

*Sharing the Voices of Those Who Are Institutionalised  
to Change Practice and Policy*

<b>Organisation(s):</b>	The University of Birmingham & Changing our Lives	
<b>Country:</b>	United Kingdom	
<b>Contact:</b>	<a href="mailto:policy@esn-eu.org">policy@esn-eu.org</a>	
<b>Theme:</b>	<input type="checkbox"/> Ageing & Care <input type="checkbox"/> Asylum & Migration <input type="checkbox"/> Young People <input type="checkbox"/> Support for Children & Families <input checked="" type="checkbox"/> Community Care <input checked="" type="checkbox"/> Integrated Care & Support <input type="checkbox"/> Co-Production <input checked="" type="checkbox"/> Disability <input type="checkbox"/> Housing & Homelessness <input type="checkbox"/> Artificial Intelligence <input type="checkbox"/> Digitalisation <input type="checkbox"/> Quality Care	<input type="checkbox"/> Labour Market Inclusion <input type="checkbox"/> Social Inclusion <input type="checkbox"/> Technology <input checked="" type="checkbox"/> Workforce and Leadership <input type="checkbox"/> Social benefits <input type="checkbox"/> EU Funding <input type="checkbox"/> Social Service's Resilience <input type="checkbox"/> Mental Health <input checked="" type="checkbox"/> Person-centred Care <input type="checkbox"/> Other, please specify:
<b>Principles of the European Pillar of Social Rights:</b> <i>Check the 20 principles <a href="#">here</a>.</i>	<input type="checkbox"/> 1. Education, training, life-long learning <input type="checkbox"/> 2. Gender equality <input type="checkbox"/> 3. Equal opportunities <input type="checkbox"/> 4. Active support to employment <input type="checkbox"/> 5. Secure and adaptable employment <input type="checkbox"/> 6. Fair Wages <input type="checkbox"/> 7. Transparent employment conditions <input type="checkbox"/> 8. Social dialogue <input type="checkbox"/> 9. Work-life balance <input type="checkbox"/> 10. Healthy, safe work environment	<input type="checkbox"/> 11. Childcare and child support <input type="checkbox"/> 12. Social protection <input type="checkbox"/> 13. Unemployment benefits <input type="checkbox"/> 14. Minimum income <input type="checkbox"/> 15. Old age income and pensions <input type="checkbox"/> 16. Health care <input checked="" type="checkbox"/> 17. Inclusion of people with disabilities <input checked="" type="checkbox"/> 18. Long-term care <input type="checkbox"/> 19. Housing and assistance to homeless <input type="checkbox"/> 20. Access to essential services
<b>Current status of the practice:</b>	<input type="checkbox"/> Concept and Design Phase <input checked="" type="checkbox"/> Execution & Monitoring Phase <input type="checkbox"/> Consolidation Phase <input type="checkbox"/> Scaling Up and Transformation Phase <input type="checkbox"/> Other (please specify)	
<b>Context/ Social issues addressed</b> <i>Please explain the problem you attempt to solve.</i>	<p>In recent years, there has been growing concern about the number of people with learning disabilities and/or autistic people being admitted to hospital for extended periods of many years with no planned date for them to leave. Although the UK decided to close asylums for people with learning disabilities from the 1960s onwards, there has been a growth in people admitted to assessment and treatment units, with widespread recognition that some people stay here for far too long, sometimes with little 'assessment' or 'treatment' that could not be provided elsewhere. This is a real problem as these services struggle to help people lead ordinary lives, can be a long way from people's homes and families, are very expensive</p>	

and have seen a number of abuse scandals – just as was the case with the asylums of the 1960s.

The benefits of social inclusion for people with a learning disability and/or autistic people, their families, and wider society have been recognised for many decades. This has led many countries, including the UK, to close long-stay institutional health campuses where people live separate from their communities for most of their lives. Whilst community accommodation and/or care options provide more individualised care, there are insufficient services to support people in a time of crisis relating to their mental well-being and/or behaviour. This can lead to admitting people to a hospital setting, enabling specialist clinicians and practitioners to undertake assessments and provide appropriate treatment and therapy. While these are planned to be focussed and short-term, many become extended indefinitely due to barriers to arranging community-based social service and health care accommodation and support for the individual.

For example, in England, there are 2,000 people in hospital at any one time; the average length of stay is 5.5 years, and 350 people have been in hospital for more than 10 years. This prevents people from being able to live an ordinary life, and they are often placed far from home, which means they are distant from their families and communities. Finally, such services are very expensive, which creates a vicious cycle whereby funding is sucked into institutional forms of care, leaving less money for community services and leading to even more people being admitted.

**Objectives:**

*Please provide a maximum of three objectives in bullet points.*

1. Identify lessons for policy/practice **so that more people can leave the hospital** and lead a more ordinary life in the community.
2. Understand better the experiences of people with learning disabilities and/or autistic people in long-stay hospital settings, their families and front-line staff
3. Understand the reasons why some people with learning disabilities and/or autistic people are unable to leave the hospital, drawing on multiple perspectives (including the lived experience of people with learning disabilities and their families and the tacit knowledge of front-line staff).
4. Create practice guides and training materials to support new understandings and new ways of working.

**Activities:**

*Please summarise the activities to achieve the objectives (maximum 200 words).*

Activity 1 – a formal review of the research and grey Literature regarding delayed discharge for people with learning disabilities and/or autistic people in long-stay hospital settings to understand what was already known.

Activity 2 – In-depth work with up to ten people with learning disabilities and/or autistic people in three hospital sites (i.e. ten in each), 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

Activity 3 Focus groups and/or interviews with front-line hospital staff in each site, purchasers of their care, social workers, advocates and social care providers.

Activity 4 – Working with a Reference Group of people who had the experience of being in such settings and an Advisory Group of policy and practice experts to co-design our approach, sense-check findings, advise on practice tools and support dissemination.

	<p>Activity 5 Setup of a national community of practice to disseminate the guide and videos and to provide peer support.</p>
<p><b><u>Evaluation of practice:</u></b>  <i>Please explain how you evaluate the practice, and what the results were/are so far</i></p>	<p>The research culminated in a <b>list of ten top tips</b> to enable people to move onto community-based options via an accessible guide and training video.</p> <p>We managed to create a <b>national community of practice</b> which will use the top tips as the template for local groups across the country to <b>reflect on their current practice</b> and agree to practical changes in the way they do things.</p> <p>We are planning to undertake future research to help us understand what happened next and if there have been any improvements in practice and policy.</p>
<p><b><u>Links to supporting documents:</u></b>  <i>e.g. website or report of the practice</i></p>	<p><a href="https://research.birmingham.ac.uk/en/publications/why-are-we-stuck-in-hospital-understanding-delayed-hospital-disch">https://research.birmingham.ac.uk/en/publications/why-are-we-stuck-in-hospital-understanding-delayed-hospital-disch</a></p> <p><a href="#">Networks suggest practical ideas for issues - IMPACT (bham.ac.uk)</a></p>
<p><b><u>Comments and tips</u></b> <i>i.e. for people willing to use your Practice</i></p>	<p>Close collaboration between rights-based / advocacy organisations, universities and the practice settings enabled people often excluded from research to participate and for the practice and policy insights to be relevant and engaging.</p>