

CLAHRC BITE

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A bite-sized summary of a piece of CLAHRC research



Responding to the Winterbourne View scandal

What?

CLAHRC East of England researchers are carrying out a longitudinal study, over a period of 12 months, of people with learning (intellectual) disabilities referred to locality-based community teams for support with a mental health and/or behavioural need, such as dementia, self-injury or physical aggression.

Who?

The study draws on previous research, the clinical experience of members of the research team, and the insights and practical guidance of our service user research advisory group.

Why?

The scandal at Winterbourne View Hospital in 2011 exposed the difficulties that specialist community teams may have in supporting adults with learning disabilities and additional mental health and/or behavioural needs to remain in their home localities. The study seeks to provide evidence to inform the development of these teams.

The study is part of a broader project examining the five integrated (NHS and local authority) locality-based community teams in a county-wide learning disability service. In this study, we focus on men and women referred for support with mental health and/or behavioural needs (such as dementia, self-injury or aggression). Data collection is wide-ranging and includes clinical and quality of life outcomes for service users, stakeholders' experiences of the community teams, and team working.

Local dissemination of emerging findings has taken place through team meetings, newsletters, and events for the service's managers and health and social care/care management staff. Our service user research advisory group has helped us write newsletters for service user and carer participants. The findings have contributed to improvements such as guidance about team meetings and information management that have been implemented across the service.

Nationally, members of the research team contribute to a number of initiatives to improve community teams' ability to support people with learning disabilities and additional needs to remain, as far as possible, in their communities. These include Professor Tony Holland's involvement as co-chair of a group that seeks to develop a model for local health and social care provision to support children, young people and adults with learning disabilities and/or autism spectrum conditions and additional mental health and/or behavioural needs.

References

Farrington C, Clare ICH, Holland AJ, Barrett M, Oborn E. Knowledge exchange and integrated services: experiences from an integrated community intellectual (learning) disability service for adults. *Journal of Intellectual Disability Research*, 2015: 59(3):238-247.

Hempe E, Morrison C, Holland AJ. Exploring the boundary of a specialist service for adults with intellectual disabilities using a Delphi study: a quantification of stakeholder participation. *Health Expectations*, 2013. DOI:10.1111/hex.12107.

What is NIHR CLAHRC East of England?

The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England is a five year programme of applied health and social care research which focuses on the needs of people with complex problems, often vulnerable, when multiple agencies are involved in their care: young people, frail older people, those with dementia, learning disabilities, acquired brain injuries or mental ill health.

The CLAHRC East of England collaboration encompasses some thirty-six organisations, with research hubs in the Universities of Cambridge, Hertfordshire and East Anglia working closely with individuals and organisations involved in the whole care pathway.

Service users and carers are at the heart of what we do, in parallel with an ambitious public health research programme. Co-production and collaboration at all stages of the research process are fundamental to making a positive impact through applied health research.

Read more about this study on our website

<http://www.clahrc-ee.nihr.ac.uk/2014/03/winter-bourne-view-aftermath-2/>

or contact Dr Isabel Clare at ichc2@medschl.cam.ac.uk

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