BECAUSE PEOPLE MATTER

Coming Home Implementation Event Report

FOREWORD

The Coming Home report was a milestone moment in adult social care. Having made the commitment to people with learning disabilities that they would be supported to live in their own community, and after nearly two decades of work to deliver that promise, this report was for those who had been left behind. Drawing attention back to the people whose needs could not be met in their home community, resulting in out of area placements that are not only costly in financial terms, but in negative impact on the person and their family, the recommendations made have set us on a course forward.

Following that course towards ending inappropriate and unwanted out of area placements will require a combined effort – no one part of this system can overcome the barriers we face alone.

This event was intended to provide an opportunity for those different parts of the system – support providers and housing providers, Scottish Government and Health & Social Care Partnerships, local authority commissioning teams, people who use support and their families – to come together. We wanted the chance to hear from the Scottish Government about the progress being made at the national level, and to consider how this is impacting in our various areas of experience. We wanted to reconnect with a human rights based approach and to consider what this means in reality, with the hope that we can work to harness the potential in wider policy efforts to protect and promote the human rights of people with learning disabilities. We wanted to acknowledge the huge importance of housing providers, to better understand their structures and processes and to consider how we can better integrate our efforts. Perhaps most importantly, we wanted to hear from the people we are working to support, to showcase what can be and has been achieved.

We believe that by listening to different perspectives we can understand our partners better, we can find common ground and opportunities to build connections and we can better inform our own practice. There is no doubt that progress has been made, but we still have a long way to go. We want to keep this momentum and maintain the attention that people deserve, particularly as we navigate the current pressures of the social care landscape. We might be facing a challenging time, but this is an area where there is a reason for hope, and we hope that this event, and now this report, will act as a catalyst to support our ongoing work.

Neil Richardson OBE QPM
Chief Executive
Turning Point Scotland

David Whitters
Head Of Forensic Services
Turning Point Scotland

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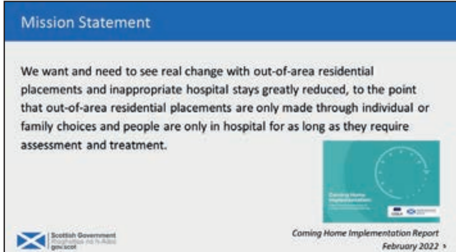
SCOTTISH GOVERNMENT UPDATE

ARRON ASHTON – COMPLEX CARE POLICY OFFICER (SCOTTISH GOVERNMENT) & DR. ANNE MACDONALD – COMPLEX CARE PROFESSIONAL ADVISOR



Definitions

Complex Care needs may also include those who in addition to having a learning disability:

- are autistic and/or have a diagnosed neurodevelopmental disorder;
- have a mental health concern;
- have a forensic history;
- have a co-occurring physical health need;
- are described as demonstrating behaviours perceived as challenging.

[From Scottish Government DSR Guidance May 2023]

Other definitions in:

- Care Quality Commission *Out of Sight - Who Cares?* (2020)
NICE Guideline 11 (2015)
Challenging Behaviour Foundation

Scottish Government
gov.scot

Spoke about the policy commitment behind the Coming Home Report and gave overview of progress to date on key recommendations. Spoke about consistency of definitions both within Scotland and internationally, as well as lack of data.

Key Recommendations

- **Recommendation 2** – A Dynamic Support Register should be developed into a tool for national use. Detailed operational guidance should be produced.
- **Recommendation 3** – A National Support Panel should be established in order to provide support and checks and balances to local management of the Dynamic Support Register.
- **Recommendation 4** – A National Peer Support Network should be established to facilitate professionals coming together to learn and share best practice.

Scottish Government
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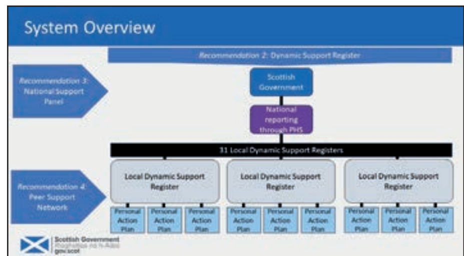

Coming Home recommendations are about increasing the visibility of people with complex care needs – seeing who we are talking about, where they are and what they need. It's about:

- improving planning and action in local areas
- providing support to achieve this
- ultimately reducing the number of people in hospital or out of area placements

A role for Government to consider complex care within complementary policy work, including but not limited to the National Care Service and Mental Health Reform.

NATIONAL DATA REPORTING

- Data reporting managed by Public Health Scotland (PHS)
- Quarterly data collection, 6-monthly publication
- First data publication was in November 2023
- Only anonymised, aggregated information is available nationally. Some further management information available to HSCPs and SG quarterly.

NATIONAL DATA REPORTING

Table 1: Number of people recorded on DSR in Scotland, as at 28 September 2023

DSR Category	Number of People	Percentage of People
In Hospital	171	13.8%
Inappropriately Out-of-Area	130	10.5%
At Risk of Support Breakdown	154	12.4%
Enhanced Monitoring	144	11.6%
Appropriate Out-of-Area	644	51.8%
Scotland	**1,243**	**100%**

Insights into learning disabilities and complex needs: statistics for Scotland - 28 November 2023 - Insights into learning disabilities and complex needs: statistics for Scotland - Publications - Public Health Scotland

Whole approach to implementation is agile. We/the sector is learning and adapting as we go.

Publication of first report was a significant milestone in the CHIR implementation. Good to have a first set of figures and we can reflect some of the feedback from that first report in future publications.

Lots of ideas and a desire to go further. We have started with adults in the first instance but know that the Dynamic Support Register should include young people as well, and there may be opportunities in legislation to address this.

Trends from Inpatient Census – LD Beds

NHS Board	Non-forensic	Forensic	Total beds	Total population	LD beds per 100,000
State Hospital	0	12	12	-	-
NHS Scotland (MH Inpatient Census 2022)	150	79	229	5,479,900	4.18
Scotland (SAY 2000 target)	-	-	-	-	4.00
NHS England	-	-	2045 inpatients (Dec 2023)	56,536,000 (ONS)	3.61
NHS England ( )	-	-	-	-	3.0

Bed Type Profile ( )

UK

- 49% Secure (High, Medium and Low)
- 27% Acute specialised LD
- 9% Acute generic MH
- 3% Forensic rehab
- 10% Complex continuing care
- 2% Other

Scotland

- 15% Secure (High, Medium and Low)
- 75% Acute specialised LD
- 10% Complex continuing care

Helpful to look at comparative data both to aid our understanding but also flag risks. NHS England has a much heavier dependence on private sector provision.

Systems Dynamics Model (SG 2022)

- Delayed discharge is a stock, where the inflow is determined by placement breakdowns (in most cases, a person is delayed because a new placement is needed), and the outflow is determined by the length of delay (the *additional* time to find a new placement).
- Both of these are determined by actors outside the "system" – social care, commissioning, housing. Reducing delayed discharges will require working with these partners
- Delayed discharge is also an unintended delayed consequence of having bed availability.

Systems Dynamics Model (SG 2022)

We commissioned a piece of work to map the inpatient journey in one large NHS Board under systems dynamics principles which looks at feedback loops. This is helpful as the results can aid the sector in understanding its separate parts. Really interesting questions resulting from this type of analysis - is the system itself a barrier to our mission?

In summary - all roads lead to bed occupancy. The more beds available, the more admissions and the longer they are occupied.

Complex Support Needs Pathway

A Complex Support Needs Pathway will contain **guidance and a set of standards** which will provide a context for the use of the Register. This will include the **person-centred steps to avoid service breakdown** and subsequent admission to hospital or being placed out-of-area, as well as the **steps to plan for discharge from hospital or from out-of-area placement** in order to help facilitate a return home.

A **person-centred** pathway for achieving discharge or return from out-of-area will provide **timescales and milestones**. It will incorporate the various standards from a range of **already existing** legislation, guidance documents and good practice reports, including from NICE, the Care Inspectorate, SSSC, the Royal College of Psychiatrists, and the Mental Welfare Commission, into one pathway.

Coming Home Implementation Report
February 2022

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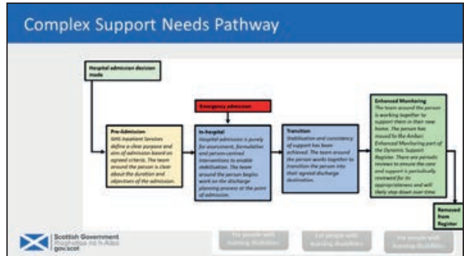


Still work to do around embedding the work done to date, but ambitions to do more.

Working under agile principles on a Complex Support Needs Pathway:

- Starting small and manageable, learning and building as we go with initial focus on hospital discharge. Pathway will set out ways to:

  a) ensure inpatient time is as short and targeted as possible,

  and

  b) work towards avoiding admissions as far as is appropriate and/or possible

- Working on this over the coming months, people with lived experience have and will be consulted
- Working towards two separate products – one for practitioners and one for people interacting with the system.

FEEDBACK FROM PARTICIPANTS

“Really good contextual start to the event....recognising the need for collaboration across all sectors especially housing. Appreciate Arron and Anne’s presentation.”

LOCAL DELIVERY

- As a provider, I work with several HSCPs but have heard no operational discussion or involvement in dynamic support registers.
- As a provider we have no operational involvement in dynamic risk register discussions we are aware they are happening and are ‘informed’ of what will be happening with no regard to input we may have been able to provide.
- “HSCPs are responsible for ensuring these are happening/kept up to date” - is there any degree of compulsion for HSCPs identifying someone tasked with leading this within partnerships? - Case management seems to be challenging for them generally at present.

HOSPITAL AND COMMUNITY PLACEMENTS

- We’re concentrating our resources in the places we want to move away FROM (hospitals) and not in the places we need to move TO (communities) - not unlike the justice system that prioritises prison over (more effective, evidence based) community interventions - again, we are investing in the supply and the demand follows.
- People with intellectual disabilities are much more likely than the general population to have mental illness and they are more likely to be seriously affected by it. Transfer of resources from hospitals to the community is therefore too simplistic and not the solution as people deserve the best possible specialist care when they are unwell enough to need inpatient care. The problem is that we are currently using hospitals for the wrong reason - to provide social care and manage risk by removing people from the community rather than to treat mental illness in people with ID which is what they were meant to be for! … it would be wrong to “Rob Peter to pay Paul” leaving people with ID being managed in general Psychiatry by people who, frankly, from personal experience don’t understand them and are too busy to take the time needed to care.

HOUSING NEED TO BE BETTER INVOLVED

- How can we ensure that housing are at the table when the people on the register are being discussed.
- This was clearly identified in the Coming Home Report as one of two key barriers to providing appropriate opportunities for this group. Where is the housing element being discussed at Scottish Government?
- Due to start building our flagship site next week. We need MUCH more support at a national level to ensure we can develop more homes for complex care across Community Planning Partnerships. Whole system planning and funding is essential to circumvent the arguments I’ve had to navigate.

"Well said Anne on the point of terms and conditions!"

"Great point from Andrea about connection with other SG policy priorities. She mentioned SDS and Fair Work, I'd add the affordable housing supply programme and the Housing to 2040 agenda - this work needs to be integrated in the housing supply programme."

"The restrictions placed on a person, and the levels of support can be reduced when the right support relationships are in place - if people feel understood, respected, that what they want and need is important, many of the risks and challenges can often be reduced."

VOICES OF LIVED EXPERIENCE

RIAN'S STORY
TOLD BY CRAIG PURVIS – SERVICE MANAGER AT CARR GOMM

Rian is a young man from Edinburgh who has Autism. He experienced a significant deterioration in his mental health at age 13 and after a physical incident involving a family member, a prolonged period of significant distress and a manic episode, emergency social work services took the decision that it wasn't safe for him to live at home.

Rian was put on a Compulsory Treatment Order, which he remained on for 11 months and was initially placed in an adult unit, before moving to a young person's unit at the Royal Edinburgh Psychiatric Hospital.

In March 2015 it was decided that it would not be safe for Rian to live in a regular home environment, and with no facilities or schools in Edinburgh that would meet his needs he would be sent out of area. Initially Rian's family were told he would be moved to Newcastle, but was then able to secure a place at a school in Glasgow.

Here, Rian lived in a purpose built house with four other boys, all with different support needs. His family would visit but it didn't feel like a proper visit, with staff always present in the living room and it not being safe or possible to take him out in the community.

This place did not work for Rian. He would be forcibly restrained if he was displaying behaviour that challenged his staff team, he'd run away from staff, couldn't go out shopping, and was isolated from his family. By the time he was 16 he was no longer engaging in the education provision, and his care provider gave notice that they could no longer meet his needs.

His family wanted him to move back to Edinburgh, and through their research and with support from advocacy services, they found Carr Gomm. I found our initial meeting with social work and Rian's psychiatrist really negative. It focused on all the things that Rian can't do, on all the limitation that have to be in place. They said that if this didn't work Rian would have to be sectioned, and the best we could hope for is for him to remain safe in his own house. It was hard to see how the life they were setting out for Rian was all that much different to being in a locked hospital ward.

Rian was different to anyone else we were supporting, and it took us time to get to know each other, to build up the trust and understanding and confidence needed for us to support Rian in the best possible way. We've tried things and learned and adapted along the way because we believed that Rian was entitled to more, and that we could support him to live a life of his own. We supported his move back to Edinburgh where he is now living in his own home, enjoying regular family visits and daily talks with his Mum on the phone. He's getting out and about in his community, living the life that everyone said he couldn't.

"Everything from day one has been centred around what's best for Rian"

"His communication challenges faded as we learned how he wanted to communicate"

AN INVERCLYDE SERVICE STORY

TOLD BY ALDO MARRONE – TURNING POINT SCOTLAND SERVICE MANAGER

Working in partnership with the local authority, Turning Point Scotland purchased a large, former children's home in which to build a service for four people with learning disabilities, brain injury and mental health support needs. This four-bedroom home, with an attached flat was earmarked for four people returning from out of area placements; two people returning from a residential service in Argyll & Bute, one from Glasgow and one from Renfrewshire, both of whom were ready for discharge from hospital.

The move home has been a success for all four people, who are now living happily and safely in their home community. Taking one person's story we can set out some of the key steps and considerations to making this support model work.

This person has experienced historic trauma and has a learning disability, mental health support needs, experiences problematic alcohol use and presents an absconding risk. The local authority holds his guardianship, and he wanted to return home to the area where he grew up.

Since moving home, this person has absconded twice and was supported home quickly. His home has been made safe and secure with relevant measures in

place to alert staff if he is attempting to leave the house. We have developed protocols that empower staff to act and respond flexibly, underpinned by a Positive Behaviour Support plan. Even with the challenges that this person can present, he is settled, happy and safe in his home. He is active in his community with support from his team, his support has reduced to 1:1 and he has enjoyed overnight stays.

The outcomes he has achieved really demonstrates the 5 R's of Citizenship, which are so critical to a full life and a successful, sustainable package of support:

- Rights – something a person is or should be morally or legally allowed to have, get or do
- Responsibilities – something you are expected to do, or something that is morally, ethically or legally required
- Roles – the part someone plays in a particular activity, situation, family, society or other group
- Relationships – the connection between two or more people
- Resources – the service or asset that can be used to satisfy desires and needs

There have been and continue to be challenges with the sustainability of this person's support. Whenever care hours are reviewed, there is concern that they will be reduced, when the person is doing well. Of course, it is often the case that the person needs that level of support in order to do well, and reducing it can have a disproportionate impact on that person's life experience, behaviour and level of risk.

Another critical element of successful support provision is having the right staff team in place. Recruiting the right people with the right mix of skills is particularly important in a shared house such as this, and retention of staff is key to continuity of support.

ROBERT'S STORY

TOLD BY SHONA JOHNSTONE – TURNING POINT SCOTLAND SERVICE MANAGER

People may show behaviours or actions that require a type of specialist support and accommodation that isn't available locally, and out of area placements are sometimes appropriate and necessary. However, when we invest in the right home, the right support team and a strong multi-agency approach, people like Robert can live safely and happily within their home community.

Robert had a lengthy history of displaying sexually disinhibited behaviours, violence and aggression. He was a risk to vulnerable people, including children, which meant added consideration had to be given when deciding on the safest environment for him and for others. After a number of community placements and a secure residential placement proved unsuccessful, Robert was detained in hospital for two years before moving to a private hospital in England in 2002, the only option available at the time.

Robert and his family remained keen for him to return home throughout this time, and in 2011 Turning Point Scotland's Perth service were approached to carry out an assessment to support a move back to the community. In 2012 Robert returned home.

There are a number of elements that we feel were key to ensuring that this move would work.

First and foremost, this had to be built around Robert's specific needs. This meant an all-male team who were trained in de-escalation and breakaway techniques, and 24/7 support. Staff had to be open to and able to engage in difficult conversations, ensuring that Robert had the opportunity – and felt safe – to discuss feelings and avoid frustration leading to aggression.

Crucially, Robert had to 'buy in' to the plan – this move home was what he wanted, and we worked with him to help him understand what this would look like and what would happen if things didn't work. Robert was engaged in his own support planning, empowering him to shape the elements of his life that he could and supporting his understanding of his own accountability. Being part of the plan provided Robert with a sense of ownership, something to work towards as well as a sense of responsibility for poor decisions and an understanding of what he stood to lose if he re-offended.

Behind everything was the relationship between all the agencies involved in Robert's support and oversight, each agency with their own set of priorities. Sometimes, the priorities of one agency conflicted with those of another, and often, these priorities did not match Robert's own priorities.

We worked to understand the needs, priorities and specific concerns of all agencies involved, and to create solutions and approaches that provided a 'win' for

everyone. We communicated openly and honestly, even when things didn't go well, demonstrating our own accountability, which developed sense of trust and respect between ourselves and the agencies. We advocated for Robert, creating a staged and carefully managed processes towards the goals he had set and demonstrating to all agencies involved that risk could be carefully enabled, and any issues responded to quickly and effectively.

Building and sustaining Robert move home has presented significant challenges to all involved, demanding the highest level of support from his staff team. We experienced 'near misses', but we learned from these, adapted our approach and addressed those risks. For example, alarms were put in place on doors and windows after Robert attempted to abscond fairly early on upon his return to Perth. It was thought at the time that this was probably a testing of boundaries.

Ultimately, Robert's move home was hugely successful. His relationship with his family had always been incredibly important, and he took great pleasure in being involved in family celebrations. He spent Christmases with his Mum and Dad or with his sister and family in Glasgow, he was supported to attend his brother's wedding and enjoyed overnight stays on more than one occasion. His family were very invested in his care and wellbeing whilst also being aware of the potential for risk which he presented.

There had to be some fairly frank conversations between Robert and his family which furnished him with expectations that instilled a true desire to manage his own behaviours in a positive manner.

Robert was actively involved in his community, and the sense of self-esteem he got from his exchanges with staff in the local shop were plain to see. He built connections with other lovers of classical music who attended local concerts, and this feeling of inclusion gave Robert a true sense of responsibility in the sense that he actively spoke of positively managing his own behaviours. He was involved in the Turning Point Scotland's Rosie's Garden Project in Perth, working alongside Perth in Bloom to help with communal floral displays, and received a long service award as a result of his volunteering at the British Heart Foundation. He took ownership of his health and wellbeing to the point that he managed his own appointments with minimal staff oversight.

He actively participated in risk management meetings which afforded him the opportunity to continue to develop through the setting of achievable goals. Robert truly valued the lifestyle he had been supported to develop for himself. Robert was very aware of regressing and subsequently jeopardising what he had achieved and where he was.

Robert died suddenly in 2022, but his last 10 years were spent living the life that he chose, and that he worked so hard to build. For Robert, coming home was everything.

DAVID'S STORY

TOLD BY GLENN HARROLD – OPERATIONS MANAGER AT KEY

David has a diagnosis of schizoaffective disorder, autism, a mild learning disability and a long standing treatment resistant psychotic disorder. At 36 years old he had spent over 60% of his life in hospital.

Originally from the Highlands David entered child protection services as a result of challenging and offending behaviours, threats of self-harm and suicide. A series of temporary placements in residential schools and children's homes across England led to an increase in concerning and violent behaviours. David was detained under the Mental Health Act, received a range of treatment including medication and ECT, required at least 3:1 support, and was moved across multiple hospital settings. He was eventually discharged to Key 22 years after his admission to an institutional setting.

David's life in hospital was highly structured and based on routine. He experienced frequent violent and aggressive incidents, received PRN medication, was physically restrained and generally distressed.

We received a lot of information about the 'patient', all about his past and all the worst parts of his behaviour. We wanted to know about David, about what was important to him and to his family. We learned what David and his family wanted from his new home, and we involved them in all aspects of decision making, from decoration to the recruitment of David's staff team.

There were a lot of challenges for us all – the 278 mile road trip from the hospital to his new home, getting used a new – and very different – daily routine, getting to know David, all his likes and dislikes and preferences, and David getting to know a whole new staff team. Recruiting that staff team was its own challenge in a remote and rural setting, but absolutely crucial to David's ability to live in his own home.

David is now settled in his own home and is thriving. He enjoys cooking and cleaning at home, getting out into his community and for regular walks, and seeing lots of his family again. He has joined a gym, is accessing mainstream health services and developing a relationship with specialist services, all supported by a dedicated, skilled, flexible and responsive staff team – who get daily feedback on their support from David, including scores out of 10!

"His Mum asked us if she could buy him a present"

"David smiles. That's not something that happened before"

DEBBIE'S STORY

TOLD BY NICOLA ODUNIYI – TURNING POINT SCOTLAND SERVICE COORDINATOR AND NICKY WATSON SERVICE MANAGER

Debbie had a difficult time growing up, at home and at school. She spent some time with foster carers, which was a positive experience for her, but after losing her Mum, and then her sister shortly after, things got worse. Her relationships at home upset her – she often showed this in her behaviours towards her brother – and she had limited friendships. She often struggled with her emotions and her reactions to trauma were often harmful to herself and to others.

A care provider was sourced for support but this didn't work for her and she spent time in and out of hospital, which was a difficult time for Debbie. Her anxiety level rose, she displayed more self-harm, was often angry about how things were, and became very focused on her physical health and fear around the losses she had experienced.

Finding an alternative that worked for Debbie was difficult. There were no female beds in NHS facilities in Scotland, so Debbie moved to a hospital in Warrington. Her time there was helpful, but it was hard for Debbie to be away from her family and she just wanted to come home.

Throughout this time, Debbie had a house waiting for her, giving her a sense of hope and something to work towards. She had regular video calls with her new staff team at home, allowing them all to get to know each other. The staff team in

Warrington helped Debbie to learn new coping strategies and the new experiences that she had there helped to build her confidence.

What was supposed to be a 6-month transition became a 2 year stay, and while the focus remained on transition and preparing Debbie for her move home, the differences between the English and Scottish systems made for a fragmented process. Communication, information sharing and planning was challenging, and moving between two separate legal systems meant that Debbie returned home without access to the mental health treatment and support that she was likely to need during such a period of transition.

Thankfully, Debbie's move home went smoothly, thanks in large part to North Lanarkshire Council's willingness to work creatively and flexibly to find solutions to Debbie's needs, and their strong co-ordination with the NHS team and us as support providers.

Now that Debbie is in her new home she is settling well, is getting to know her support team and spending much needed time with her family. She spent Christmas and New Year with her family and celebrated her first birthday at home in 5 years.

She still requires support with her emotions and continues to have a strong focus on her health concerns, but she is learning about her local community again and enjoying new groups and outings. She's attending social groups, swimming and bingo, and is seeing Pink in concert this summer.

"Longest I've been in my own home in numerous years."

"It's all about my future, making the best of every minute."

ANDREW'S STORY

TOLD BY JULIE ANNE MCGHEE (TURNING POINT SCOTLAND SERVICE MANAGER), BARRY RYAN (TURNING POINT SCOTLAND SERVICE COORDINATOR) AND ANDREW

Andrew had a difficult home life growing up, and was removed from home by social work at 16. He also has a learning disability and a chromosomal disorder which made finding the right place for him very difficult. He initially went in to Assessment and Treatment, and was then discharged into a series of inappropriate and ultimately unsuccessful placements. These included foster homes and residential units, each increasingly secure and increasingly further from home. On his 21st birthday he was taken from his own home in Dumfries, where he was supported with a staff ratio of 4:1, to a secure unit in Hexham. When we met him he was living in a wing on his own.

Andrew felt a great deal of anger at the system that had taken him away from home, and put him in places that had rejected him over and over again, leaving him increasingly isolated and increasingly traumatised. He had very little interest in engaging with us when we first met, he had been so hurt and let down.

Now, we support Andrew in his own home, in his home community, with a staff ratio of 2:1. He enjoys swimming, going to the cinema, playing pool and going to see shows. He sees friends and family, celebrates special occasions with them and attends Turning Point Scotland events.

In facilitating this shift, we have been consistent, both in our actions and in our ongoing commitment to work with Andrew. Every time Andrew has behaved in a violent or aggressive way, we review and we learn. We don't give up. We involve Andrew in this and in our efforts to keep finding creative solutions that can best support him. Andrew has control over as much of his life as he can, and we support him to understand the impact of his behaviour as well as the consequences. He has come to understand the incentives, all the things that he can do as his behaviour improves. Over time he has come to trust us, to work with us, and his behaviour is consistently improving.

We have set and maintain clear boundaries that minimise risk – to Andrew, to his staff team and to others – as well as support Andrew to understand what we will and won't accept. For example, we know that when angry Andrew will lash out physically and verbally, always in the most offensive way that he can. This has on occasion crossed over into racism and a criminal offence. In these cases, staff have been encouraged to report the incidents, maintaining our boundaries, respecting our staff team and reinforcing the consequences of this behaviour.

We have built a strong and specifically equipped staff team around Andrew, who really represent the level of skill, expertise, compassion and resilience required in effective social care and support. Staff were employed specifically for Andrew, and fully understood the challenges they would face in working with him. They

have been trained in the skills, policies and procedures that underpin his support plan and importantly, they are able to balance the nuances of Andrew's support. They are firm without being threatening or confrontational. They maintain clear and rigorous boundaries while also having fun. They manage the physical and emotional demands of working with Andrew while also remembering that he is a person, not just a set of behaviours.

Things have been – and continue to be – challenging, but we continue to learn and develop our support and our relationship, and Andrew continues to work on his behaviour. He still has regular interactions with the police, but they are less frequent and less severe. In his first four weeks in his home he has smashed four TVs, so together with Andrew we decided that there wouldn't be a TV in his home. There still isn't, and he engages with other activities instead.

Looking ahead, Andrew's improvement with his behaviour has allowed us to start to plan to get his house redecorated. This is a big goal for Andrew this year and he's very involved in deciding how is house is going to look. He will need to spend some nights away to let the workers complete the decorating in his house; he will spend these nights in a local hotel. If the nights away go well Andrew understands that this opens up the opportunity to look at holiday breaks.

"Something that I would love to do in the future is go on holiday. I would like to go to a caravan park. "

"I will spend a couple of nights in a local hotel which will be the first step towards going on holiday."

"I would like to go on holiday with my friend Darran."

CATHY ASANTE

LEGAL OFFICER – SCOTTISH HUMAN RIGHTS COMMISSION (SHRC)

Independent living – Article 19 CRPD

The right to choose where and with whom to live, and the support to do so
End all forms of institutionalisation
Replace them with personal choice and support
No new institutions
No more placements in institutions
Restoring autonomy, choice and control about how, where and with whom they live

Defining institutions

- **Little or no choice and control over your day-to-day life**
- Little choice over who you live with and who supports you
- Isolation and separation from the community
- Lack of control over day-to-day decisions
- Lack of choice over who you live with
- Rigidity of routine regardless of will and preferences
- Identical activities in the same place for a group of individuals
- Not defined by size

Institutional settings put Human Rights at risk and should be abandoned as a model of care.

Most relevant is the right to Independent Living set out in Article 19 of the UN Convention on the Rights of People with Disabilities.

Importantly, an institution is not defined by its size, but by a lack of choice and control.

How to realise independent living arrangements

To happen over time but must start now
Immediate planning
With disabled people
As quickly as possible
As much money as possible

The UN acknowledges that we have set a high bar, and that this shift will take time. That is ok, but it must start now, and move as quickly as possible.

Human rights measurement

- **Commitment**: how serious is the country about making sure the human right is protected?
- **Efforts**: how much effort is being put into fixing the human rights problems?
- **Results**: What has changed after all the plans and effort?

Structural
Process
Outcome

Indicators

Action plan/strategy
DPOs involvement
Access to support services
Training/retraining
Awareness of support
Empowerment
Monitoring
Complaints/Redress
Living arrangements
Institutions
Involvement in deciding where to live
User control

SHRC are working to measure progress moving away from institutions.

"Human rights measurement is a way of taking the ideas of human rights and turning them into things we can count or look for. It shows what is being done and what is not being done. It tells us what components are missing on the way to delivering human rights in reality."

The Coming Home Report is our commitment. The Dynamic Support Register is one effort. Now, what are the results?

FEEDBACK FROM PARTICIPANTS

"Cathy's presentation was excellent and the focus on research and measurement that's in the pipeline sounds really exciting and worthwhile."

"Institutionalisation affects not only person detained but also whole family, and extending out in wider circles, community and national community."

"Picking up on Cathy's presentation what work are we doing to ensure that new inappropriate out of area placements are not starting - surely if we can support people to come home we can support people to stay at home in the first place."

"Along with this, we see closure of specialist community activities resources leaving people who move out of a group environment not ready to use mainstream activities quite isolated. We need to ensure as part of planning when people come home there is productive meaningful resources left for them. It's often a lack of something that has led to an out of area move, let's not make a lack of community activities be a contributing factor to service breakdown."

TONY CAIN

POLICY MANAGER – ALACHO (ASSOCIATION OF LOCAL AUTHORITY CHIEF HOUSING OFFICERS)

Understanding the way that housing planning works is fundamental to creating solutions and directing investment.

Coming Home Report: Recommendation 5 – Identify suitable housing options for this group and link commissioning plans with housing plans locally.

This is a shared responsibility – HSCPs should identify the need, housing providers should identify the response.

National data on housing need and learning disability is weak, if not non-existent, and largely excludes people who are already housed – if we don't have the data to tell us who and where people are and what they need, then we can't plan effectively. The Dynamic Support Register is critical for visibility.

Some form of shared or core and cluster accommodation may work, as long as the rights of individuals and the preferences of their family and carers are respected, but solutions designed for specific individuals will have to be bespoke to a significant degree. Bespoke solutions are not difficult but they are expensive and take a minimum of two years to deliver. The earlier you start the conversation the better.

We need stronger collaboration – between HSCPs and housing providers, with the people who need these homes and with their support providers.

Have to consider the longevity of a house, prepare for it to be in use for at least 100 years. Once it's built, change is difficult, need to build in flexibility.

Need a better way to manage voids, particularly those relating to hospital admissions and which put a person's tenancy at risk.

People's tenancies aren't always as secure as they should be – issues of capacity are not always well understood in the housing sector.

FEEDBACK FROM PARTICIPANTS

"Tony is revealing an honest perspective which I am hearing for the first time. We need more of this to develop forward thinking developments."

"It was mentioned in the morning session that one gentleman was costing £1.8 million in specialist hospital placement and we have 67 + delayed discharges each costing an average of 1/2 million approximately PA all out of the govt NHS budget, it therefore makes no sense to have funding hurdles such as £180k to build a new home if this is the rate limiting step to overcome a delayed discharge. Aside from the human rights issues, this is a very poor way of spending public money. Please politicians let see some leadership here. We need to see the funding limited by management silos taken down."

"People with lived experience all talked about being involved in their community - are communities open enough? Welcoming enough? Are there the right opportunities? This needs to be part of our planning too."

"Somebody has commented that all of the examples of lived experience referred to being involved in community. My lived experience of creating a home for my son, who had been detained, focused strategically from the start on building 'intentional community'. Everybody's 'community' is different. Elements might include a particular shop, cafe, library, faith group, library, bus stop. All the people in the network of relationships around a person contribute to this community."

"Housing providers do indeed have a responsibility to minimise void loss, not just in terms of being a public body, but financially and as a business - if referrals for accessible accommodation are not forthcoming and there is no capacity to pay void costs, providers will be required allocate that elsewhere."

"Is there any appetite - among HSCPs? Among housing providers? - to be more formally integrated into health and social care structures?"

LIZ LOTHIAN – SERVICE MANAGER, PBS SERVICE (TURNING POINT SCOTLAND)

WHAT IS PBS?

Positive Behaviour Support (PBS) is a values-led approach to supporting people with complex support needs; it is not about changing the person's behaviour but changing the way support is delivered in order to ensure the person is supported in a manner that makes sense for them and to improve their quality of life.

The Coming Home Report suggested that PBS could be a key component in preventing and resolving out of area placements. However, they found little evidence of PBS use within social care settings. My experience reflects this finding. It's something I've seen predominantly provided in health care settings, and when it is used in social care settings it is often integrated into a physical intervention approach, where it doesn't get the attention it deserves.

TURNING POINT SCOTLAND'S PBS SERVICE

Turning Point Scotland's Positive Behaviour Support Team was launched in 2022 with myself as the service manager and 3 PBS lead practitioners. We currently provide support to our learning disability, forensic, mental health and complex need services. Turning Point Scotland are not the first, nor will we be the last, to recognise the value of investing in PBS, but the drivers of our investment include:

- We have been supporting people with learning disabilities, including those with more complex and in some instances forensic behaviours, for many years, and are continually looking to strengthen and improve the support we provide.
- We recognise the fundamental value of our staff team, and the demand that this work can place on them; PBS helps them to manage and prevent burnout, it empowers them in their role and lessens the frequency and severity of challenging periods.
- PBS aligns with our commitment to delivering psychologically and trauma informed environments for the people we support and our staff, and to a Citizenship approach.
- Training alone is not enough; staff need ongoing support to understand and implement what they've learned effectively.

We support staff with all aspects of understanding the behaviour of the people they support. We work alongside the person and others in their life to carry out a range of assessments specific to their needs and circumstances, gathering as much information as possible to inform a person-centred PBS plan and a range of proactive interventions. We work to develop capable environments and to upskill our workforce through practice leadership, and ensuring that the interventions developed are understood by teams and they feel confident in implementing them.

This is all with the aim of improving communication between people and their staff team and in preventing the situations that people find difficult.

It was important to recognise and what the organisation had in place already; we weren't starting from scratch with a new approach. We already had a comprehensive induction and training programme that fitted within the workforce development expectations of PBS and the values and beliefs set out within the Citizenship approach, were very much in line with the PBS model. My role was to build on these strengths by integrating PBS into existing structures and approaches.

CHALLENGES AND BARRIERS

The wider PBS community in Scotland has been a valuable resource as we've worked to develop this service and meet the challenges that any new service has to face. Common barriers to the development of PBS in organisations can come in many guises, including the ethical debate surrounding PBS.

A lot of people have concerns around PBS, with its roots in applied behavioural analysis or ABA, which historically used approaches not based in human rights. It often requires work to challenge preconceptions, because PBS is NOT ABA. Behavioral science does underpin elements of PBS but these elements must be considered within the context of PBS values, including co-production, respect and dignity, and a focus on quality of life.

Often barriers are more practical though, with the potential for teams to feel that they have tried everything and that they know the person best, or that this is another thing on top of an existing heavy workload. Our experience in services however has predominately been one of positivity and a willingness to engage, accept support and to understand what needs to change and why. Ultimately, we are all working towards the same goal, and most people appreciate the extra resource.

BENEFITS:

PBS helps us to really listen to and understand what the people we support are communicating, meaning they rely less on behaviours perceived as challenging.

By providing a rapid response internally, we are better able to assist in the prevention of placement breakdown, and the crisis that can lead to out of area placements. As well as responding more effectively to challenges, we are also better equipped to prevent those challenges arising. Staff are equipped with the skills and confidence to provide support that is proactive, that meets the persons need and understands their preferred communication, which we have seen reduce instances of challenging behaviour and the use of restrictive practice.

There is evidence to suggest that, while there may be an additional demand on resources to introduce and support PBS, this can offset others financial costs

such as reduced staff sickness and improved staff retention, leading to reduced recruitment costs.

Working within a PBS framework ensures that we see the person and not just the behaviour. It is not about “fixing” the person, it is about understanding what the communicative intent is behind that behaviour, listening and changing how we do things to meet their needs. I think that PBS encourages us to consider that when the people we work with are experiencing difficulty they are often described as being at their worst…this is exactly the moment that we need to be at our best, so we need to look beyond the behaviour in order to identify and address the person’s physical & emotional needs. THAT is the challenge that our staff must take on, and we are here to offer the guidance, understanding and support that they need to meet it.

THE VIEW IN THE ROOM

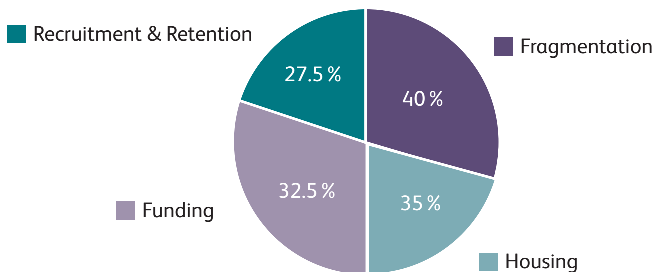
We wanted to capture how participants are feeling about the Coming Home agenda, and to identify what they see as key priorities at this point. We asked four questions through the course of the day

Question 1 – What are the main barriers in the way of delivering the Coming Home ambition.

Responses fell in to four main categories:

Funding – It's not enough and it's concentrated in the wrong places

What are the main barriers to ending inappropriate out of area placements?



- Investment in community based alternatives to hospital placements is not prioritised – because the resources are concentrated in hospitals that's where the accommodation is.
- Short term funding and competitive tendering are limiting the role that third sector providers can play.
- We are not investing enough in the building or refitting of accommodation, in community based support services or in resourcing the planning and transition phases.

A fragmented system – we don't work well enough together

- No single agency can identify, understand and meet the needs of people in or at risk of Out of Area Placements – HSCPs, housing providers and third sector support organisations all have a part to play, but we are not well coordinated.
- We don't have a clear enough understanding of what other parts of the system can or could contribute, or how our own work fits in the wider system.

Recruitment and Retention

- Without the right people to provide the support, there is no community based alternative to hospital placements.
- We cannot attract the right people to these roles unless this work is more widely understood and valued, and is better rewarded.

- We must invest in this workforce – in their pay, in their training, development and career progression, and in their ongoing management and support.
- £12 per hour is not enough.

"Accommodation, Accommodation, Accommodation"

- Along with the people to provide the support, the right accommodation is fundamental to community based alternatives to hospital placements, and there isn't enough.
- There isn't enough integration between Health & Social Care Partnerships and housing providers – we're not planning together.

"Resourcing the sector on an equal basis for staffing and terms and conditions."

"Funding silos, HSCP's lack of incentive to have people in long stay hospitals move out as the HSCP needs to find the funding."

"Appropriate housing & equipped staff in the community- the need for joined up thinking."

"Lack of alternate community options that provide specialist support that can function as places of safety, crisis support, respite, meeting people's needs."

"Without adequate, long term funding we will never develop the workforce and resources required to deliver high quality community-based services. There is inequality in the system (driven by the government) to value NHS based services and professions over social work, social care and community-based professions which needs to change."

"During today we've heard about Hospital T&C's are better and better pay. However, this is a concern with HSCP also."

"Insufficient pay for social care in what is a skilled job."

"Social care recruitment crisis."

"The correct property is so important."

"Lack of appropriate accommodation."

"Additional resources, especially to provide high quality support and housing in the community."

Question 2 – What are the main enablers that could help us make progress towards ending Out of Area Placements?

Again, responses followed some key themes that largely matched the barriers set out in Question 1.

Funding – it's not just about more, it's about where it goes.

"The right resources in the right places."

"Transfer of resources from NHS to housing and social care."

"Funding & ownership at senior strategic level to drive forward."

"Reducing the size of the long stay hospital footprint & having the political will to move the funding associated with hospitals like Strathmartine in Dundee and moving that funding with the patient."

Collaboration

"Transparent and honest communication, resources and everyone being equal in the process with a realistic understanding of the barriers and timescales to address these."

"There is significant experiences and skills in the sector and doing more of the same isn't always helpful. Use the expertise of people & their families as a baseline to develop personalised services."

"Sessions like this targeted at key people- helps address the barriers."

Housing

"Having suitable housing built to a good standard with adjustments available for people to move into."

"More Housing."

"Housing partners involved in all discussions from the beginning."

Staff

"Having well-trained and supported social carers."

"Getting right staff, valuing staff financially to ensure retention."

In thinking about what helps – or could help – to drive change forward, participants also identified enablers. Culture change was a further theme.

"Joint ownership of risk."

"Acceptance that things will go wrong. Learn from them."

"Focus on people's interests rather than their risks"

"Having a real focus on quality of life & problem solving to ensure this happens."

"Early intervention that looks into the future, beyond education and adult life."

"Proper long-term partnership and collaboration. No point involving providers very late in the day."

Other enablers

"Proper application of the (Millan) principles of the Mental Health Act."

"Don't reinvent the wheel- SDS is a key driver and resource that's underutilised."

"Provider organisations are talking much more about collaboration and sharing."

"Hearing more positive stories where people have experienced good outcomes."

"Trauma understanding."

The final two questions put to participants aimed to get more targeted. We asked people what action they wanted to see, and who should take it, and we asked them to consider what they themselves could do to help drive these changes.

Question 3 – "What ask would you make, and of which partner"

Perhaps unsurprisingly, most asks were made of the Scottish Government, but HSCPs, commissioning teams and housing providers all have their asks too.

Who	What
Scottish Government	- Get the provision of this specific type of accommodation tied into Section 75/Developer Obligation and tie up so that it cannot be wriggled out of. - Set a common human rights aspiration for people with a learning disability. - Equity of pay for vol sector to ensure that strategy can be delivered into reality – Funding is needed to take things forward. - Link with teams to ask for monies to be made available for a push in taking this forward, some added investment that will mean savings later. - Set same targets for closing beds as England to release funding for social care. - Allocate more funding for the Health & Social Care sector to help those who need it. - Pay more attention to role of housing in implementing the Coming Home agenda including through the LDAN Bill. - Help to ensure a social care work force is no longer in crisis and adequately paid for the support they give.
Commissioning	- Commission PBS/Challenging Behaviour services to support care providers and act acutely to “save” ‘placements at risk of breakdown.’ - Rethinking the model of competitive tendering which leads to providers working in silos. - Revisit Human Rights based commissioning. - Work together with providers around long term planning for individuals. - Promote the need for PBS in services and reflect this in funding.

Who	What
HSCP’s	- Housing be more present at local strategies. - Respect and properly consider the Millan principles of the Mental Health Act. - Sense check the social care we need now & for the next 5-10years then invest and stay committed. - More inclusive discussion before planning and allocation of budgets and other resources are committed.
Housing Providers	- I would ask for a more responsive & flexible approach in regard to access to housing and cut out some of the unnecessary bureaucracy. - Flexibility around housing- support for housing associations to understand the Coming Home agenda and encourage them to work with us.

Some specific asks were made around Positive Behaviour Support (PBS)

- Funding of good PBS supports required to reduce admissions/readmissions which could cost hundreds of thousands of pounds.
- Explore the role of PBS further.
- Revisit our PBS Strategy, integration and practice.

And asks were made that we all need to respond to:

- Collaborative working across sectors as a consistent embedded approach. Not a unique one off good practice example.
- ΩWe need to celebrate and recognise the amazing work that’s out there within the sector and share best practice and celebrate success more.
- Advocate for measures that support independent living for people with learning disabilities and complex needs in the LDAN Bill.
- Commitment to ensure that families are aware of what their rights are.

Question 4 – What action will you commit to taking forward in your role?

- Continue to work with colleagues and address challenges together. More action less talking.
- Keep going! It takes time but we’ll get there.
- Maintaining commitment to supporting individuals who present with more challenging and complex support needs.

- To keep advocating for people to get the best possible support, care and treatment to allow them to have the best quality of life.
- As a provider, proactively ask our commissioners where things are at with their Coming Home priorities and how we can help.
- Commitment to ensure that families are aware of what their rights are.
- Revisit our PBS strategy.
- Building a community around the individual I support.
- Working towards getting those in harmful long stay out, even if it's one person at a time.
- Avoid using the term "challenging behaviour", which is vestige of restrictive practices. Better term is "distressing behaviour", it is kinder and less aggressive in terminology.

THANK YOU EVERYONE WHO ATTENDED THE COMING HOME: OUR PROGRESS TOWARDS BELONGING, WELLBEING AND HUMAN RIGHTS COLLABORATIVE EVENT.

Thank you to the Turning Point Scotland working group for organising the day.

Craig Winter

David Whitters

Emma Adams

Faye Keogh

Hayley van den Brink

Karen Sutherland

Paul Airlie

Sam Hughes

Susanna Harper

Finally, thank you to the speakers on the day for delivering informative presentations.

Andrew

Arron Ashton

Barry Ryan

Cathy Asante

Craig Purvis

Dr. Anne MacDonald

Glenn Harrold

JulieAnne McGhee

Liz Lothian

Nicky Watson

Nicola Oduniyi

Shona Johnstone

Tony Cain

Photo credit: Nicholas Knox

BECAUSE PEOPLE MATTER