

‘Why are we stuck in hospital?’ Barriers to people with learning disabilities/autistic people leaving ‘long-stay’ hospital: a mixed methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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Scientific summary

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Background

Transforming care so that people with learning disabilities and/or autistic people can receive support at home rather than in inpatient units, secure settings or assessment and treatment units (ATUs) is a key policy priority, which has significant implications for people's quality of life as well as for public finances. Over time we have witnessed a series of abuse scandals and significant public anger at such outmoded service models, often provided out-of-area and in the commercial sector at significant expense and with poor outcomes. A key aim of the national 'Building the Right Support' and 'Transforming Care' programmes has been to enhance community capacity and reduce inappropriate hospital admissions/length of stay. In spite of this some 2185 people with learning disabilities and/or autistic people were hospital inpatients at the end of January 2020 (58% of whom had a hospital stay of over 2 years) and progress on discharge has been slow.

Despite significant national debate, very little previous research has engaged directly with people with learning disabilities/autistic people or their families to understand the issues from their perspective. Whilst professionals often see the individual at a particular point in time (often in a crisis), it is only the person and their family who have a longitudinal sense of how their story has unfolded: their informal networks; their contacts over time with formal services; their experience of hospital; the different options considered; and what has ultimately helped/hindered in securing desired outcomes. Failing to take into account this lived experience is not only morally wrong, but also deprives us of a major source of expertise with which to improve services. Similarly, there has been little consideration of the perspectives of front-line staff, who are being asked to practise in very different ways in a difficult environment, arguably without the support needed to do this well.

Objectives

Against this background, the University of Birmingham and the rights-based organisation Changing Our Lives carried out this joint project in order to better understand the experiences of people with learning disabilities and/or autistic people in long-stay hospital settings, their families and front-line staff – using this knowledge to create practice guides and training materials to support new understandings and new ways of working.

Our aims are to:

- review the literature on the rate/causes of delayed hospital discharges of adults with learning disabilities and/or autistic people from specialist inpatient units, National Health Service (NHS) campuses and ATUs (referred to as 'long-stay hospital settings' as a shorthand);
- more fully understand the reasons why some people with learning disabilities and/or autistic people are unable to leave hospital, drawing on multiple perspectives (including the lived experience of people with learning disabilities/autistic people and their families, and the tacit knowledge of front-line staff);
- identify lessons for policy/practice so that more people can leave hospital and lead a more ordinary life in the community.

Methods

Initially, we 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. Studies were included if they reported original empirical data on rates of delayed discharge and were published from 1990 onwards (the year of the passage of the NHS and Community Care Act).

Next, we worked with three hospital sites from across the country in order to conduct:

- in-depth work with up to 10 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, the kinds of lives they would like to be living, and the barriers that are preventing them from leaving hospital (i.e. interviews with up to 30 people with learning disabilities and/or autistic people, and family members who also agreed to participate); in the end, 27 people took part;
- interviews/focus groups with hospital staff in each site, commissioners, social workers, advocates and social care providers who support people after they leave hospital.

Sites included two NHS Trusts and one independent-sector provider, with a mix of service models (forensic services, ATUs, different levels of security etc.) and a range of people (male/female wards, people with learning disabilities and/or autistic people, people with experience of the criminal justice system, and people with experience of long-term seclusion and segregation). When defining 'long-stay settings', our study followed NHS Digital technical guidance.

Results

There is a well-known saying that 'every system is perfectly designed to get the results it gets' – and the experience of people with learning disabilities and/or autistic people in long-stay hospitals seems a classic example of this maxim. Despite exploring the issues at stake from a range of different perspectives (including people in hospital, families, hospital staff, commissioners and various different social care workers), this research has identified a series of very consistent themes and experiences. In particular:

- There is limited prior research (in terms of both the number of previous studies and a series of methodological issues) and a widespread tendency to neglect insights based on lived experience and practice knowledge.
- People in hospital report widespread frustration, feel that hospital environments are not conducive to getting and staying well, and face all kinds of barriers to leaving hospital – with an overriding sense of people's lives being on hold while health and social care systems try to find ways to support people in the community. Without someone (or various people) to really fight for them, people struggle to overcome the inertia built into our current systems and processes, and continue to experience very long hospital stays and very significant delays.
- Front-line staff are equally frustrated and describe a complex and seemingly dysfunctional system which they find almost impossible to navigate. When people do come out, it seems to happen almost in spite of the current system rather than because of it.
- Hospital staff from different professional backgrounds do not have a shared sense of how many people really need to be in hospital or how many people could be cared for in different settings – suggesting that different definitions, world views and professional judgements might be at play.

- Hospital staff are frustrated about what they see as the difficulty of discharging people into community services, while community services are equally frustrated about what they see as a risk-averse approach which they feel can lack an up-to-date knowledge of what is possible to achieve in the community.
- Despite over a decade of policy attempts to resolve these issues, very significant barriers remain.

Conclusions

This was a difficult and often distressing study to conduct – although nowhere near as difficult and distressing as for people with learning disabilities and/or autistic people living in long-stay settings, or for health and social care staff trying to support people to leave hospital and lead more ordinary lives in the community. Throughout we have been struck by an overwhelming sense that this is a situation that no one planned, that no one really wants and that no one really knows how to resolve. Despite this, we remain convinced that we will struggle to make further and long-lasting progress unless we draw more fully on lived experience and practice knowledge, recognise these as valid and important ways of knowing the world, and work with the people who are most affected and – by definition – are most expert in the issues at stake to develop better, more inclusive solutions in future.

Study registration

This study is registered at www.researchregistry.com (researchregistry6124).

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