



## Lessons for the Care of People with Learning Disabilities and Challenging Behaviour

A major health problem in people with learning disabilities can be managed effectively by specialist care

## Briefing

Challenging behaviour (eg aggression, self-injury, destruction of environment) is a long-term high-impact health problem in people with learning disabilities which is seen in about 10–15% of the population. It peaks at the ages 20–50 and has severe impact on individuals and their social network as it can lead to exclusion and placements out of area.

It has been reported often that care of people with learning disabilities who also have challenging behaviour should be locally provided and be specialised. However, there are still systemic failures that allow service users with challenging behaviour to be treated in inappropriate settings away from home, as a BBC *Panorama* documentary showed in May 2011<sup>1</sup>.

The Randomised Evaluation of Behavioural Intervention in Learning Disabilities (REBILD) study investigated the most commonly used behavioural intervention, Applied Behavioural Analysis (ABA). It found that ABA reduces challenging behaviour at six months. Furthermore, follow-up analysis found that this effect was maintained up to two years after the trial ended, when compared with treatment as usual. The treatment appeared to be cost neutral both at six months and at two years. The family carers of the participants in the intervention arm showed less burden in looking after their relatives.

Therefore, a major health problem in people with learning disabilities can be managed effectively by specialist care.

The mainstay of treatment to date has been pharmacological therapies – mostly antipsychotic medication but also other agents such as antidepressants or antiepileptics. However, there is no evidence that these medications improve behaviour and in fact a recent study suggested that they may be no better than placebo.

Behavioural therapies have been used widely over the years in treating challenging behaviour but there has been little high-quality evidence for their effectiveness. Furthermore, there is a paucity of studies regarding their cost effectiveness or the kind of care model that can successfully deliver such behaviour.

## Recommendations

We recommend that specialist teams are set up as part of the overall provision of community-based mental health care in learning disabilities to provide specialist treatment to a vulnerable group of service users, beyond treatment as usual. This may have financial implications but could be easily done with commitment from the Department of Health (similar to their ordering of mental health crisis teams).

We recommend that out-of-area specialist services must employ behavioural specialists to provide ABA in addition to standard treatment. They should be subject to monitoring with implications for registration and possibly subject to financial penalties if they fail to comply. This can be implemented via commissioning arrangements and conditions of practice (there are some such descriptions currently available, and a few areas such as South Essex provide this care model) in existing guidance.

## Background to the research

The REBILD study was funded by the South Essex Partnership University NHS Foundation Trust and was carried out between 2005 and 2009. It used a randomised controlled trial design that included two arms, the intervention and treatment as usual arm and the treatment as usual arm only. The study was successful in promoting a close collaboration between NHS and university partners and led to some important findings which have significant implications for the care of people with learning disabilities.