

Forward: Responding to a changing world

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Since the last edition of the Challenging Behaviour Handbook was published in 2011, a great deal has changed in the world of services for people with intellectual disability who present challenging behaviour.

Prior to 2011 a quiet evolution of best practice in supporting people was taking place, and the term Positive Behaviour Support was increasingly heard. In practice this meant different things to different people, but broadly it implied challenging behaviour was to be understood as carrying a message. Through understanding this message, support could be tailored to better meet a person's needs. Positive Behaviour Support requires us to change the manner in which we support people, and importantly, change how we think about challenging behaviour.

Since 2011 there has been significant growth in Positive Behaviour Support (PBS). We have seen the development of the PBS Academy and its definition of competency standards becoming increasingly relevant. The Academy has helpfully set out what PBS looks like in practice. Significantly in 2011 the need for the wider implementation of the values and practices of PBS was highlighted by the horrific events at Winterbourne View. This private hospital was the subject of a BBC undercover investigation showing emotional and physical abuse. Not only were individuals held responsible for the ill-treatment of vulnerable people at Winterbourne View, the systemic failures of methods of keeping people safe were highlighted. A national debate began concerning the suitability of hospitals in supporting people with intellectual disabilities.

Central Government was quick to respond and initiated the *Transforming Care* programme. This was formally launched in 2012. It recognised that what happened in Winterbourne View was not a case of 'bad apples' but a wider and fundamentally more dangerous 'bad barrel'. Winterbourne View was merely the tip of an iceberg – an iceberg that had in fact been previously represented on the cover of the Mansell reports of 1993 and 2007 (Department of Health 1993; 2007).

Transforming Care stated that reviews undertaken in the wake of the Winterbourne scandal had revealed a 'widespread failure to design, commission and provide services which give people the support that they need close to home, and which are in line with established best practice. Equally, there was a failure to assess the quality of care outcomes being delivered for the very high cost of placements at Winterbourne View and other hospitals' (p8). It made the powerful statement that 'we should no more tolerate people with learning disabilities or autism being given the wrong care than we would the wrong treatment being given for cancer'.

The policy rightly identified one of the problems being the model of provision which involves taking people far away from their homes, families and loved ones, and placing them in large 'assessment' or 'hospital' facilities which struggle or fail with their sole purpose, that of assessing, understanding and treating people. The multi-agency solution was to review all hospital placements, focus on reducing the numbers of people in such facilities and increase the inspection and regulation of these places. Alongside these recommendations came specific endorsement of PBS.

Since that time *Transforming Care* has failed to meet its objectives. It unfortunately remains the case that large numbers of people with intellectual disability and/or autism are still placed in hospital care some distance from their homes and that, while in such placements, many will experience high-risk physical interventions, contrary to current policy guidance. The people living in such places will experience the risk of assault from others. Dave Allen, in a recent critique of the policy, concluded

'The inappropriate use of inpatient facilities for this group stems in the first place from a fundamental lack of competence to meet needs at a local level. Failing strategically and systematically to develop such competence fails to address the principal reason for admissions to such services. Unfortunately, though the policy did flag this as an objective, the main focus of Transforming Care has been closing hospital beds. To use a crude analogy, rather than turning off the taps, attention has been focused on emptying the bath. The revolving pattern of admissions described above is an inevitable consequence.' (Allen, 2019).

This brings us to the purpose of this handbook. It could be argued that the remaining legacy of *Transforming Care* has been to highlight, endorse and increase awareness of the importance of PBS as a framework for designing services for people with intellectual disabilities in order to avoid or manage challenging behaviour. Our intention then has been to produce summaries of different aspects of the PBS framework that are both accessible and practical.

The handbook is written for those people who work or live directly with people with intellectual disabilities who present challenging behaviour. We have taken a 'reference lite' approach to make the content speak for itself. Our intention is that the book will be life changing – in as much as the lives of people with intellectual disabilities will change for the better as a result of people who are important to them, namely family members and support staff reading, and more importantly, changing how they understand people and behaviour as a result of reading it.

The editors' fees from this book go to The Challenging Behaviour Foundation (CBF). The CBF has for many years provided a voice for parents supporting children whose behaviour challenges those around them. The CBF are advocates for person-centred support and the implementation of research and policy. Their work has proven a lifeline for parents as well as a perspective many policy makers and service providers have benefitted from hearing. We are pleased this book will contribute to supporting the work of CBF.