# Final Report

# IMPACT Local Network on people with learning disabilities / autistic people leaving long-stay hospitals

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### Background

The IMPACT Local Networks met across the four nations of the UK to discuss the topic of people with learning disabilities / autistic people leaving long-stay hospitalsthrough an approach that promotes **exchanging knowledge, learning together and supporting each other** in local development work to **create change**.

Each Local Network met four times with the goal of creating an ‘action plan’ for change that drew on what they had learnt from:

* The [evidence review](https://impact.bham.ac.uk/our-projects/networks/) IMPACT provided in their first meeting
* Evidence from people with lived experience of working in adult social care (including care workers; social workers; service providers; advocacy and support groups and commissioners)
* Evidence from people with lived experience of disability and/or learning disabilities and carers.

IMPACT’s ethos **values all of these types of evidence equally,** and aims to understand the barriers to putting evidence into practice to make positive change, so we can truly make an impact through our work as a centre and ensure a diverse range of voices are heard and listened to.

This document summarises some of the key elements raised at these meetings, and it presents the final action plans that **each local network has co-produced** throughout the four meetings together.

### IMPACT Evidence Review

Professor Jon Glasby conducted an evidence review to create discussion material for the first IMPACT network meeting. Some of the main points were:

* All 4 UK nations are characterised by **alarmingly high levels of people with learning disabilities and autism admitted in long stay hospitals** with an average stay of 3 years (and more).
* Data shows that often discharge plans are delayed due to **lack of adequate community services.**
* There has been surprisingly little research on why people with learning disabilities and/or autistic people spend so much time in these settings. In particular, previous **research has often failed to talk directly to people with learning disabilities/autistic people**, their families and front-line staff about their experiences and what they see as the main barriers and what would help more people to leave hospital.
* The review identified the existence of a guideline based on [‘10 top tips’ for helping people to leave hospital](https://www.birmingham.ac.uk/schools/social-policy/departments/social-work-social-care/research/why-are-we-stuck-in-hospital)

**About the local networks**All Networks included a different mix of people who draw on care and support, care workers, front-line staff, providers and commissioners of services and other stakeholders from the adult social care sector. In some Networks, new people were added to the meetings over time.

There were five local networks:

* [**In Control Scotland**](https://www.in-controlscotland.org/) coordinated one network in **Scotland**,
* [**Bild**](https://www.bild.org.uk/) ran a network covering all **England**,
* [**St Andrews Healthcare**](https://www.stah.org/our-services/learning-disability) coordinated a network based in **Northamptonshire, England**.
* [**MacIntyre**](https://www.macintyrecharity.org/) coordinated two networks -
	+ one in **Manchester, England** (This network concluded early)
	+ one in **Wrexham,** **Wales.**

###

### Key themes that emerged from the Networks

Networks identified a number of challenges that delay or prevent discharge from long-stay hospital:

* **Lack of alternative accommodation** readily available for people to move into.
* **Lack of communication between professionals / organisations** in a system that is disjointed and fragmented.
* **Lack of accountability**, and where there is accountability, it is still focused within organisations, rather than responsibility to the person and their family.
* **Lack of understanding of the individual needs of each person.** Each person’s autism, for example, is different.
* **Lack of involvement:** the person needs to be much more involved in the choices about what happens to them. One Network includes a person with experience of long-stay hospital who found the process of ***providers coming in and ‘bidding’ for him made him feel ‘like he was cattle***’. Families too should be involved in the whole process and at every stage, not informed of decisions after they have been made.
* **Lack of information:** in one network in particular, which was attended by people with learning disabilities who never experienced hospitalisation, participants were ‘shocked’ about the statistics on long-stay hospitals. One of the participants said, ***“Oh my God, could this happen to me if I was to be sick?****”.* Therefore, there is the need to inform people about their rights and what can happen to them if admitted to hospitals.
* **Lack of funding.**

**Other challenges included:**

**Needing resilient staff with correct skills-set** (again lack of funding means salaries that don’t bring in the high calibre of staff needed). **Recruiting and retaining staff** who are there for the right reasons, have the right balance of resilience and values/compassion and the ability to understand and follow often very complex support plans is **a real challenge**. A lack of consistent staff in hospital has often created repeated trauma which then results in a label of ‘attachment issues’.

**Risk aversion:** In institutional settings, a fear of things going wrong means even when people try to change things, they are often unable to make a significant change outside of the quality of their own interactions. Participants recalled statements like ***‘you’ll never be able to make this work’ / ‘you’ll never be able to remove X restriction*’** or live in the community, with various “hoops people need to jump through and moving goalposts” to navigate.

**Vicious cycles:** In hospital environments, behaviour happens in the context of the environment and hospitals therefore often escalate rather than decrease ‘behaviours’. This can lead to the real person getting lost / forgotten and makes it extremely difficult to risk assess for a community environment. In some settings, **rewards based on behaviour creates a vicious cycle** – this institutionalises people and leads to them losing the skills they do have to live well in the community.

**Pressures to move quickly** can mean that commissioners move forward with the wrong provider / housing / staff team or removing community support too soon can then lead to re-admission. **This also shows a lack of true person-centred planning.**

**Trust:** Many people who have been through the traumatic experience of living in a hospital setting have experienced significant trauma and so **building or re-building trust takes a long time.**

Although the number of challenges and barriers to tackle this issue are **significant**, the networks came up with a number of actions to create real change, both locally and across the 4 nations.

### Areas where change would make the most impact:

Based on the discussions around the key challenges and the ‘Top Ten Tips’, Networks started to think about where they might want to focus their activities to make a positive change:

**Language:** Many network members with lived experience of hospital inpatient settings felt the language in the Top Ten Tips **needed to be stronger to acknowledge the severity of the harm caused if the tips are not followed**. There needs to be more emotive language to acknowledge the fact that this is a **human rights and an inequality issue**. This sparked a discussion about language used in services and long-stay hospitals.

**For example:**

***‘George’ declined to take part in the activities on offer*** *= ‘George’ is the problem,*

***“None of the activities on offer appealed to ‘George’****”
= Suggests a different course of action, requiring a change to the activities offered to align with George’s interests.*

*Taking a* ***person centred-approach,*** *rather than framing George as the problem*

**Early intervention,** including in childhood and prevention: we received the feedback that “‘the ‘top ten tips’ seemed to be adult-oriented and more widely **children are marginalised in these discussions”.**

**The importance of planning:** Planning for discharge at the point of admission, including the importance of restriction reduction before the person transitions or of creating ‘halfway’ opportunities. It’s also important to make sure the person being cared for understands the plan.

**Evidence sharing and examples of what works well:** Change continues to be **small scale and exhausting**. Lessons learned from one person’s situation are not often carried over to other situations, **the only way to make real change is to try different approaches.**

**Labels and ‘hefty reputations’:** Labels might be helpful from a hospital perspective- they ultimately create services for specific conditions- but as a result, the way people were written about often described them from an **institutional point of view** and **whether they comply with rules rather than about their personality, wants and needs**. This forms unhelpful labels and ‘hefty reputations’ rather than seeing them as a person and understanding why they are distressed and acting a particular way (and then working to help them to not become distressed).

**Collaborative working:** Between professionals involved in a person's care in the hospital and the community, and the importance of talking to people who know the supported individual best (eg. the person being cared for, their family etc.)

**Inequality and humanity: There is clear and evidenced inequality** for people with learning disabilities and autistic people in rates of admission and length of stay. The top 10 tips within the initial evidence review currently don’t acknowledge this.
People with lived experience stated that sometimes their **basic needs weren’t being met unless they demonstrated “good behaviour”.**

### ‘Call for Collective Action’

Each network has chosen different areas of focus depending ontheir network membership (see Individual Action Plans in the next section). However, some key themes bringing all of the networks together were evident throughout the network process.

**Common themes:**

1. **Collective action around prevention of admission to long stay hospital**

Throughout the IMPACT network meetings, it has become clear that the issues and **challenges are collectively felt across the 4 nations**, and a collaborative approach with Networks working together would be most effective to raise awareness and encourage local and national action.

1. **Equality and human rights**

Another key theme that was shared across the networks is the importance of taking an equality and human rights approach. Changing practice is important but there is the need for a **wider change in the approach and the language used**.

Networks would like to highlight **the negative consequences of the risk management culture** in institutional settings, alongside the missed opportunities, human rights breaches and unmet needs. Key messages will include:

* Nobody is risk-assessing the impact on people's lives and their future lives by maintaining the status quo,
* This is about shared positive risk taking

*“You're not making these plans in order to put people at risk, the risk comes as part of a decision to* ***try and have a good life****, as it says, you know,* ***it's not just about having services”.***

1. **Co-production**

Networks also agreed on pursuing an overarching effort on how to make sure that in every activity carried out by the Networks on the local and national level, we can ensure that **the voice of people with lived experience is heard and included.**

People using services are often not involved in their treatments, plans and in the creation of services.

Networks are looking for more creative ways to include the voices of people with lived experience, e.g. involving them in the development of Care Programme Approach (CPA) templates, invite closer people to talk of their story when they don’t feel comfortable to tell them directly, and make videos with the real stories of individuals.

*“One thing we're hoping is that from the perspective of capturing patient voice…feeding back on how that works for them and getting some really direct feedback in a way that will be meaningful to them because it has just been used as part of their care planning.* ***I'm really hopeful for when we run the pilot of our new approach for our Care Programme Approach template****”*

**These themes were linked to one main and shared Activity:**

*To launch an awareness raising campaign across the all 4 nations networks.*

**Suggested key messages from networks so far:**

* Human rights violations have, and continue to occur in long stay hospital settings
* The human impact on people’s lives and their families
* The importance of language when talking about patients in hospital
* Sharing examples of good practise alternatives to ineffective ways of working

**We want to create:**

* Videos - see Bild’s action plans for more details about the video
* Case studies - preventative and effective examples
* A community of practice

### Local Networks’ action plans

IMPACT Networks were asked the following questions after discussing the local and national context for their area to help them develop their own action plans:

* What is the local and national context?
* What are we trying to change?
* Who will be leading the change?
* What are the main activities?
* What are the main barriers and challenges?
* Who will participate in these activities?
* What are the key outputs?
* What are the benefits in the medium term?
* What are the longer-term goals?

##### Bild, England

**What is the local & national context?**

Participants in the network found that there is a **general awareness about the problem** (getting stuck in hospital) but there is **missing evidence to move past this.** e.g. the cost of a hospital bed vs a home in the community, and how there is no definitive data on the cost of a hospital bed.

**Professionals do not have enough knowledge of alternatives to long-stay hopsitals**.

The **government** claims to have met a target for 50% reduction for people with learning disabilities even though **length of stay remains far longer than the rest of the population.**

**Number of autistic people has increased further.** Concerns that autistic people fall down the gaps between learning disability services and mental health services. Hence the number of autistic people in inpatient settings is increasing.

**What are you trying to change?**

* **Create awareness about the problem** and bring the issue on the **political agenda**
* Working to ensure the **problem** is **included in other political parties** **manifestos** including Greens and Lib Dems
* **Focus on stories and human rights**. The group were particularly keen this included a focus on prevention.

**What are the main activities?**

* Develop **a video of 3 peoples’ stories** (See Appendix A) explaining missed opportunities for prevention and impact in terms of human right breaches.
* **Create events to share the video** and create awareness about prevention

**Who will be leading the activity?**

Bild in partnership with IMPACT

**Who will be involved in the activities?**

* Work with BTRS (Building the Right Support) advisory group
* People with lived experiences - include people with learning disabilities and autistic people
* Including stories across the 4 UK nations

##### In Control, Scotland

**What is the local & national context?**

Scotland has some **excellent legislation** that is not being enforced strongly enough. The Scottish Mental Health Law Review strongly criticised the fact that Learning Disabilities and Autism are classed as a “Mental Disorder”. This has been considered inaccurate and dangerous.

Whilst the language is based on Human rights, practices are still far from words.

**Main barriers to coming out of hospitals** identified by the network in Scotland:

* Lack of structure and routine
* **Lack of privacy** and **control** over their life
* The ability to comply with demands in a hostile environment.
* **Limited engagement from professional**s with the person using the services to understand their real needs.
* **Cultural issue:** A fear of things going wrong means that even when good people try to change things in an institutional setting, they are often unable to make a significant change outside of the quality of their own interactions.

**Missed opportunities:**

* **Report:** Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge - But nothing has been changed.
* Attempts to demonstrate our concerns to the **Mental Welfare Commission that had little success.**
* **Scottish Commission for People with Learning Disabilities Scottish Mental Health Law Review 2022 - Response** April 2023 to the decision to class Learning Disability and Autism as a “Mental Disorder”

**Resources:**

* **New Routes Home short animated video** on 12 months in hospital for one Autistic young man: <https://youtu.be/-heiwEBktF0?si=TQRkff0AejBEL_vm>
* **Disclosure Scotland Locked in Hospital BBC Documentary** 2022 (featuring some IMPACT group members): <https://youtu.be/84bjO-8lvH8?si=son0LEUFxaPrQUMr>

**What are you trying to change?**

* **Raise Awareness about the problem in Scotland** - bring and maintain the problem on the top of the political agenda
* **Change the Language from being based on risk to focus on prevention**, and how we avoid things escalating due to lack of support, and a recognition of trauma informed practice.

**What are the main activities?**

* **Gather evidence on more positive, sustainable ways of working and demonstrate that is possible**. Put these evidence together in a way that can be shared easily (See Appendix B)
* Half day [conference](https://www.youtube.com/watch?v=KZlJ8hEjkw8&t=6s&ab_channel=NewRoutesHome) and protest at the Scottish Parliament.

##### **St Andrews Healthcare, Northamptonshire, England**

**What is the local & national context?**

St Andrews network focused on **the organisation level.** In the first meeting, the network looked **at good and bad practices in relation to hospital discharge** and **planning community interventions**.

Some of the points discussed were:

* **Experience of community teams** conflating complex “case” with complexity of supporting that person to move out.
* **Experience of community teams** requiring unrealistic guarantees around level of risk (nothing is risk free), especially regarding males with sexualised risk.
* **Lack of mapping** needs provision, requiring stronger links with commissioners.
* **Pre-planning support needs ahead of time** and tapping into the right resources is also key, including for providing care closer to home. Both tie into a lack of clarity from community teams about the “person specification” for placement.

**Problematization of present practices:**

1) Monthly leadership team meetings include a challenge to clinician thinking: why isn’t someone out of hospital? If that question can’t be answered then there is an issue. Also includes a non-blame approach to the question: “*what could be done differently*” for individual cases. (PERSON CENTRED)

2) CPA forms that lead with a “background” section – i.e., using all the legacy “bad stuff” to set the scene with decision-makers. Staff can then fail to see the person behind the label. (NOT CHALLENGING LABELS)

3) Example of a person who moved out into the community with a great support package in place; the community decided that level of support was no longer required, removed it, and the person ended up back in hospital. There was no liaison with the hospital, who had informed the level of support needed, before it was reduced. (DISJOINTED APPROACH)

4) Example of a person who has moved into “step-down” accommodation that is in the community but provided and supported by the hospital. Great example of a tailored package that provides a smoother transition. (PERSON CENTRED)

**What are you trying to change?**

Improve internal practices in the organisation - focusing on two areas:

* **Care plan** for discharge in the community
* Improving **CPA template**

**What are the main activities?**

*Two main projects:*

1) **Self-assessment against Top Ten Tips** (agreed in meeting 1) – questionnaire developed and sent out to clinical teams within LDA Division.

2) **CPA project** (now: From Admission – Discharge) (Project 2) - A number of offline discussions have taken place and the remit has now expanded to look at the whole admission to discharge process (See Appendix C)

a. **Review of admission to discharge flowchart** – feedback from all attendees was that this is a very useful document. This is particularly important, given external representation at the meeting from a Commissioner, Senior Intervener and Lived Experience Facilitator:

i. It shows the process very clearly – helpful for existing staff, but particularly useful for new staff and patients/carers

ii. The creation of such a visual representation has enabled us to highlight the areas we need to concentrate on to support discharge

iii. Once finalised, it will provide us with the structure upon which to streamline the person-centred documentation, which is anticipated to be clearer for patients, better reflect patient voice (and highlight where patients have not contributed), save time for professional staff (by reducing the repetitive paperwork that currently surrounds this process) and maximise the helpful structures that exist already (e.g. using CTR activities to better effect

##### **MacIntyre, Wrexham, Wales**

**What is the local & national context?**

* 149 people currently in ATUs/Inpatient mental health settings across Wales. Average stay of 9 years. Worse as a percentage of the population and length of stay than England. There are also 195 in patient beds in Wales
* North Wales priorities – build houses, skilled staff (PBS), step up / step down, commissioning as a barrier e.g. need to re tender every 5 years not co-production in action.
* North Wales partnership is the only regional LD strategy group across Wales. Focus areas – accommodation, step up-step down, skills (PBS)

**Previous change initiatives**

* **2019 Commissioning Guidance** – commissioning for good lives - good but it was lost during COVID
* **Structured planning for Supported Living in Wrexham is unique** and has helped them plan ahead more effectively than other North Wales local authorities.
* Takes **3 years to set up specialist support living.** Early waiting lists therefore need to be foreseen 3 years ahead to prevent crises and admissions.

**National policy & practice issues**

**Supported Living and county boundaries** are acknowledged as **specific barriers to attracting providers and housing associations in Wales**. Can’t place out of county as the person becomes an ordinary resident so harder to work collaboratively across county barriers.

**What are you trying to change?**

**Engaging providers and providers** able to deliver really **good PBS support** - building a network

**What are the main activities?**

* Stories / glimpses of the future / co-production (This output is going to be a joined action with Bild video)
* Campaigning
* PBS
* Relaunch 2019 Commissioning Guidance

**Medium term benefits?**

**Overcoming barriers to bring health and social care together around behaviour** (‘behaviour is a health thing’). Be great to bring providers along to 🡪 united front around good PBS implementation.

##### **Compass, Northern Ireland**

**What is the local & national context?**

The network decided to focus on the experiences of the people with learning disabilities and autism. Participants reported experience of little cooperation between the professional staff and carers and people drawing on care. Decisions are taken with very little consultation with the person and the family.

The network also highlighted the lack of awareness from participants about this issues (Hospitalisation of people with learning disabilities and autism/getting stuck in the hospital).

**What are you trying to change?**

**Raise awareness about what people with learning disabilities want** across professionals.

**Who will be leading the change?**

In co-production with people with lived experience and communities

**What are the main activities?**

* **A video:** where participants to the network can express who they are, what are the real needs and the importance of having their voice heard.

### Next steps

The first half of the IMPACT network project is complete. In terms of what happens next:

* **Within 3 months** - IMPACT will give feedback to our embedding and communications team at IMPACT with your requests for support with moving forward, and come back to you with updates.
* **In 6 months** - **Coordinator evaluation -** Reflections on taking part, has there been any change? What are the challenges/blockages? How can IMPACT help?
* **Within 9 months** - We’ll update you on any embedding activity via an update
* **In 12 months** - **Coordinator evaluation -** Reflections on taking part, has there been any change? What positive outcomes have you seen as a result of the network? What are the challenges/blockages? How can IMPACT help?

IMPACT will update our assemblies with the work that we’re doing to hold the IMPACT centre accountable with any actions or areas we can act and we will publish materials such as further evidence reviews, updates and any produced material to the IMPACT website and share with our networks.

### Appendix A - collaborative video, facilitated by Bild



Bild are the coordinators of an IMPACT Network on “long stay hospitals in the UK.” Focusing on a preventative approach Bild have been hosting the England-wide network of Homes not Hospitals.

Bild’s network, and other IMPACT Networks across the UK have highlighted the lack of focus on prevention and keen to develop an awareness piece focused on prevention (as opposed to inpatient provision or discharge) – highlighting missed opportunities to put right community-based support in place, the consequences of this including any human rights breaches.

Participants of Bild, In-Control Scotland and Macintyre’s networks will be invited to participate.

| Aims, Objectives and Outputs |
| --- |
| Aim | To raise awareness of the importance of preventing admission to long-stay hospitals, and showcase examples of community-based support. |
| Objectives | 1. To produce a video rooted in the lived experience of people with a learning disability.
2. To share examples of community-based support that has helped to prevent admission to long-stay hospital.
3. To share this video with sector stakeholders, raising awareness of both the importance of prevention as a principle, but also examples of how it can work in practice.
 |
| Outputs | 15 minute video |

Brief specifics:

| Style | Talking heads and animation |
| --- | --- |
| Length | 15 mins |
| Audience | Predominantly decision makers, influencers and professionals working in areas associated to health and social care, including politicians.Secondary: the public, those working in adult social care, people with autism and learning disabilities and their families. |
| Where it may be shown | Showcase event; policy roundtables; launch webinar, IMPACT partner events. |
| Content and message | Film is focussed on prevention of admission – highlighting missed opportunities to provide the right support for people within the community, that could have prevented admission. The video will highlight the human rights breaches and the impact it has on individuals detained in inpatient settings and their families, and to showcase a different way of working in the community to demonstrate that a different way is possible.  |
| Participants | The video, facilitated by Alexis who has lived experience, will include stories from people with a learning disability and autism as well as people from different nations in the UK.Impact will fund video editing, animation costs and lived experience participation costs. Bild (and The Restraint Reduction Network) will fund Alexis’ time to facilitate. Bild/Alexis will work with participants directly. |
| Approvals |  It will be joint- branded and joint- hosted with both Bild and IMPACT. It will be free to share publicly. Bild and Alexis will manage personal data and consent of the participants |
| Deadline |  End of March 2024 |

### Appendix B - InControl Scotland ‘Are we heading in the right direction?’

### Appendix C - NHFT CPA template - Good practice

### Appendix D - Person Spec colour coded by profession