
CONFERENCE ABSTRACT

Stuck in Hospital: how can we make integrated care a reality for people with a learning disability and / or autism who experience long stays in assessment & treatment settings?

23rd International Conference on Integrated Care, Antwerp, Flanders, 22-24 May 2023

Robin Miller¹

1: University Of Birmingham, Birmingham, United Kingdom

Introduction: Integrating care so that people with learning disabilities and/or autistic people can receive support at home rather than in institutional assessment and treatment units is a priority in the UK and many other countries. Despite the recognition of its importance, progress on timely and coordinated discharge has been slow. Surprisingly little previous research has engaged directly with people with learning disabilities and/or autistic people, their families or front-line care staff to understand the issues from their perspectives. This project has sought to address this gap.

Community of Interest: Professionals, policy makers, researchers, people with a learning disability and / or autism, and family carers connected with this area of integrated care policy and practice.

Engagement: We worked with a Reference Group of people with learning disabilities and/or autistic people and their families to co-design our approach, sense check findings and support dissemination. Reference Group members were reimbursed for any expenses, paid for their time, and received appropriate support and training for the tasks in which they are involved. The project was also designed and delivered in collaboration with a self-advocacy group.

Overview: We initially conducted a formal review of the research and grey literature, identifying rates of delayed discharge for people with learning disabilities and/or autistic people in long-stay hospital settings, the methods used to identify such rates and the solutions proposed.

Next, we worked with three long-stay hospital sites from across the UK in order to conduct:

In-depth work with ten people with learning disabilities and/or autistic people per site, and with a family member, to understand their journey through services over time, their experience of long-stay hospital provision, how care was co-ordinated to meet their aspirations, the kinds of lives they would like to be living, and the barriers that are preventing them from leaving hospital

Focus groups with front-line staff and interviews with a commissioners for each of the 30 people with learning disabilities and/or autistic people.

The perspectives of social workers supporting our 30 participants, as well as of advocates and social care providers working with people leaving long-stay hospital settings

Results: The data from the study is currently being analysed with the final report due by the end of December 2022.

Miller: Stuck in Hospital: how can we make integrated care a reality for people with a learning disability and / or autism who experience long stays in assessment & treatment settings?

Insights: From our analysis to date, we have identified the following recommendations for policy & practice: see the person behind the labels; don't make people jump through more hoops than is really needed; help hospital staff know what's available in the community; give people the chance to try life outside; help people with the trauma they've experienced; and. don't let people fall through the cracks between services.

Next steps: Alongside completing the report, the research team have a practice guide in publication, a film highlighting main implications, and an accessible practice guide. The team are planning a follow up study with our lived experience reference group which will explore people's quality of life post-discharge in relation to different approaches to facilitating more co-ordinated and person-centred care.