

CONFERENCE ABSTRACT

Models of community based integrated care for people with a learning disability and/or autism: evaluation findings from a national implementation programme

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Improvements in the rights and opportunities for people with a learning disability and/or autism (henceforth described as ‘people’) have led many countries to move away from long-term institutional care to community based models. However, people with behaviour that challenges and/or severe mental health problems often continue to lack the integrated support they need to make choices about how they live, resulting in poor outcomes and severe health inequalities.

In 2015, following successive scandals relating to abuse and poor quality of care, the NHS in England initiated the Building the Right Support national plan, which sets out an integrated service model to reduce dependence on hospital care. Local partnerships were established to oversee integrated working between health and social care commissioners, and specialist and community providers of care, support and housing, so that people could be supported closer to home.

To understand the implementation process a national, three year evaluation was commissioned by NHS England to identify good practice, and understand the success factors and barriers that lie behind consistent implementation of the service model.

The evaluation has used a longitudinal mixed methodology. Data sources include repeated in-depth interviews with national and regional policymakers (n=66), a survey of practitioners, people and family members (n=232), and detailed case studies of implementation in ten localities. The evaluation has directly engaged people with lived experience and their families through workshops and focus groups and has also sought perspectives from local and national representative groups and forums.

We found that despite common endorsement of the integrated service model:

There are continued gaps in care and support: receiving integrated care was not a common experience of most people and their families. Autistic people with mental health conditions, and children, are particularly poorly served. Many more people than expected remain dependent on hospital care.

Implementation difficulties arose in areas that did not have a shared understanding of what was required to introduce the service model and a willingness to collaborate differently to achieve it. Conversely, local areas that had inherited and/or sought to develop a shared culture and trust-based relationships between commissioners and providers (as opposed to transactional ones) were most successful.

Good quality co-design is critical to implementation, so that the priorities of local services match the needs of people and their families. The time and effort required for this was not usually prioritised, despite national and local commitments to do so.

Progress in implementing the model after the end of the formal programme period in March 2019 is at risk due to constrained budgets (especially in social care), recruitment and retention difficulties within the care workforce, and a loss of momentum, should the policy focus change.

Therefore, while the service model is based on a widely supported model of integration, the blend of incentives, guidance, resources and compulsion has not led to consistent implementation. Honest appraisal of the scale of cultural and societal change required was somewhat overlooked, especially regarding ways that national and local bodies could work together to fund, manage and evaluate care.

Keywords: evaluation; learning disability; policy implementation; models of care; system development
