are likely to be inadequate. The Royal College of Psychiatrists’ Faculty of the Psychiatry of Learning Disability, the British Psychological Society and the Royal College of Nursing along with other professional bodies would need to take a significant role in facilitating this.

All new studies in this area need to adopt a standardised and transparent approach. In particular, the nature of the intervention should be clear and well defined, so that it can be replicated elsewhere.\(^15\) Outcome measures should be appropriate, preferably using validated instruments and standardised. Effective communication between intellectual disability health professionals will also ensure that current work is not duplicated elsewhere and facilitate collaboration.

The lack of a sufficient number of trials with adequate sample sizes appears to be a crucial issue. Recruitment problems in research can be partly solved by a mult centred approach supported by research networks. Networks must be developed to promote, support and sustain ongoing dialogue between researchers, interested clinicians and user and carer groups. The social validation of such evidence is likely to be promoted through the involvement of users and carers.

As behavioural interventions are used routinely in most services, prioritising research in this area is urgent. Cognitive–behavioural therapy has the strongest evidence base in the general population and is being increasingly used in the intellectual disability population. Thus, this is likely to be an important psychological intervention that needs further research through well-conducted RCTs. Conversely, psychodynamic therapy for people with intellectual disabilities is still a developing area and needs further validation of its applicability, perhaps through qualitative research at this stage. It might also be important to identify the characteristics of individuals who respond to psychodynamic approaches. For all these interventions, future research needs to have valid and reliable outcome measures, homogeneous study groups and adequate sample sizes for the evaluation of their cost-effectiveness.

Developing a research-based evidence base is not only critical to the establishment of new services or interventions, but also necessary to support the value of existing services.\(^5\) A good evidence base does not always need to be derived from RCTs,\(^16\) especially in areas where recruitment into research is still a challenge. However, good research questions and well-designed studies are still invaluable in building an evidence base and every effort should be made by all professionals, researchers and user and carer groups to support such research endeavours.
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Access the most recent version at DOI: 10.1192/bjp.bp.110.085084

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