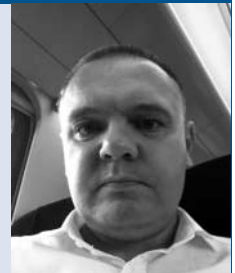


Editorial

Running to catch up: rapid generation of evidence for interventions in learning disability services†

Richard P. Hastings

**Summary**

Few high-quality trials have been conducted in intellectual disability mental health. Trials such as Willner *et al*'s have a 'close-to-market' focus. I argue that rapid generation of evidence for individuals with intellectual disability is the

priority, alongside a new research focus on mental health in those with severe intellectual disability.

Declaration of interest

None.

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Adults with intellectual disabilities ('learning disability' in UK health service terminology) face significant mental health inequalities as well as challenges accessing appropriate support from services to address their mental health needs. Like the rest of the population, adults with intellectual disability clearly deserve to be supported or treated using approaches that are evidence-based. However, there is a danger that the current paucity of evidence in the intellectual disability mental health field can be used as an excuse for lower-quality care. Services can point to the lack of high-quality research trials and argue that there is no consensus about the interventions that need to be delivered. Professionals can argue that decisions about how best to support individuals with intellectual disability can be left to their personal judgement and interests. It is difficult to hold services and professionals to account when evidence is lacking.

Do we need separate evidence for interventions in intellectual disability?

How do we rectify this situation? Certainly, the intellectual disability field has some running to do to catch up with the evidence base for mental health interventions generally. This assumes that catch-up is necessary in relation to intellectual disability-specific evidence. Perhaps we can adopt the general evidence in the mental health field? Why should people with intellectual disability need their own special evidence? One answer to this question is values-based. Inclusion means that we should assume that adults with intellectual disability are just like all other adults and their mental health needs can be supported using mainstream mental health services. A second answer to the question of whether we need special evidence focuses on some clear differences relevant to adults with intellectual disability. Specifically, we have argued¹ that: individuals with intellectual disability are typically excluded from mental health intervention research; research on the causal variables explaining mental ill health in intellectual disability is lacking; we lack an understanding of whether the processes underlying putative therapeutic success in

psychological therapies (e.g. using visual imagery or meta-cognition) are sufficiently established in adults with intellectual disability; and a key component of psychological therapy in intellectual disability may be the person's response to their disability and their experience of stigma.²

'Closer to market' evidence in intellectual disability

Although debate is needed about the wisdom of working to generate a separate evidence base for mental health interventions in intellectual disability, there seem to be enough differences and unknowns to support the special case position for the time being. Given this position, what sort of evidence do we need? Following frameworks such as that described by Thornicroft *et al*,³ theoretical development and basic science research are needed, model development and initial testing, efficacy trials of promising interventions, effectiveness studies and, finally, implementation research. Although frameworks such as Thornicroft *et al*'s do not necessarily specify a rigid linear process for the development of evidence, the fact remains that carefully building evidence stage by stage can take years and potentially decades.

Slow, incremental progress in the development of evidence is probably not a luxury that can be afforded in the field of intellectual disability. Rather, evidence is needed now. A more rapid development process is required. Without sacrificing the quality of research design, or the quality of theory and synthesis of relevant evidence underpinning an intervention, research evaluations are needed that are much 'closer to market'. Interestingly, three randomised controlled trials in the field of intellectual disability mental health carried out in the UK have, probably implicitly, adopted this position. These three studies have all addressed questions of immediate relevance to the management of mental health in adults with intellectual disability.

In the first of these trials, Tyrer *et al*⁴ examined the pharmacological management of aggressive challenging behaviours in adults with intellectual disability. Antipsychotics are often used to manage individuals with aggressive behaviour. However, Tyrer *et al*'s results demonstrated that antipsychotics were no better than placebo in reducing aggressive behaviours. Thus, their therapeutic role is called into question. The second trial also focused on challenging behaviour, but this time on the evaluation of the main service model applied to managing individuals with challenging behaviours in the community. Hassiotis *et al*⁵ randomly allocated adults with intellectual

†See pp. 288–296, this issue.

disability to support as usual or to a specialised positive behaviour support team. Outcomes were better for those assigned to the positive behaviour support team, and overall costs were also slightly lower. Thus, this trial offered evidence to support the design of services for adults with intellectual disability and challenging behaviour in the community.

The evidence generated in the Tyrer *et al* and Hassiotis *et al* trials could be implemented immediately by services supporting adults with challenging behaviours. Patients can probably be removed from antipsychotics, thus reducing some of the associated risks to physical health, especially since earlier randomised controlled trial evidence showed that drug reduction could be achieved safely and without leading to increased challenging behaviours.⁶ Instead, patients should be treated by community-based specialist positive behaviour support teams. Implementing this evidence may also save money while delivering better outcomes. Of course, such recommendations for practice assume that the quality of the evidence from these studies is high and probably that we have some replication of the findings. However, these studies both illustrate how it is possible to evaluate interventions close to market with implications for service delivery in the relatively short term.

The third trial is published in this issue of the *Journal*. Willner *et al*⁷ report results from a carefully designed and run cluster randomised trial of cognitive-behavioural group therapy for adults with mild intellectual disability living in the community and with problems of anger control. Although perhaps there is no knockout large-scale efficacy trial already in the research literature, there is a history of theoretical development, small evaluation studies and established clinical practice in the treatment of anger in adults with intellectual disability.⁸ The Willner *et al* study was designed in a way that makes it close to market. Day-centre staff were trained and supervised by clinical psychologists to deliver anger treatment to groups of adults with intellectual disability. This is a model that is typical of service delivery and something that could be replicated in most national health services and in social care settings in the UK. Thus, the results of the study could be rapidly applied and rolled out.

Tyrer *et al*, Hassiotis *et al* and now Willner *et al* may have hit on the solution to the problem of how we rapidly generate evidence to inform mental health interventions and services for adults with intellectual disability. More high-quality studies of this close-to-market type are needed to provide the catch-up in evidence that adults with intellectual disability and their families deserve. There are likely many other examples of interventions that could receive this rapid evidence development attention. Psychological therapies in particular that have been recommended for the general population can be adapted swiftly and tested within typical service settings, and using typical clinical staff.

The challenge of severe intellectual disability

A final point worth making is that the preceding arguments clearly apply to the mental health needs of adults with mild to moderate

intellectual disability. These adults often have sufficient communication skills to benefit from adapted psychological therapies and can report their mental health symptoms using modified assessment tools.⁹ A considerable challenge presents itself in the form of adults with more severe intellectual disability. We understand much less about mental health problems in this population, and very little about how to then conceptualise and deliver treatment, especially of a psychological nature. By focusing on the rapid generation of evidence relevant to the support of adults with mild to moderate intellectual disability, the exclusion of those with severe intellectual disability from the mainstream of mental health may become even more obvious.

Therefore, my call in this editorial is twofold: first, consider further how evidence relating to mental health interventions for adults with intellectual disability can demonstrate 'catch-up' by focusing on rapid evidence generation of close-to-market data; and second, for a new research effort to understand and to develop treatments for the mental health needs of those with more severe intellectual disability.

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First received 2 Mar 2013, accepted 25 Jun 2013

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