Coming Home Implementation:

A report from the working group on complex care and delayed discharge

COSLA

Scottish Government
Riaghaltas na h-Alba
gov.scot

Vision: The human rights of everybody with complex care needs are respected and protected and they are empowered to live their lives, the same as everyone else.

Vision:

Mission Statement:

By March 2024 we want and need to see real change with out-of-area residential placements and inappropriate hospital stays greatly reduced, to the point that out-of-area residential placements are only made through individual or family choices and people are only in hospital for as long as they require assessment and treatment.

Vision:

Vision Statement:

Scotland is committed to meeting its Human Rights obligations for people with learning disabilities, which are outlined in the **United Nations Convention on the Rights of Persons with Disabilities** (UNCRPD)

This commitment has been set out in the Scottish Government's **National Performance Framework** and as proposed in legislation through the **Human Rights Bill**.

Scotland must provide the best possible services for people with a learning disability to enable them to lead high quality lives within their family and/or their community where they experience personalised support consistent with a Human Rights Based approach.

The current situation must change. It is unacceptable that people are spending large portions of their lives in hospitals or other settings if they are medically fit for discharge. 'Care in the Community' as first mandated in The Same as You (Scottish Executive, 2000) has still not been universally realised and we are failing those who are still delayed in hospital or in inappropriate out-of-area placements through the lack of provision of proactively-planned quality care and housing in community.

Vision:

All people with complex care needs must receive excellent continuity of care. Everybody with a learning disability and complex care need who can should be able to live in their own home, supported by specialist staff. Where there is a genuine therapeutic reason for individuals to stay in hospital they should receive appropriate specialist support in the short term, with a clear plan in place for them to transition out of hospital and back into their community. A nowhere else to go but hospital scenario will be extinguished.

The wishes and needs of the individual must be at the heart of this process. We want to ensure that all adults with complex needs have choice and control over the care and support that they receive. Each individual should be supported and enabled to be included, respected, treated with dignity and protected throughout their life journey.

Professional and expert support through genuine allyship is key, staying true to *nothing about us, without us*. This allyship must aspire to truly know the person, listen to them and their families, be ambitious with them and always act in their best interest. There must be good communication and involvement at all times.

Vision:

To achieve this vision will require a transformational change through committed thinking and planning and genuine collaboration across the entire system. We recommend a new framework, underpinned by strong local and national partnerships, to deliver the innovative and quality services needed to support people with learning disabilities and complex support needs who are placed in unsuitable out-of-area placements, or who are inappropriately admitted to hospital, due to breakdown in their community-based support. This must happen without delay and there must be real visibility and accountability going forward.

Participation
People should be involved in decisions that affect their rights.

Accountability
There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.

Non-Discrimination and Equality
All forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.

Empowerment
Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.

Legality
Approaches should be grounded in the legal rights that are set out in domestic and international laws.

Case Study – Louis' Life

The view from a mother: What it is like living in Scotland with a complex and profound learning disability

Louis is in his early 30's and lives with Complex and Profound learning disabilities, and is also autistic. He had enjoyed six years of high quality of life in a care home, with a stable staff team who understood his 'language' and needs, until the home's closure was announced. Ordinary Place of Residence rules meant there could be no continuation of care staff with a change of designation to 'supported living' as the local authority stood to gain responsibility for all 8 additional placements. Residents were therefore to be placed by their own authorities.

"Ordinary Place of Residence rules meant there could be no continuation of care staff"

Louis' mother and social worker searched for an alternative placement however there was nowhere in Scotland. Louis' mother began planning for long-term solutions, but soon found nothing was achievable within the six months' notice period. As Louis faced eviction, a home was identified in England, 250 miles away. It was privately run specialising in 'challenging behaviour.' The facility was far away, institutional, but there was no alternative and so Louis was moved there. Louis' mother had no option but to travel to visit him there.

"The facility was far away, institutional, but there was no alternative"

Vision:

No transition was offered for Louis or his new care team. Instead, Louis' mother drove him there personally, staying overnight at personal cost for days and weeks to offer reassurance and love to Louis. Given her expert knowledge of caring for Louis she was able to assist with training staff and she returned weekly to support this transition for Louis. The primary barrier for Louis and staff was communication. Staff did not understand what Louis was saying and vice versa. This emphasised a power imbalance. Louis needed skilled care that accounted for his fear, bereavement and homesickness. However, staff were relatively inexperienced and unfamiliar with Louis, with no professional support for therapeutic approaches. They were required to do a job that was more skilled than they were equipped for. Louis expressed himself through the only language left to him: destructiveness towards property, and aggression to people.

Louis' challenging behaviour was managed through restraint, which was both pharmacological and physical in nature. Over three months, the cycle of restraint and protest grew. It was traumatic and injurious for Louis, his mother and staff. Professional services within the facility were later engaged including clinical psychology, speech and language therapy and occupational therapy. Louis' desire to return home was identified as a major factor in his distress in reports, along with his need for skilled communication, routines, a mix of activities, and a greater understanding of autism and complex needs. Local authority commissioners noted the consequent rise in costs. Nobody from the commissioning team ever visited.

"a greater understanding of autism and complex needs"

Vision:

As costs rose towards £6,000 per week, the local authority planned to bring Louis back to Scotland. They identified a vacant city centre flat, managed by one of their social care organisations. They proposed care provided by two organisations, one of which had previously been commissioned and another organisation, who had been originally designated for Louis' long-term care. Louis' mother objected, as did managers from the second care organisation. The flat had no garden, no safe access to outdoor spaces. Combining two care organisations created complications in delivery of services. The family and senior managers' objections were overruled.

Louis returned to Scotland to the new care provision, again without transition. Recruitment and retention of staff was a problem, even before Louis arrived. The primary barrier between staff and Louis was communication. There was a lack of skilled care suitable for Louis' complex and profound needs.

After seven weeks, Louis was admitted to the NHS Learning Disability Assessment Unit under non-clinical crisis following service breakdown and challenging behaviour. Louis remains in the unit 3 years later.

"There was a lack of skilled care suitable for Louis' complex and profound needs"

Vision:

Louis has been detained in hospital for three years. He was declared ready for discharge in April 2021 and has been in Transition to his own home since February 2021. His experience of hospital can be characterised as 'containment', with lack of meaningful occupation, poor therapeutic understanding of his verbal communication, who he is as a person (his spiritual needs), resulting in unhappiness and protest behaviours.

Louis continues in transition to his own home. It has taken sixteen months to date. The major constraints are recruitment of care staff and development of systemic management practice to ensure all staff are skilled and confident in supporting Louis. Louis' underlying needs are profound and multiple, requiring flexibility and ongoing learning for individual carers, managers, the care organisation, commissioners, Louis, and his mother, to integrate and use available resources. As Louis' mother I have led the project, motivated by Louis' best interests. I purchased accommodation, as Deputy to the Court of Protection; I also exercise an oversight and integrating role, as Welfare Guardian.

Forewords:

Our NHS in Scotland provides vital enduring support and healthcare. During the pandemic, we have never been clearer about the benefits of our NHS and the skills and dedication of the people who work within the NHS.

However, no matter how we value it, we also know that a hospital is not a home.

No one should be subjected to unnecessary delayed discharge due to incomplete care arrangements. For every day spent unnecessarily in hospital, that person loses part of their connection with their community, their family, and their friends. Stories like Louis' are unacceptable.

We are not protecting the rights of people with learning disabilities and complex needs if we have to keep people in hospital when they should be living at home or in a homely environment with the right support.

We have a collective responsibility to make this happen.

That is why the Scottish Government has already provided over £20 million of funding in 2021 dedicated to helping Integration Authorities fulfil the vision that out-of-area placements and hospital stays are greatly reduced by 2024.

The experts on the group who have produced this report have set out a way forward. We are very grateful for their work.

This isn't an easy task – reports by the Mental Welfare Commission in 2016 and the Coming Home report in 2018 have highlighted this as a long-standing issue. This additional work and funding recognises that we have to do more.

Success will require a high level of collaborative and partnership working, and of innovative thinking. It requires us to commit to solutions for individuals despite the challenges. It requires us to make best use of the successes that have been achieved for some people and to build on that.

We are fully committed to working together to make this happen.

Kevin Stewart MSP
Minister for Mental Wellbeing and Social Care

Forewords:

On behalf of COSLA and Scottish Local Government I welcome the Report and thank the participants of the Short Life Group and its sub-groups for their work in producing the recommendations contained within it.

We recognise and share the frustration that individuals are delayed in hospitals or accommodated inappropriately out-of-area and are fully committed to ensuring that local community services and accommodation are developed, are available and are sustainable.

It is important to acknowledge that this won't be easy and undoubtedly there will be challenges in different areas of the country in developing new places and attracting and retaining support staff and engaging and maintaining a mix of service providers and in house support services.

The Change Fund to support the development and establishment of those local solutions is welcomed, as is the Reports recognition that we need to see resource transfer from inappropriate settings to ensure local support is sustainable.

The proposals around the development of a Dynamic Support Register, to review, maintain focus and achieve positive outcomes for those currently delayed or at risk of requiring support are welcome, and COSLA look forward to assisting in developing these proposals fully.

We share, with the Scottish Government, the view that success will require a high level of collaboration, partnership working and innovative thinking, and that we all have responsibility to make this happen.

Thank you.

Councillor Stuart Currie
COSLA Spokesperson for Health and Social Care

Forewords:

I believe that people with learning disabilities should be given the right support so that they can live fulfilling lives in the community. This support should always be person centred, supportive, flexible and responsive.

People should only be admitted to inpatient assessment and treatment services when there is a clear clinical need which will benefit from in-patient based intervention.

Behaviours perceived as challenging can describe a range of behaviours people may display when their needs are not met. Expressions of this behaviour, with no identified clinical need, is not an appropriate reason to admit people to inpatient assessment and treatment services.

Professor Sir Gregor Smith
Chief Medical Officer, Scottish Government

High-quality care and support that is flexible to meet the needs of the individual is central to our social care values. Every day we work to meet these aspirations for everyone living in Scotland, with human rights central to our approach. We are committed to ensuring a right to family life for everyone. However, when people are inappropriately placed far from their communities, or are delayed in hospital settings, we are not delivering on the high standard of care we set ourselves.

People deserve the services around them to be delivered in a person-centred and enabling way.

Collaborative and innovative working across the sector, which puts people with learning disabilities at the heart of co-design, will be necessary to create and develop solutions for people with the most complex needs so they can be supported into their own home. We must overcome the structural barriers which prevent us currently delivering the best care for each individual, so that people with learning disabilities and complex care needs are effectively supported to live in their home communities.

Iona Colvin
Chief Social Work Advisor, Scottish Government

Introduction

1. Introduction

The same as you? published by the Scottish Executive in 2000 was the catalyst for Scotland's long stay Learning Disability hospital closure programme. The need for deinstitutionalisation, and alternative care in the community was made clear and backed with significant financial support. The aspiration was clear, all long-stay hospitals were to close by 2005.

However, for a small number of Scottish citizens – namely people with complex care needs, hospital has still taken the place of a home. These people are facing lengthy delayed discharges from modern-day clinical settings and some have been sent to places far away from their homes. Hospital wards, including Assessment and Treatment Units, or out-of-area care facilities are often institutional in nature. They are not a home.

The Scottish Government and COSLA's **Keys to Life** (2013) referenced the long standing issue of delayed discharge and out-of-area placements as a result of wider system failure. The **Mental Welfare Commission's No Through Road** report (2016) and Dr Anne MacDonald's **Coming Home** report (2018), commissioned by the Scottish Government, both highlighted the significant number of people with learning disabilities who are delayed in hospitals in Scotland, sometimes for many years, despite being clinically assessed as ready for discharge into community settings.

A short life working group[1] (SLWG) was set up at the instruction of the Scottish Government and COSLA by the then Cabinet Secretary for Health & Sport and the COSLA Spokesperson for Health & Social Care. The remit was to undertake a joint focused piece of work in relation to delayed discharge for people with learning disabilities and/or enduring mental health conditions.

1 Details regarding membership of the SLWG and of the sub-group are listed in Appendix Five.

1. Introduction

The SLWG met during 2020 and heard from various experts and stakeholders in the field to understand the challenges with the current system and how solutions were being found. It quickly became evident that **whilst there was a range of reports on the issues of delayed discharge for people with learning disabilities, there was a lack of available evidence for people with enduring mental health conditions.**

The expertise of the group was primarily made up of learning disability sector specialists and family carers of people with learning disabilities. **The discussions therefore focused mainly on issues for people with learning disabilities and are the focus of this report.** The group agreed early on that further work would be required to address the issues specific to those with enduring mental health conditions, recognising that the solutions may not be the same.

This report describes the groups findings and recommendations.

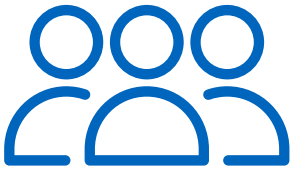
Contents/Navigation

Within this report we describe why a refreshed approach is needed, what work has already been done in this area, and the collaborative working that is needed to achieve a modern and human rights based approach to care for people with learning disabilities.

Action Summary

The SLWG previously made two main recommendations to Scottish Government and COSLA to:

- Establish a **Community Living Change Fund** over the next three years to be used to design local community-based solutions to bring home those placed outside Scotland and to discharge those whose discharge from hospital was delayed. **This was implemented as an early priority in 2021 with £20 million distributed**.



- Develop a national **Dynamic Support Register**, owned and maintained locally in order to create greater visibility of people with learning disabilities in terms of strategic planning and to allow for performance monitoring of admission to hospital and inappropriate out-of-area placements. Supported by a **National Support Panel** that can provide support and expertise to HSCPs and checks and balances for the local management of the Dynamic Support Register. The Panel will bring sector expertise together to provide an open collaborative forum that can troubleshoot individual cases in partnership with local areas. **This was accepted in principle with a need for further work**.

Action Summary

Other recommendations for the Scottish Government and COSLA included:

- Supporting Integration Authorities and local areas in their work on disinvestment planning to run alongside the change fund. NB: Scottish Government has allowed the change fund to be held in reserve for up to 3 years if necessary while local plans are progressed.
- Develop the supporting arrangements and build capacity for local areas to adopt a programme budgeting approach;
- Establish a detailed understanding of the revenue cost of different care packages to aid Integration Authorities on resource planning;
- Establish a greater understanding of the experiences of people with learning disabilities in specially adapted housing provision and understand how to better influence planning for new housing and adaption of existing properties;
- Explore and develop guidance, if necessary, on considerations of housing benefit rules for supported accommodation; and
- Produce a guide to support commissioning and procurement of complex care packages.

The recommendations to undertake further work in these areas were accepted by the Cabinet Secretary and by COSLA Leaders in November 2020. A sub-group of the SLWG then worked to develop the proposal for the Register, including how it would be used and maintained, and who it was for. This sub-group was led by Dr Anne MacDonald, author of the Coming Home report, and included representatives from the health and social care sector, as well as data experts from the Scottish Learning Disability Observatory. This report brings together all of this work.

Definitions:

Complex Care Needs:

The term used in this report when describing the care required around the person with learning disabilities in order to ensure that they can live as independently as possible in a more appropriate setting.

Therefore complex care needs may include those who in addition to having a learning disability:

- are also autistic;
- have a mental health diagnosis;
- Have a forensic need, and/or who are described as demonstrating challenging behaviour.

Challenging Behaviour:

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion[2]

It is a communication from the individual and a product of the environment they live in and of the support they receive. It refers to behaviour which challenges services and support providers, rather than implying that the person is themselves challenging.

Challenging Behaviour is not a diagnosis and although such behaviour is a challenge to services, family members or carers it may serve a purpose for the person with a learning disability.[3]

Delayed Discharge:

A delayed discharge refers to a situation where a person in hospital is clinically ready for discharge from inpatient hospital care and who continues to occupy a hospital bed beyond the ready for discharge date.[4]

2 **Challenging Behaviour: A Unified Approach' Royal College of Psychiatrists,** British Psychological Society & Royal College of SALT 2007

3 Defined in **Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges** NICE guideline 11, 2015

4 Delayed discharge was defined as per the **NHS Scotland Delayed Discharge Definitions Manual** (NHS National Services, 2016) See also Appendix 4.

Definitions:

Family:

This report takes a wide definition of family, recognising that this term is often rooted in love and affection for an individual. It is right that it includes biological relatives: parents, grandparents, siblings; but also includes welfare guardians, partners, friends and supportive and paid carers in the definition.

Institution:

While not formally defined, the Care Inspectorate states: all care services provided in Scotland must be in keeping with nationally recognised guidance, good practice, and Scottish Government strategy. It must support living, citizenship and inclusion in the community and operation must be underpinned by a human rights based approach, particularly the right to live independently and be included in the community under the UNCRPD. This means consideration of the service design, size and location, and proposed operation must be assessed against Scottish policy, irrespective of the location of the provider.

Scotland's Care Inspectorate remains responsible for the registration and monitoring of Care Providers in Scotland and is currently consulting on a policy position on Accommodation-based Care and Support for Adults with Learning Disabilities and/or Autistic Adults.

Out-of-area:

For the purposes of this report, out-of-area is defined as living within a placement not within the individual's funding authority. This could include living in either an NHS or a private hospital or care home. It is important to stress that being out-of-area itself is not problematic when this is through the choice of the individual and/or their family. This report describes "inappropriate out-of-area placements" as those which do not reflect the individual's choice of community they want to live in.

Underpinning Principles

2

2. Underpinning Principles

All of the recommendations in this report are based upon the foundation that people with learning disabilities have the same human rights and should have the same opportunities as anyone else to live satisfying and valued lives and to be treated with the same dignity and respect. This by definition is irrespective of any complex care need or behaviour that challenges, either present or historic. Everyone living in Scotland has a right to a home within their local community, to be able to develop and maintain relationships, and to get the support they need to live a healthy, safe and fulfilling life.

Being placed in an inappropriate out-of-area placement, in a poor-quality institutional setting, or being admitted to hospital for an inappropriate reason (e.g. due to behaviour that challenges) is an excessive restriction on liberty and the right to home life.

The core commitment made here is a zero-tolerance approach to inappropriate placements for people with learning disabilities.

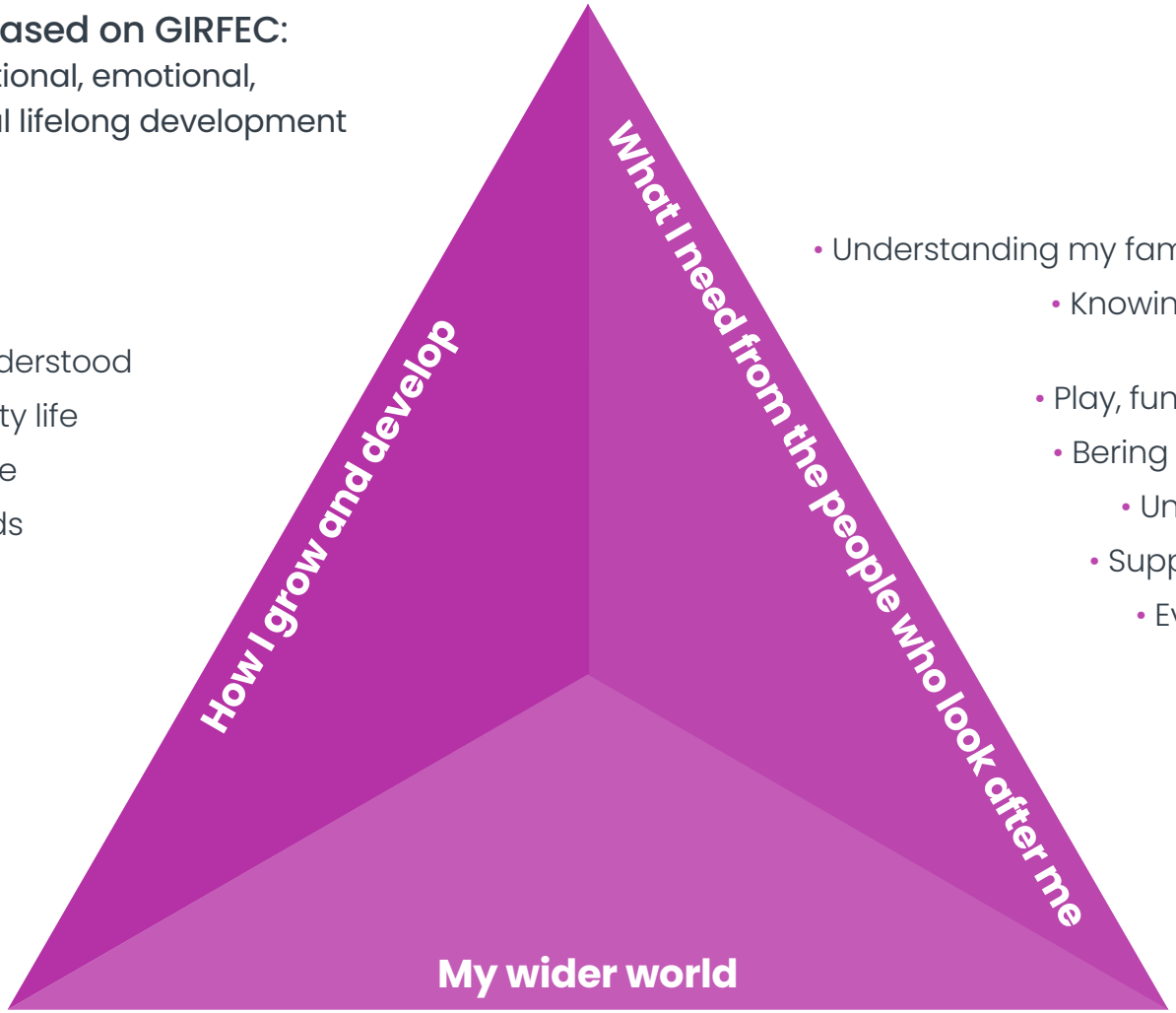
This report recognises that although progress has been made in many local areas, more could be done to prevent delayed discharge and inappropriate out-of-area placements for people with learning disabilities. Many people with learning disabilities continue to be failed by the current system, and for people with complex care needs these failures often begin early in life, with a lack of early intervention and minimal support around communication needs or behavioural challenges.

The framework outlined in this report is an indication of the fact that change is required for people with learning disabilities and complex support needs. The range of reports written on this issue, the concerns raised over many years about inappropriate and institutional placements, and a number of scandals in relation to the treatment of people with learning disabilities in institutions, provide a wealth of evidence to support the need for change and for additional mechanisms to achieve it.

2. Underpinning Principles

A Well-being model, based on GIRFEC:
for physical, social, educational, emotional,
spiritual and psychological lifelong development

- Communicting/being understood
- Participating in community life
- Learning to be responsible
- Enjoying family and friends
- Confidence in who I am
- Lifelong learning
- Being healthy



- Understanding my family's history, culture, beliefs
- Knowing what is going to happen and when, to reassure me
- Play, fun, encouragement, exercise
- Bering there for me: commitment
- Understanding my language
- Support to make good choices
- Everyday expert care & help
- Keeping me safe

- Support from family, friends, wider community
- Comfortable, suitable housing
- Belonging
- Committed, skilled carers
- Enough money
- Local resources

Background

3

3. Background

Previous Reports

In recent years there have been several reports highlighting people with learning disabilities living in hospitals. The Mental Welfare Commission's report *No Through Road* (2016) and the Scottish Government commissioned *Coming Home* report (2018) have highlighted the significant number of people with learning disabilities who are delayed in hospitals in Scotland, sometimes for many years, despite being clinically assessed as ready for discharge into community settings.

Out-of-area:

Coming Home reported delayed discharge and out-of-area placements from all but one (large) HSCP. As of 2017 data, there were 705 people out-of-area in Scotland from 30 Health and Social Care Partnerships (HSCPs)[5]. Of these individuals, there were 109 people who had not chosen their current placement and were identified as being priority to return. There were also 79 people placed outside of Scotland, in either England or Wales. Many of these placements would have been agreed with families but more than half of these people were placed in the rest of the UK because of a lack of local alternatives.

Delayed Discharges:

The report evidenced unacceptably long delays to discharge. That same dataset showed 67 people experienced a delayed discharge and therefore resident in a hospital. At the time, more than 22% had been in hospital for more than ten years, and another 9% for five to ten years. Only 12% had been admitted less than a year, albeit this data does have limitations as explained in the full report. The majority of those placed out-of-area or delayed in hospital had behaviour that staff found challenging and this was often a reason for service breakdown.

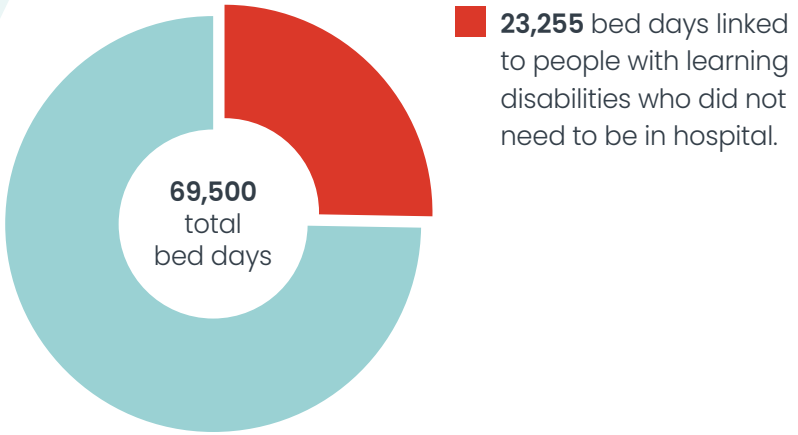
5 This does not include one HSCP which did not provide data.

3. Background

The Mental Welfare Commission's *No Through Road* report 2016, referred to 58 delayed discharges. This followed visits to all 18 hospital units in Scotland for people with learning disabilities. It reported the main reasons for delayed discharges to be a lack of funding; accommodation; or an appropriate care provider. In many cases, a combination of all three existed.

The latest **Mental Health and Learning Disabilities Inpatient Bed Census 2019** showed 54 delayed discharges in learning disability specialties, with an average length of delay totalling just under four years. The overall length of stay for these people in hospital was 1,451 days, suggesting a period of about four weeks where assessment and treatment occurred followed by a further 4 years of delay before they could be discharged. Both the *Coming Home* and *No Through Road* reports refer to little discharge planning actually happening during this prolonged period.

From the Public Health Scotland data, in 2018/19 (the latest complete year of costed data), there were 23,255 hospital bed days linked to people with learning disabilities who did not need to be in hospital (10,336 code 9[6] and 12,899 code 100[7]). The bed days were used by a total of 108 people but average out at 63 hospital beds in use per day. There were a total of 69,500 overall bed days in learning disability specialties, therefore around a third were taken by people who shouldn't be in hospital.



6 See Appendix 3
7 See Appendix 3

3. Background

Most of the inpatient beds are provided for assessment and rehabilitation, yet the data demonstrates we have people spending their lives in these hospital beds as a result of delayed discharge. In looking at the overall provision, if we could reduce the overall lengths of stay and remove the delayed discharge element, overall capacity should reduce by about half.

Data on delayed discharge for people with learning disabilities is not routinely collected. There is no mechanism to track re-admission data and there is a lack of evidence to know what types of care and accommodation are required regionally and nationally. This makes medium and long term planning almost impossible. These reports are the best evidence of the situation in Scotland and it is clear that the recommendations of past reports have not yet been fully implemented.

These reports highlight that people living in hospital, or in inappropriate out-of-area placements, have restricted life opportunities, including their use of the community, access to work or meaningful day activities, personal relationships, and autonomy. This is a clear failure to uphold their human rights. It is not suitable for people with learning disabilities awaiting discharge to be living alongside people requiring therapeutic clinical care. This provides unnecessary challenges for staff in the delivery of safe and effective care.

3. Background

There is evidence from a number of facilities in England of the risk of human rights abuses when people are unnecessarily homed out-of-area or in multi-bed institutions. A BBC Panorama investigation broadcast in 2011 exposed physical and psychological abuse suffered by people with learning disabilities at Winterbourne View. Eight years later undercover BBC filming showed staff intimidating, mocking and restraining autistic people and/or people with learning disabilities at Whorlton Hall. The Muckamore Abbey scandal evidenced a 1 in 4 chance of being abused and is currently the subject of a public inquiry. The tragic deaths of three people (Joanna, Nicholas and Ben) with learning disabilities at Cawston Park show the worst possible consequences of poor care. An independent safeguarding review into their deaths uncovered "excessive use of restraint and seclusion by unqualified staff, "overmedication," or the Hospital's high tolerance of inactivity – all of which presented risks of further harm. The review made a number of recommendations including a review of the current legal position concerning private companies, their corporate governance and conduct by the Law Commission.

3. Background

Cost

Out-of-area placements and delayed discharges come at a high cost, not just in terms of the human cost to the individual and their families but also financial cost to the commissioning authority. There are also issues around effective scrutiny and monitoring of individuals who have been placed outside of Scotland.

NHS data showed that the cost of all learning disability inpatient stays was estimated at £48m in 2018/19, with the cost of beds for people with learning disabilities and/or enduring mental health conditions who are subject to an unnecessary delayed discharge estimated at £16m (or averaging £252,000[8] per person).

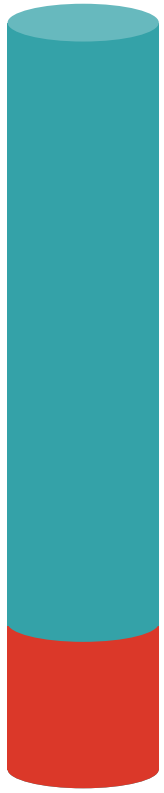
Delayed Discharge

£48 million
total cost on learning disability inpatient stays

- **£32 million** clinical learning disability inpatient stays
- **£16 million** unnecessary delayed discharge

In terms of out-of-area placements, a survey of all Health and Social Care Partnerships carried out by the SLWG in 2020 received 22 responses. These showed 47 people placed outside of Scotland at a cost of £7.748m, which would scale up to approximately 70 people across Scotland at a cost of £11m[9]. A further 469 people were placed within Scotland but outside of their own local authority at a cost of £48m.

Out-of-area



£59 million
total cost of out-of-area placements

- **£48 million** 'placed within Scotland but outside own local authority'
- **£11 million** 'placed outside of Scotland by Local Authority'

8 Public Health Scotland data (2018/19)
9 Calculated on a population share basis

When adding in NHS out of Scotland placements, we can assume on average 90 individuals are placed out-of-area in community placements in the rest of the UK at an annual cost of £15m (or an average of £167,000 per person).

Scotland Excel has estimated the average annual cost of a complex package of care in the community for people with a learning disability at £172,000 (taking in to account only packages that were valued at over £100,000 – there are likely to be far smaller packages of care where family members provide most support). These packages ranged from £108,000 to £201,000.

Housing

Due to the invisibility of many people with learning disabilities it is not possible to quantify how many people should be living in their own home rather than a care facility. However, Scotland's ambition is that as many people as possible are cared for in a domestic setting. It is very unlikely that a suitable house already exists or will become available within a reasonable or predictable time period. As a consequence, for those for whom housing is the appropriate outcome, it is likely that a bespoke solution in the form of an individual dwelling or some arrangement of shared accommodation or core and cluster provision is likely to be most appropriate. For a small number it may be possible to secure the appropriate house in the private sector. In most situations where housing is required the only deliverable solution will be in the social rented sector provided by either a local authority or a housing association.

"Scotland's ambition is that as many people as possible are cared for in a domestic setting"

3. Background

New homes for social rent and to meet particular needs are delivered though the local strategic housing planning system. **Local Authorities prepare a local housing strategy (LHS) every five years and a Strategic Housing Investment Plan (SHIP) every year.** The LHS provides an analysis of housing needs and identifies medium term priorities for service development and investment. The SHIP sets out the specific investment projects to be delivered in the current year and the following four years based on local needs, the resources available through the Scottish Government's Affordable Housing Supply Programme, and individual landlords' own investment plans. Grant rates are set nationally but allow for a degree of flexibility in the case of homes designed to meet particular needs.

The delivery of specific projects is driven through joint working arrangements between the council as Strategic Housing Authority and social landlords (including the council as landlord) and other partners.

Local Housing Authorities also prepare a Housing Contribution Statement (HCS) as part of the Integration Joint Board's (IJB) commissioning plan. The HCS sets out how housing related services including new supply will contribute to meeting the IJB's heath and care priorities including the provision adaptations and the supply of housing designed to meet particular needs.

For this system to be effective all three planning documents (LHS, SHIP and HCS) need be consistent in identifying the full range of needs, establishing relative priorities and identifying the necessary resources to support delivery. In the case of specialist and supported housing the IJB's commissioning plan also needs to identify people with learning disabilities; the nature and scale of provision and the revenue resources available to provide the care and support required.

The LHS/SHIP process can also help identify alternative or innovative funding options including private sector investment, home ownership options and the use of alternative funding including, for example loan finance where these are appropriate.

3. Background

Accurate data on the needs and requirements of people with learning disabilities is the first necessary step to ensure that those involved in assessing local housing needs are aware of the specific needs of people with learning disabilities.

There are mechanisms in place for this that have been successfully used in local areas to develop specialist housing for complex need such as core and cluster models. This would require the appropriate data at a local level to support planning and the alignment of strategic commissioning and housing plans with appropriate links to Housing Contribution Statements.

"This would require the appropriate data at a local level to support planning and the alignment of strategic commissioning and housing plans with appropriate links to Housing Contribution Statements."

For Adults who lack capacity, the **Joint statement by the Scottish Government and The Mental Welfare Commission on supporting discharges from hospital for adults with incapacity** was published in October 2021 and references the additional guidance published to navigate discharge planning in the **Adults who lack capacity - discharge process: key actions** (November 2020). However the statement is clear:

When people are clinically well enough to leave hospital, they should receive all necessary information and support to return to their home, whether that is their own house or an alternative community setting which is their home. It is not in anyone's interests to stay in hospital when there is no clinical reason to do so.

For those people who do not have the capacity to fully participate in discharge planning processes, legal frameworks must be considered to ensure appropriate lawful authority and respect for the person's rights.

3. Background

It is important to acknowledge that there are examples of good planning, commissioning and experience across Scotland in achieving sustainable discharge and in avoiding inappropriate hospital admission in the first place; however it is also clear that more can be done to ensure better outcomes for this group of people.

Although hospital discharge and commissioning are the remit of local HSCPs, the risk of human rights abuses is an urgent issue which needs to be addressed at a national, strategic, and system-wide level in order to find innovative, resourced, and sustainable solutions.

"The risk of human rights abuses is an urgent issue which needs to be addressed"

Case Study – ENABLE

In partnership with one HSCP, ENABLE Scotland has worked on a successful plan to support a young man, aged 27 who had been delayed in hospital for 3 years, out of an acute setting and into a home of his own.

This required development beyond the 'traditional' provider approach and required an 'all in' approach across the whole organisation to do whatever it takes. As a provider, ENABLE took a lead role in advocating for the rights of the young man to fully direct his own support; delivered a salary rate in excess of the Scottish Living Wage rate to attract and retain a committed, skilled and sustainable staff team; allocated a dedicated service manager to oversee the development of the service from design to recruitment to delivery of support, including the design of the property; and invested in an organisation wide practice development team, led by a registered Learning Disability Nurse to lead the training and development of the team.

Following a significant process of integrated planning, clinical governance, targeted recruitment of a larger 5:1 support team, (matched with the young man's preferences, for example to have a greater ratio of male Personal Assistants), the provision of specialist input and training for that team, and work with local housing services to procure and design an appropriate and safe home setting, the HSCP and ENABLE have now successfully enabled this young man to move out of hospital into his own home. He is supported by his bespoke team, and currently enjoys time outdoors in his garden, which has emerged as one of his favourite things to do. On his first night at home, he sat on his own sofa for the first time in 3 years.

3. Background

Barriers to Change

The SLWG heard from a range of professionals from different sectors around the current challenges and barriers faced. While not an exhaustive list nor derived from a consultation, the themes discussed can be helpful in understanding the context in which different sectors are working.

Providers:

- Social care packages inadequate as limited non-contact time to allow for planning, staff support, debriefing, on-the-job coaching, team meetings, supervision and training.
- Suitable accommodation, or accommodation that can be adapted, or is flexible, is not available and will need longer lead time for development and planning phases as well as access to capital funding.
- Recruitment and retention of staff with the necessary specialist skills.
- Support from specialist services and integrated team experts does not often include direct support and is not quickly and easily accessible.
- High risk of financial loss to providers if they have vacancies in their accommodation, so the need to fill voids often rushes placements without proper funding and time for adequate pre-admission planning and visits.
- No true assessments at the start of the process leading to lack of knowledge when identifying triggers, behaviours, and analysis of this.
- Delays can be caused due to practical issues around buildings and property, handovers from hospital to providers and due to neighbour relations.

3. Background

HSCPs:

- Hospital admissions can be the fall-back position as a result of a breakdown in care packages, usually related to behaviours that challenge. Admission is seen as a response to risk rather than a clinical decision.
- Difficulty in finding providers who are able to provide the right level of specialist support that may be required.
- Small numbers of individuals in each HSCP.
- Lack of agreement about who can live in the community and what level of risk is acceptable in the community, which can vary across partnerships.
- Some individuals have a history of failed placements, are increasingly traumatised and therefore find it more difficult to settle in any new environment.
- Historic funding arrangements for those effectively living in hospital may de-incentivise HSCPs to work towards discharge. Integration was established to resolve this. The process is there it is just not being followed.
- The current use of and interpretation of exclusion codes within the Delayed Discharge recording system does not motivate or place any urgency on finding a community placement.

3. Background

Commissioners and commissioning Process:

- Competitive tendering is unhelpful in terms of engaging social care providers in a frank and person-centred discussion of the good support requirements, challenges for people with complex care needs and compatibility between the provider and the individual.
- Often an individual package of care will be in excess of £250,000 per annum requiring a very long term commitment from social care budgets.
- Commissioning is rarely co-produced and families often have very little say in how services are developed for their family member. People with learning disabilities and their families should be involved in commissioning, however it often doesn't happen. There can also be a disconnect between Integration Authorities as the commissioners of care and local authority housing departments.
- Quality of assessments are variable and in some cases poor and too generic with little detailed understanding of the complexity of people's needs.
- Commissioners feel limited in what they can provide due to lack of specialist providers within their areas, and they feel constrained by available funding, and/or ability to cultivate the experience locally.

3. Background

Commissioners and commissioning Process:

- Ordinary Residence regulations act as a disincentive to HSCPs to commit to building or acquiring group accommodation that could be deemed to be housing. It is also a barrier more generally, for example there is a lack of incentive to find a care package in their locality if they are in a hospital in another authority or to take over the care package for individuals who have moved to their area.
- Commissioning of accommodation including the challenges of finding a site in a suitable location for everyone; the design and specification challenges in the case of very high support needs accommodation; issues of capacity when it comes to signing a tenancy; the perceived risks on the part of housing providers around the subsequent occupation of a highly adapted dwelling and the likely concerns about void and re-let processes including rent loss and the likely ability to identify subsequent occupant.
- Unrealistic expectations leading to the process being rushed and the placement breaking down.
- Changing needs of the person requiring accommodation due to a change in their health. Events such as a stroke may render their current accommodation no longer suitable.

Dynamic Support Register

4

4. Dynamic Support Register

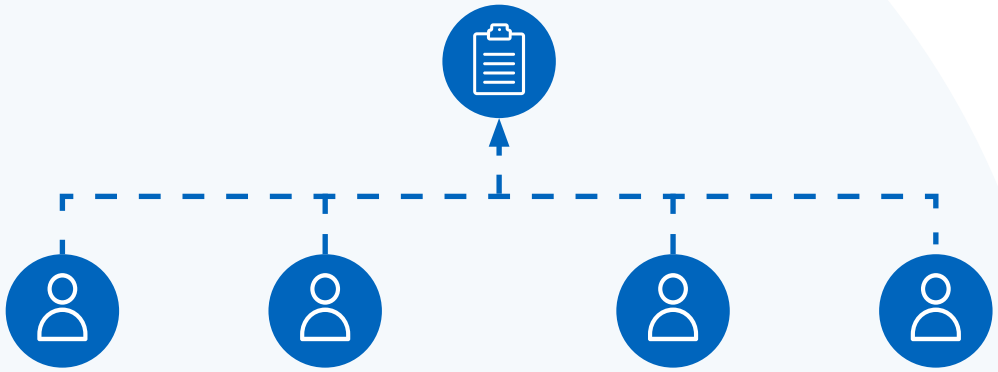
4.1 Purpose of the Register

The purpose of the Dynamic Support Register (referred to as the Register) is ultimately to avoid people with learning disabilities living in hospitals, or in out-of-area placements which they/their family have not chosen. It has been designed to help professionals working with people with learning disabilities to better respond to situations where there is a need for a more intensive level of care management.

It aims to:

- Identify and address risks of admission to hospital or out-of-area placement
- Support the development of local community placements

The Register is a tool that should be key to supporting local planning and decision making. It will be utilised and maintained by each local area, however will be owned nationally so that there is consistency and uniformity in data recorded across all areas. This should help local areas overcome the challenges in fully articulating the nature of individual needs, care requirements and risk assessments when collaborating across both health and social care. It will improve the visibility of this group of people both at a local strategic level and nationally, and allow local areas to monitor their own progress against reducing delayed discharges and out-of-area placements. It will also embed anticipatory care into practice via proactive and preventative measures, to enhance support when people are most at risk.



The Register will be applicable to adults with learning disabilities who are regarded as having complex support needs. While formally undefined, complex support needs may include those, who in addition to having a learning disability:

- Are also autistic
- Have a mental health diagnosis
- Have a forensic need, and/or who are described as demonstrating behaviour that challenges.

4.2 Who the Register is for

The Register will be used for adults with a learning disability whose support is funded by a Scottish Local Authority or Health Board, who are within one of the following groups:

- **Currently admitted to hospital-based assessment and treatment units.**
  This will apply to anyone within these units, whether they are formally regarded as delayed or not. It will apply to those in either NHS or private hospitals, either within Scotland or elsewhere in the UK. Those recently (within the last 6 months) discharged from an assessment and treatment unit will also be included in this group in order to monitor readmission risk. Given that some areas use Mental Health beds when Learning Disability units are full, it will also apply to anyone using an NHS inpatient bed in an inpatient setting.

- **Living in an unsuitable/inappropriate out-of-area placement.**
  This is defined as a placement which the person and/or their family did not choose, and which has been used because of a lack of suitable local resources, or a placement defined as poor quality, or that meets the risk criteria[10].

  This applies to placements either in Scotland or elsewhere in the UK.

  It does not apply to those living out-of-area if they/their family have chosen for them to be there and if they/their family approve the placement (unless there are serious, legitimate concerns about the placement raised by the HSCP or others).

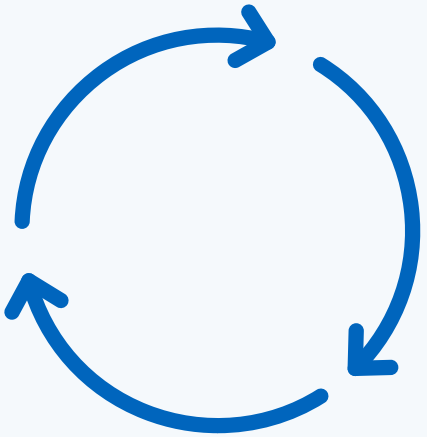
10 Noted in appendix 2, section 2

4. Dynamic Support Register

- **At risk of placement breakdown - current living situation is becoming unsustainable.**

  This may be for those living within a family setting or those who receive support from a care provider. The individual may be at risk of either admission to hospital or having to move to an out-of-area placement. This may be for any of the following reasons:

- Significant increase in severity and frequency of behaviour that challenges over a sustained period, resulting in service providers or family carers who are no longer able to support the person safely or effectively.
- HSCP concerns about the suitability, stability, or sustainability of a placement (e.g. a young person coming near to the end of their school placement).
- Family carers who are becoming unable to continue caring for their family member, or death/illness of family carers.



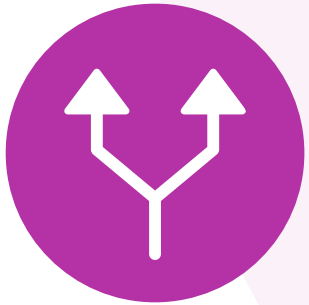
Framework to Support Register

5. Framework to Support Register

Without a framework to support the use of the Register, it may be ineffective in facilitating the broad systemic change required to address this long-term and challenging issue. The following framework will support the purpose of the Register and will consist of:

5.1 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.

5. Framework to Support Register

5.2 Peer Support Network

It is acknowledged that many clinicians and practitioners for people with learning disabilities and complex support needs may not have contact with others nationally who are doing similar roles, or who are working through similar challenges. Recognising how uniquely complex some of the care circumstances can be, this can only be solved by bringing people together to help each other and to provide peer support. Working more closely together as a sector can help us to provide better services across Scotland for people with complex care needs. A process of peer support will help give guidance and advice to HSCPs for people with particularly complex care needs whose support has been challenging to get right.

A Peer Support Network should be established to facilitate people coming together to learn and share best practice, and to get support when planning services for individuals with particularly complex care needs.

This support and advice will be provided from clinicians, commissioners, social care providers and family members from around Scotland who have expertise and experience in developing and delivering services to people with learning disabilities and very complex support needs. The purpose is primarily to put HSCPs in touch with peers who have expertise in particular areas, so that local teams can learn from others who have already done what they are working towards, and to provide a safe space to share experiences, pool resources (staff/buildings) and learn from each other.

Local areas may wish to consider appointing a dedicated "change champion." This person will have expert knowledge of the needs of people with learning disabilities and an understanding of the challenges faced in their area. By having ownership, this individual is then best placed to collaborate regionally and nationally and utilise the support offered through the Peer Support Network.

5. Framework to Support Register

5.3 National Support Panel

A National Support Panel should be established as a national body who will work on behalf of the Scottish Government and Local Authorities to ensure that the Register is achieving positive outcomes for people with learning disabilities who are currently in hospital or living in out-of-area placements. The primary purposes of the Panel are:

- To work with HSCPs and partner organisations by providing support and expertise for their decision making and solutions for individuals in a collaborative forum.
- To provide checks and balances to ensure that people with learning disabilities are receiving the best care in the most suitable environment.
- To understand and hear from families and individuals about their individual circumstances.

The Panel will work with and support nominated HSCP leads and hold regular reviews for anyone on the Register, monitoring progress towards discharge or out-of-area return against the Complex Support Needs Pathway. The Panel will work with HSCPs to assess if the milestones within the Pathway are being met. This will include requiring information from the responsible HSCP in order for the panel to work with commissioners to provide person-centred assistance such as:

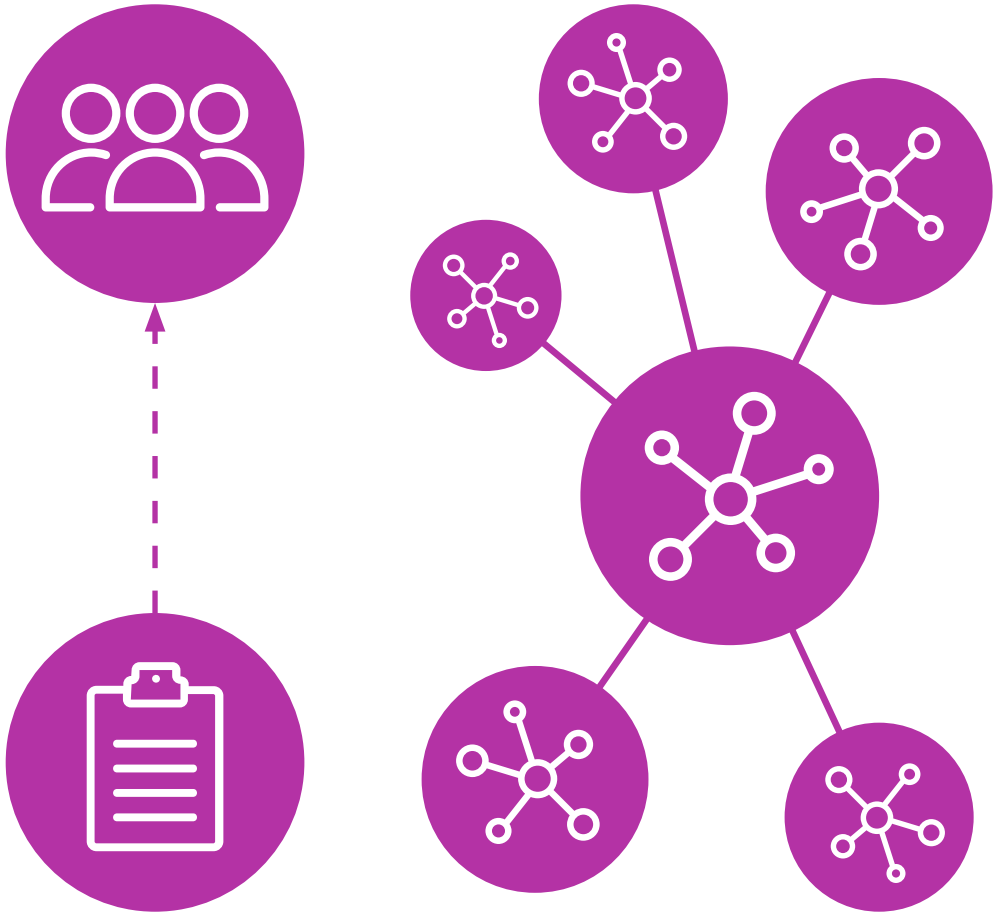
- Progress towards accessing suitable accommodation
- Progress in relation to financing the support package
- Identification of a suitable provider
- The support plan in the person's current placement
- Any issues or concerns, e.g. use of restraint, high levels of challenging behaviour or serious risk factors.

5. Framework to Support Register

The expertise available via the panel will, for example, help to match HSCPs with other areas who may be looking to pool resources, share existing good practice that has led to sustainable solutions and provide additional advice about staffing, training and suitable providers. This is designed to help address the barriers recognised earlier in this report.

Recognising that call for expert support and expertise the Scottish Government should establish the panel urgently.

The SLWG view is that the panel should be backed with statutory powers in order to support their function, including the authority to require any information that enables the panel to carry out their role, as well as powers to make placements and/or require funding of a support package.



Community Change Fund

6. Community Change Fund

6.1 Purpose of the Community Change Fund

It was the view of the members of the SLWG that most people with learning disabilities and complex care needs require a radical redesign of services in their local community. In order to facilitate this, the group proposed a short-term Community Living Change Fund which was accepted as an early and priority need and distributed by the Scottish Government following receipt of Barnett consequentials for similar work by UK Government.

£20m was allocated to Integration Authorities in February 2021 and can be held in reserve for up to 3 years. The Scottish Government is working with local areas to monitor the use of this funding.

The purpose of the Community Living Change Fund (referred to as the Fund) is to drive the redesign of services for people with learning disabilities and complex care needs. The goal is to provide high-quality, local, community-based services where, regardless of complexity of need or behavioural challenge, people's right to live a full and purposeful life, free of unnecessary restrictions can be realised.

The Fund is available to accommodate the re-provisioning of long-term hospital and inappropriate out-of-area care and to create a powerful lever to a longer-term shift from institutional care. The Fund is not intended to replicate current inappropriate arrangements but rather act as a facilitating mechanism to bring about change.

Specifically, the purpose of the Fund is to help people with learning disabilities although this could be extended to support people with enduring mental health conditions where this was deemed appropriate. The Fund should be used to support people to:

- Be discharged from hospital quicker, and not face any unnecessary delays to their discharge;
- Come home back to their local area if they have been inappropriately placed out of Scotland;
- Feel better connected to their communities through an increase in local community service provision for when they have been placed in inappropriate or institutional out-of-area placements;
- Receive better services through redesign of existing provision that is better tailored to the specific needs of the person.

6. Community Change Fund

6.2 Use of the Fund

The Fund should be broadly used to improve community-based support to people with complex care needs with the aim that by March 2024 out-of-area placements are only made through individual family choice and people are only in hospital for genuine short-term assessment and treatment.

This includes ensuring that no one is admitted to hospital because of behaviour that challenges, and that where individuals are admitted to hospital, this is short-term and for a clear clinical purpose of assessment and treatment, rather than due to lack of appropriate community placements. The Fund should also be used to ensure that out-of-area placements are only made based on the choice of the individual and/or their family.

It is recognised that this has been a long-term challenge for the sector in Scotland and across the UK, and that service redesign requires whole system change. This may be a lengthy process and will need local leadership and vision for the changes required in local areas. The challenges facing each HSCP may be slightly different, depending on a range of factors such as current local services, geographical challenges, and/or workforce issues. The specific solutions may also therefore be slightly different and as such guidance for use of the Fund has not been specifically prescriptive.

However, it is clear that the overall aim of the Fund is to support redesign of services in order to achieve the above objectives. It is therefore important that the Fund is used in this way, rather than to simply make up for a shortfall in local services.

> *"This has been a long-term challenge for the sector in Scotland and across the UK, and service redesign requires whole system change."*

Equally, the Fund should not be used to develop institutional services which lack connection with the community and do not allow for people to live a full and rewarding life.

6. Community Change Fund

Some of the suggestions for how the Fund could be spent in order to achieve the overall objectives are noted below. These are supplied in order to help local areas think through how best to achieve the overall objectives of the Fund. It is recognised that HSCPs remain best placed to decide how best the Fund should be spent:

- Use the money from the Fund collaboratively, for example linking with other HSCPs with similar challenges (remote, rural, or island communities may have similar needs).
- Take a board-wide approach to use of the Fund, in order to achieve more fundamental and systemic change, i.e., local HSCPs within the same board area may find it more useful to take a board-wide approach.
- Provide bridging finance in order to support the closure of inpatient beds.
- Invest in collaborative local commissioning solutions, bringing together third sector partnerships.
- Develop a 'place of safety' or crisis service to provide short-term accommodation options for people experiencing significant challenges or approaching crisis in their current service.
- Consult with social care providers to determine their workforce development needs, with an aim to achieve a wider range of providers able to develop successful community-based services for people with challenging behaviours and complex needs.
- Provide specialist training to commissioners to enable them to feel more confident in commissioning services for people with the most complex and challenging needs.
- Develop a local complex needs 'Change Champion' role, with responsibility to oversee the Fund's objectives.
- Develop local expertise and resource in Positive Behaviour Support or other similar person-centred approaches, recognised as effective evidence-based approaches to supporting people with learning disabilities and behavioural challenges.

Case Study – Teviot Court, Midlothian

Midlothian is one of the fastest growing Local Authorities in Scotland with a rapidly increasing population. It is fairly small geographically, covering the 9 miles from Dalkeith to Penicuik. Therefore one housing development is local for everybody. Midlothian has land, and a well-established local authority house building programme. It is close to Edinburgh, and therefore issues around recruitment and retention are not as acute as other areas.

Early discussions took place about a cross-HSCP regional approach but ultimately it was easier to build alone.

The first step was to build the houses. It took five years until the properties were completed. Without the properties everything else was felt to be compensating for the wrong environment. The appropriate houses cost twice as much as a usual council house but can be used variously and independently as design allows for differing needs. The design is 12 council tenancies in a cluster of four flats around three courtyards. This allows for efficiencies of support, provided in a town centre location. Properties are twice the size of standard housing and a pleasant place for people to live in a high quality environment. These properties were suitable to support people who may have been at risk of having to live out of the local area or of being admitted to hospital. The design is safe, comfortable and a homely environment. The designs are physically robust, single storey, barrier free and non-institutional. The layout is designed in a simple clear manner so that, intuitively, it requires less effort for people with complex needs to use and inhabit the environment.

Various capital approaches were considered but Midlothian ultimately settled on utilising the Housing Revenue Account. This was supported by Phase 2 of the Housing Build Programme plus 50% from the General Fund. Placements are supported through rent charges. Complementary properties in Phase 3 are currently being built as part of the house building programme.

6. Community Change Fund

6.3 Monitoring of the Fund

The Scottish Government should actively monitor spending from the Community Change Fund to ensure that the Fund is being used to meet the objectives noted above.

Informal monitoring will be carried out collaboratively and co-operatively through partners such as the Social Work Scotland Learning Disability Network.

However, the use of each Integration Authority's share of the £20m must be recorded in their annual financial statement and the outcomes delivered detailed in their annual performance report.

Summary & Recommendations

7

7. Summary & Recommendations

This report sets out a new framework for people with learning disabilities and complex support needs who are placed in unsuitable out-of-area placements, or who are inappropriately admitted to hospital, due to breakdown in their community-based support.

This is the group who were the subject of the Scottish Government's *Coming Home* report of 2018, and recognising that implementation of the recommendations of this report have not been fully realised at the scale or pace required to meet the national ambition, many of the recommendations within this paper echo the findings and recommendations of *Coming Home*.

It is therefore recommended that the new framework be referred to as the ***Coming Home Implementation Framework***.

7.1 Summary

It has long been Scottish Government and Local Government policy that people with learning disabilities are supported to live well in their local communities, and that people are not unnecessarily delayed in hospital. The £20m Community Living Change Fund has been issued to Integration Authorities and can be held in reserve to be used over a three year period from 2020/21. This framework will support local and national government to meet their policy commitments in relation to people with learning disabilities, as outlined in the **Keys to Life**. It will also support meeting the obligations contained within the UNCRPD[11].

It is recognised that there are inherent risks in living within institutional settings, and that there has been documented abuse linked with these types of services. People with learning disabilities in Scotland should feel assured that this report and framework give an indication of the serious commitment in Scotland to respect the human rights of people with learning disabilities and complex support needs. The positive use of the framework has the potential to support the development of greater public trust in services provided to people with learning disabilities.

11 Obligations listed at Annex 5

7. Summary & Recommendations

For people with learning disabilities, particularly those with complex support needs, there are many benefits of the framework set out here.

The framework will set a foundation that will help people to live well in their local communities, to have fulfilling lives, and to have their needs met. This includes ensuring that people are only admitted to hospital for appropriate reasons. Behavioural challenge and the service breakdown which often accompanies it, are no longer a reasonable reason for admission to hospital. The framework also aims to ensure that those who are admitted to hospital do not become stuck there, and have to wait for long periods of time until they can be discharged to a suitable community setting.

If we can establish local placements/homes and source, recruit and retain adequate staffing then people would no longer be placed in out-of-area placements due to lack of suitable local resources or not through individual choice, which often results in fractured relationships with friends and family and loss of connection with their local community. Locally, resource transfer should be considered to ensure that community placements are sustainable. The framework also seeks to ensure that people are no longer placed in unsuitable or poor quality out-of-area placements, which do not meet their needs, i.e. which are large, institutional, provide an inadequate level of care, and/or are disconnected from the local community.

The framework is also designed to ensure that the needs of people with learning disabilities and their families drive the local commissioning strategy, which is there to support them, and enable better planning.

Essentially, the framework aims to provide greater local visibility for people with learning disabilities and complex support needs, and to ensure people do not get forgotten about, or lost in the system.

7. Summary & Recommendations

In addition to directly impacting people with learning disabilities, the framework will also impact on services and how these are planned and commissioned. It will support better local long-term planning to meet the housing and support needs of individuals with complex needs. This should include proactive development of specialist multidisciplinary teams that are focused on providing the necessary services and support in the community to prevent admission to hospital. It should also include proactive development of appropriate housing.

"The framework will provide national oversight and a set of principles and standards"

"The National Support Panel will bring together expert advice available to help HSCPs to deliver"

The framework will provide national oversight and a set of principles and standards to support HSCPs to improve their performance for this group of people and to receive support and expert help to do so. This will include promoting accountability for delivery through a named local lead, helping to identify people at risk of placement breakdown and allowing risks to be proactively managed to prevent admission. There is also a clear emphasis on providing a collaborative and solutions focussed approach, developing local positive community alternatives to hospital and helping HSCPs to develop their skills and share their approaches. The National Support Panel will bring together expert advice available to help HSCPs to deliver.

The use of the framework will provide accurate national information in relation to the support required for people with learning disabilities and complex needs. This will provide useful data-driven planning information about the current and future needs of this group and lead to opportunities to adopt a more evidence-informed and strategic approach to addressing barriers on a national basis.

7. Summary & Recommendations

"Scotland will provide the best possible services that are consistent with a Human Rights Based approach"

Louis' Story, which opened this report, is an example of how Scotland has failed people with complex care needs. It is an aspiration that Scotland will provide the best possible services that are consistent with a Human Rights Based approach, as set out in the Scottish Government's National Outcomes Framework and as proposed in legislation through the Human Rights Bill.

The successful implementation of this framework should promote the development of good quality local support services, monitored through appropriate quality assurance systems and reverse the trend of developing large, institutional services. This is the route to upholding the Human Rights of people with learning disabilities and complex needs.

7. Summary & Recommendations

7.2 Recommendations

1) **Scottish Government and COSLA should make a policy commitment to take forward the proposed framework.** There may be a financial implication for Scottish Government and Local Government, e.g. to set up the Register and to support the Panel, in addition to administrative and civil service support. The framework may also require legislative support and will sit alongside other relevant ongoing work such as the National Care Service and Mental Health Reviews.

2) **The current sample Dynamic Support Register should be developed into a tool for national use.** This will require digital and information management expertise and resource to produce a secure and useful electronic database that gives visibility to this hidden population on both a local and national scale.

   Detailed operational guidance should be developed for the use of the Dynamic Support Register, co-produced with HSCPs. (Initial draft guidance is attached at Appendix One).

3) **A National Support Panel should be established in order to provide support and oversight of the Dynamic Support Register.** The National Support Panel will bring sector expertise together to provide an open collaborative forum that can troubleshoot individual cases in partnership with local areas. Scottish Government should consult on the precise role and remit in order that the panel provides value and achieves the objectives of reducing inappropriate hospital admissions and out-of-area placements. (Scoping work is included in Appendix Two).

7. Summary & Recommendations

4) **A National Peer Support Network should be established to facilitate people coming together to learn and share best practice**, and to get support when planning services for individuals with particularly complex care needs. This network should offer support and advice informally to allow cases to be discussed openly and frankly, with input from clinicians, commissioners, social care providers, social workers and family members from around Scotland who have expertise and experience in developing and delivering services to people with learning disabilities and very complex support needs.

5) Recognising the lack of available evidence for people with enduring mental health conditions and the expertise of the contributors to the SLWG, **further work should be undertaken to explore the issues in relation to people with enduring mental health conditions who are subject to delayed discharge from hospital.** This should include sector experts in mental health and social work, as well as people with lived experience.

7. Summary & Recommendations

What does good look like?

Building on the content of this report, success will be measured against the mission statement: By March 2024 we expect to have seen out-of-area residential placements and inappropriate hospital stays greatly reduced, to the point that residential out-of-area placements are only made through individual or family choice and people are only in hospital for as long as they require assessment and treatment.

Work is already underway against this objective both nationally and locally as a result of the long term ambition to reduce delayed discharges.

The Mental Welfare Commission's *No Through Road* report (2016) suggested that the Scottish Government in partnership with integrated joint boards, should develop a plan to end delayed discharges, in the context of health and social care integration, and ensure that the monitoring and reporting of delayed discharge was robust.

The Scottish Government's *Coming Home* report (2018) recommended that a more proactive approach was taken to planning and commissioning services and to identify suitable housing options. The need to provide Positive Behaviour Support (PBS) training was also highlighted.

The Scottish Government and COSLA's *Keys to life implementation Framework* (2019) also recommended investment in the development of positive behavioural support through the creation of a university post and provide direct support to Health and Social Care Partnerships to consider the findings, including the need for different models of care to bring home people identified as priority to return.

The route to achieving this will require multi-sector multi-disciplinary collaboration at a number of levels, and the decisions taken will be variable across the country to account for local need.

Case Study – The Richmond Fellowship Scotland: Colin's Story

Colin grew up in a rural area with a close extended family nearby, receiving local community support. He has complex brittle diabetes type 1 and organic personality disorder. His diabetes required blood tests up to six times daily, including during the night.

In 2009 Colin's diabetes became unstable and resulted in an Acquired Brain Injury (ABI). Following initial treatment, he was admitted to a specialist unit in Glasgow. The result of the ABI included a range of behavioural concerns including:

- Impulsiveness
- Physical aggression
- Absconding behaviour
- Difficulty understanding when things will happen,
- Difficulty with problem solving and reasoning skills.

A behaviour management plan included daily use of physical interventions to manage his behaviour. Colin had limited community access due to absconding behaviour and the ratio of staff required and he had limited opportunity for independence and developing active support skills and developing skills of daily living. His family were keen for him to return to his home area to be near family and live within his local community.

Colin's family spent the next 10 years campaigning to access the right support in the community to allow him to return home however it was suggested there were insurmountable barriers to achieving this goal. These included:

- The behavioural challenges that he displayed
- The risk of physical aggression to a District Nurse who would require twice daily visits to manage Colin's diabetes.

7. Summary & Recommendations

In 2017 after over 10 years out-of-area an individual tenancy was identified in his home area with 24 hour support provided by The Richmond Fellowship. It was recognized that a transition would need to be fully coordinated and a true collaborative approach taken. The transition team included the views of family, Occupational Therapist, specialist diabetes nurse and the District Nurse who would be attending twice a day. Overseen by a Team Manager competent in PBS (he had previously completed a six-month placement in the PBS team, completed his Professional Development Award, has many years' experience of working in complex services and designing new packages of support).

All frontline staff received PBS and Active Support training and a suite of bespoke training was developed including; comprehensive support planning and developing proactive plans. A programme of alternative communication systems was implemented including teaching Colin to use a social story outline why the district nurse takes blood and what to do as well as a visual keyring to help plan and structure the day.

How are Colin's Human Right now being upheld?

- Regular quality contact with him family
- Part of his local community and uses a bus pass with staff to access the community every day
- Has choice, control and independence in his life
- Has a job – supported 2 days per week at the local foodbank
- Developed a social network – attends a drama club and has a girlfriend
- Wants to develop his skills and is supported once a week to attend a skill building course at the collage.

"My life has changed so much for the better."

- Colin

7. Summary & Recommendations

Next Steps

In this final section we have given an indication of the kind of actions required nationally and locally to implement the key recommendations in this report.

True partnership working, in a meaningfully collaborative way, is necessary to meet the vision aspiration – this includes but is by no means limited to: those with lived experience of complex care needs including individuals and their families and welfare guardians; clinicians working with people with learning disabilities and complex support needs; those with experience of both commissioning and providing services.

In addition, the collaboration of stakeholders such as the Mental Welfare Commission, Care Inspectorate, People First, Social Work Scotland, SOLACE, IJB chief officers, NHS chief executives, housing sector professionals, SCLD, Scottish Learning Disability Nurse Leads Group advocacy and carers' organisations is essential to achieving this aspiration.

One of the main barriers is a lack of visibility of the population of people with learning disabilities. Success can be evidenced with an increased visibility of both data and actions to address the needs of this neglected population. Whether through data publication, Commissioning Plans, Strategic Housing Investment Plans, or the National Care Service, collaborative working to ensure this population is no longer ignored is critical.

7. Summary & Recommendations

What should happen nationally?

National Government has a role in providing the leadership and direction to support nationwide systemic and cultural change. National Government should:

- Progress development of a national system that will host the Dynamic Support Register to identify those currently and at risk of admission, so that local areas can provide a dynamic and flexible response for these individuals.
- Establish an expert National Support Panel to assist HSCPs with delayed discharges and to provide leadership and sharing of good practice in order to problem-solve any barrier to repatriation or discharge.
- Comprehensively invest in social care to support skilling up of the sector and to fund services at the level needed for the particular needs of people with learning disabilities. This potentially includes increased pay or direct provision on a national level for those working with those with the most complex needs.
  The Independent Review of Adult Social Care has a specific recommendation (recommendation 10) that *"packages of care and support plans must be made more portable and supported people should not have to fight to retain support because they have moved home"* and the Scottish Governments National Care Service was their response to the Review.
- Develop alternative methods of commissioning that address the specific challenges facing people with learning disabilities who require the most complex care needs, considering legislative changes where necessary. This includes supporting local areas with an evidenced piece of work on accurate revenue cost of care packages.

7. Summary & Recommendations

What should happen nationally?

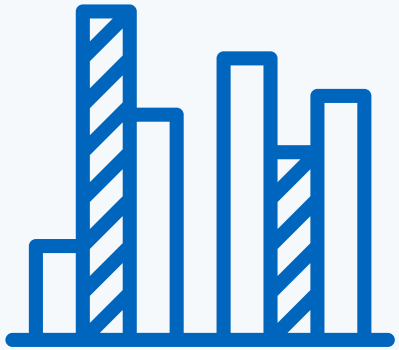
- Foster greater engagement and collaboration with the Scottish housing sector nationally and local strategic housing planning with a view to supporting publication of guidance in relation to housing specifications for complex care. The Scottish Federation of Housing Associations ***"Future Models of Housing, Care and Support"*** report summarises a number of "asks" the cross over with the issues identified in the delayed discharge of people with learning disabilities and/or complex care needs. There is significant good practice in local areas that demonstrate how housing and care and support services can be developed by reconfiguring hospital and community budgets and staff.

- Encourage Programme Budgeting. Programme budgeting is an approach that collects resource allocation by "programme" groupings, enabling the analysis of historic total expenditure on each programme; programmes may be defined in terms of client or care groups; or diseases; or service categories. It looks at resource utilisation within a certain programme rather than resource allocation between programmes. Programme Budgeting Marginal Analysis (PBMA) is an approach to commissioning and redesign of services that can accommodate care professional, service user and management perspectives within a single, transparent decision making framework. It is a practical health economics tool for prioritising investment and disinvestment decisions within the programme budget that allows for the complexities of health and social care provision to be examined alongside the economic concepts of opportunity cost and the margin. Adoption of a programme budgeting approach should include the totality of the resources available, which must include the hospital budget, and agree via collaborative commissioning how it could be used more effectively to provide better outcomes.

7. Summary & Recommendations

What should happen nationally?

- Consider the problems associated with Ordinary Residence and support local authorities, health boards and Integration Authorities on how to manage these challenges, with consideration for legislative changes where necessary.
- Publish analysis based on the Census 2022 returns, when available, that allows local areas to benchmark performance and need for people with complex care needs, e.g. number of inpatient beds.
- Recognise and understand the legal status of Welfare Guardianship as a court-conferred power with formal procedures for accountability and ensure Welfare Guardians are incorporated into national and local policy frameworks and practice.



7. Summary & Recommendations

What should happen locally?

Local Government, NHS Boards, Integration Authorities and the Third Sector are key to providing the services and supports for people with learning disabilities alongside their family and welfare guardians. Their decisions and actions are pivotal to achieving the vision and ultimately reducing the number of delayed discharges and out-of-area placements:

- There should be collaborative work between health, social care and housing and NHS Boards to consider whether opportunities for resource transfer exist to better utilise the current spend on complex care. Local areas may wish to consider adopting a programme budgeting approach. This will enable areas to explore whether there is potential to re-profile out-of-area spend to be reinvested in a better way to meet an individual's needs more locally. It is acknowledged that in some areas, closure of one or two inpatient beds may not result in any substantial resource. However, in other areas, ward closure could have the potential to provide significant resource to re-profile.

- Integration Authorities should actively plan the use of the community change fund in accordance with this report.
- All bodies should support better planning at transition age to identify those at future risk of admission and consider early interventions in order to mitigate crisis placements:
  - Provide support for challenging behaviour at an earlier age, particularly PBS or similar rights based approaches and support for alternative communication.
  - Improved joint working between children's services and adult services for people with learning disabilities.
  - Greater support for family carers, including access to specialist training and respite.
- Develop multi-agency contingency planning for crisis: clarify roles and responsibilities if a placement begins to fail, including what additional support can be offered, governance issues, changes to working conditions etc.

7. Summary & Recommendations

What should happen locally?

- Consider intensive support for existing placements as they start to fail, thereby preventing closure and eviction that can trigger this process.
- Ensure mechanisms for quality assurance and evaluation are incorporated into the commissioning of care packages for complex cases.
- Ensure potential for mediation is incorporated into commissioning care packages for complex cases.

- Ensure there is appropriate available housing – the key to ensuring a person can remain in the community. Areas may wish to refresh their policies around the housing needs assessment and strategic planning process. When a person is admitted to hospital in a crisis, they may be at risk of losing their tenancy and then become delayed if they have nowhere to return to. Bespoke homes are expensive, need to be carefully designed and subsequent uses need to be thought through with effective joint working and planning. This must also include close working with individuals, families, carers and other service providers.

7. Summary & Recommendations

What should people with learning disabilities, their families and Welfare Guardians do?

People with learning disabilities, their families and welfare guardians are experts and an incredibly valuable resource. They may be the allies and advocates for people who are unable to advocate for themselves and have been pivotal in seeking change. People with lived experience and their families can:

- Continue to advocate for themselves and their loved ones. This could be through contributing to local processes, e.g. via Care & Treatment Reviews. Families are vital in ensuring that the voice and choices of their loved one with a learning disability are at the centre of the process and their choices are properly taken into account.

- Seek support from advocacy experts such as **People First**, who have expertise in advocating for people with learning disabilities who are delayed discharge in hospital.
- Obtain Welfare Guardianship through the courts to ensure voice has legal force.
- Use legal mechanisms open under civil law, invoke Human Rights frameworks and Scottish legislation to make a case for change where it is needed.
- Collaborate with MSPs and local councillors, social workers, commissioners, and health managers in work to improve care.
- Hold the life story of the person.
- Work with care staff on the history and language of the person being cared for.
- Contribute to and seek support from charities such as **ENABLE Scotland** and **PAMIS** who can provide advice and support to people with learning disabilities and their families.

7. Summary & Recommendations

What should clinicians do?

- Refocus local policies and procedures to ensure criteria for admission to hospital does not include challenging behaviour and is clinically justified.

Appendices

Appendix One

Dynamic Support Register: Draft Guidance

1. Including Someone on the Register

To decide whether a person should be added to the Register, discussions should take place across the HSCP Learning Disability Team at a multidisciplinary team meeting. Using risk screening criteria, the team will agree if the person should be added to the Register and at what level of priority.

Local procedures may differ, but these meetings should be chaired by a senior member of the HSCP Learning Disability Team and should typically include all relevant disciplines from the Learning Disability Team including social workers. Senior representatives from the HSCP commissioning team and from local housing may also be required.

Once a person has been placed on the Register, a lead must be allocated to the case if there is not already one allocated, and a multidisciplinary discussion must be held within 2 weeks. The group should agree on the lead worker; this should be the professional best placed to support the overall co-ordination of the resulting action plan.

2. Levels of Priority on the Register

There are two levels within the Register; red, which is high risk, and amber, which is moderate risk, but still requires monitoring. Individuals can be moved between levels if their circumstances change or there is progression in the planning process.

Red: High Risk

People who will be included in the red section of the Register are as follows:

- Anyone with a learning disability in a NHS learning disability or mental health bed, whether delayed or not
- Anyone in an unsuitable out-of-area placement, defined as one where any of the following applies:
  - The person and/or their family did not choose to be there
  - Very poor inspection grades in the most recent report, indicating concerns at quality standards within the service
  - Where Adult Support and Protection or safeguarding issues have been raised in relation to the service as a whole
  - Where there is escalating use of restrictive practices, particularly physical restraint, seclusion or any use of prone/supine restraint or intramuscular medication

  - Where there are concerns about the person's human rights
  - Where the individual, their family members, or the HSCP have significant concerns about the placement
- Anyone who is at risk of their support breaking down or ending, either support provided by family carers, or by a social care service provider, or a school placement.

For those who are in the red section, there must be a multidisciplinary discussion, every two weeks. These meetings will focus on reviewing and updating a detailed personal action plan. For those in hospital, or unsuitable out-of-area placements, or whose residential school placement is within 12 months of ending, this review will address the following:

- Progress towards accessing suitable accommodation
- Progress in relation to financing the support package
- Identification of a suitable provider
- Timescales for the above
- The support plan in the person's current placement
- Any issues or concerns, e.g. use of restraint, high levels of challenging behaviour, serious risk factors.

For those at risk of service breakdown, this will address changes needed to the support plan to sustain their support. This may include the following:

- Crisis plan, particularly around high levels of behavioural challenges
- Potential for use of out-of-hours support
- Referral to specialist support teams, e.g. Positive Behaviour Support Team/Additional Support Team/inpatient services (depending on operational procedures locally)
- Contract compliance conversations with social care provider if appropriate
- Additional short-term financial support agreed if required, e.g. for respite care for family carers, for additional staff into a provider, for specialist training for staff teams etc.

Appendix One

Amber: Moderate Risk

The amber level of the Register is a monitoring phase, which ensures that people are not lost sight of once immediate crises are past. The information from those in the amber level should be of benefit to HSCPs to aid strategic planning and to inform commissioning. These cases require less intensive input from the support team and will be discussed monthly by the HSCP Learning Disability Team.

People who will be included in the amber section are as follows:

- Those who have left hospital or an out-of-area placement within the last 6 months.
- Those at risk of placement breakdown, but where their action plan has been implemented to the extent that their risk has reduced to amber.
- Those in poor placements, but where there has been sufficient reassurance that quality issues are being addressed.
- Those who mental or physical health is declining to an extent that their placement may begin to be under threat.
- Those who are placed out-of-area, anywhere, whose support has not been reviewed within the past 6 months.

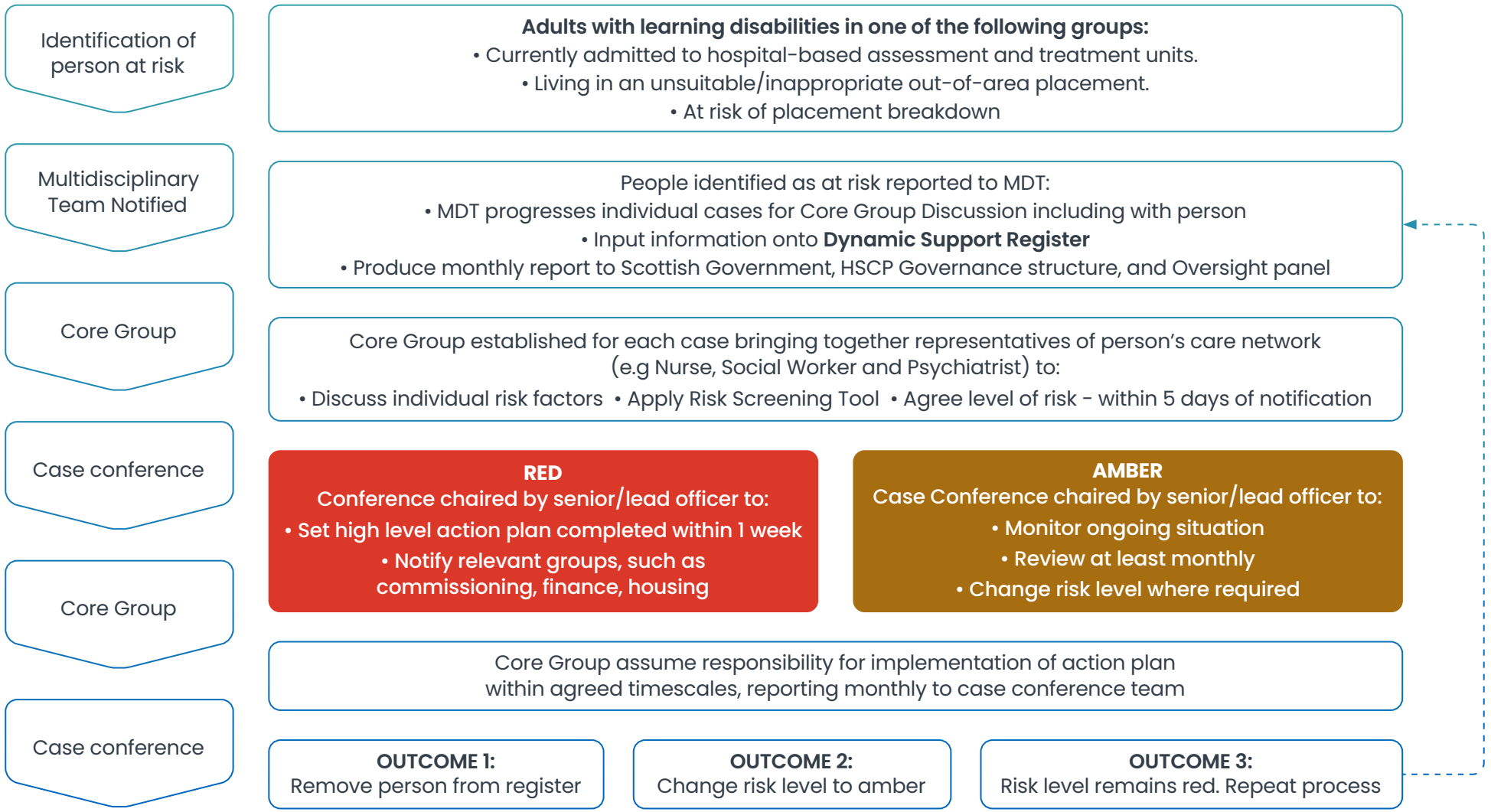
3. Coming off the Register

Individuals will be judged able to come off the Register when one of the following standards can be met:

- The individual is more than 6 months discharged from hospital or other placement and is judged to be settled and no longer at risk.
- The service where the person is living has improved considerably and would no longer be considered a poor, inappropriate or institutionalised service.

Appendix One

Flowchart for the Dynamic Support Register



Appendix Two

National Support Panel: Initiation Paper

Data from the red section of the Dynamic Support Register in each HSCP will be integrated into a national dataset, to allow national overview and long-term monitoring by the Panel of anyone within the red section throughout Scotland.

The Panel will meet regularly (including virtually) and each HSCP will report progress in relation to meeting the milestones within the Complex Support Needs Pathway, for every individual flagged as red on the Register. The Panel will monitor and support progress towards meeting milestones.

The Panel will assess and monitor progress of HSCPs' plans to develop suitable support for people with learning disabilities who are in hospital or inappropriately out-of-area. They will monitor progress against the milestones and timescales laid out in the Complex Support Needs Pathway and will provide support with action plans. The recommendations made by the panel must be informed by the wishes and desires of the individual.

The Panel will require reports, pathway updates, individual support plans, commissioning plans, and any other relevant information to assist with the primary aim of enabling people who are inappropriately placed to get the suitable support package that meets their needs within their own community. They will make recommendations to HSCPs in relation to this issue.

The Panel will report to Scottish Ministers on outcomes, themes, issues, and recommendations. This will be shared with the individual and their family, as well as the relevant Health Board, Integration Authority, HSCP and Local Authority where appropriate. The Panel will also report to communities of interest and associated partners such as the Mental Welfare Commission and the Care Inspectorate. Reports will focus on trends in local areas, such as numbers and use of inpatient bed, as well as on national trends.

Appendix Two

It is proposed that the Panel will have a chair who will take national responsibility to lead and drive the work of the Panel, and who will lead on developing the initial implementation.

In addition, the Panel will consist of:

- Expert by experience, probably a family member with lived experience, or a representative from a carers' organisation, e.g. PAMIS
- Expert clinician with expertise and experience in relation to people with learning disabilities and complex support needs
- An expert with experience of commissioning and/or developing services for this group
- A social worker
- Individuals with lived experience, including family members.

For each person whose action plan is being reviewed by the Panel, the following should attend:

- Senior representative from the responsible HSCP
- The person's Care Manager
- The person and/or their family member, and/or their advocate, and/or their legal proxy, or other preferred person
- Responsible clinician from the person's current place of residence
- Others, as required, e.g. Chief Officer from the HSCP.

Appendix Three

What is delayed discharge?

A delayed discharge refers to the process when a person who is clinically ready for discharge from inpatient hospital care continues to occupy a hospital bed beyond the ready for discharge date.

Put simply, when someone has been in hospital for a period of treatment or diagnosis, and have been determined as ready for discharge, if they are unable to leave hospital for a more appropriate setting then they will be considered to be delayed in their discharge.

The ready for discharge date is essentially a clinical decision, ideally taken in collaboration with the wider multi-disciplinary team, and is the point at which the person no longer requires treatment in a hospital setting. If that person is then still in hospital after midnight at the end of the ready for discharge date then the person is classed as a delayed discharge.

What we count

Adults, aged over 18, who have been delayed in their discharge from inpatient hospital care are counted in the statistics on delayed discharges. For the purposes of the delayed discharge census, hospital is defined as any inpatient bed provided in a substantial NHS facility. Information is collected by NHS Board of treatment, hospital and specialty (but not diagnosis), and also by the local authority of residence. The data is further broken down by age, sex and duration of delay. It is published in two sections – the first a snapshot of delays on the last Thursday of each month, which is shown by principle reason for delay on that day, and second by the overall bed days associated with the delays for that calendar month.

How we count

Data is collected from NHS Boards by Public Health Scotland and generally published on the second Tuesday of the month, approximately five weeks after the relevant monthly period.

Appendix Three

Reasons for delay

The data is broken down by three broad headings – 'health and social care reasons', 'patient/carer/family related reasons' and 'code 9 cases'. Health and social care reasons are where the delays is in the hands of the NHS or local authority, whether undergoing an assessment or waiting for care arrangements, a care home place, funding or transport. Patient, carer or family related reasons are where the delay is mainly within the hands of the person themselves or their carer or family are the cause of the delay. This may include withholding of information, legal interventions or simply refusing to leave. It should be noted that people have the right to appeal the ready for discharge decision and that while that process in underway the person is not deemed as ready for discharge and therefore cannot be considered a delayed discharge. The third broad category is known as 'code 9'.

Code 9 – complex delays

All code 9 delays should have a "secondary reason code" that essentially provides the underlying reason for delay, despite its complexity.

These codes are:

24DX – People awaiting place availability in a specialist facility for high level younger age groups (<65) where no such facility exists in the partnership area and no interim option is appropriate (not to be used where a facility exists but has limited availability).

24EX - People awaiting place availability in a specialist facility for high level older age groups (65+) where no such facility exists in the partnership area and no interim option is appropriate (not to be used where a facility exists but has limited availability).

25X – People awaiting completion of complex care arrangements in order to live in their own home.

Appendix Three

51X – People delayed due to the requirements of the Adults with Incapacity legislation (This code should be applied after it has been agreed that the person lacks capacity; the use of S13za of the Social Work (Scotland) Act 1968 to discharge the person has been ruled out; and an application for Guardianship or Intervention Order is to be progressed through the Courts. Once the process has been completed the person will revert to another reason code and the delay will be calculated from a new ready for discharge date.)

71X – People exercising their statutory right of choice where no interim placement is possible or reasonable. (This code should only be used where long travel distances or limited transport infrastructures restrict the ability of families and friends to visit and where the placement may isolate the individual from a vital family and social network. This code should only be applied where remaining in a hospital setting is a more appropriate outcome and is the only viable alternative to an interim move.)

Code 100

In addition to the delayed discharge codes there is a further set of people, not classed as delayed under the definitions, but who are going through a planned, phased commissioning process to develop alternatives to hospital in the community. Although not formally recorded as delayed discharge, data on these people is collected under “code 100”.

Some concerns were raised in the group that there is inconsistency across Scotland as to how these codes are applied to people with learning disabilities. It is anticipated a national Register would address data inconsistencies.

Appendix Four

Obligations under the UN Convention on the Rights of Persons with Disabilities

Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Appendix Five

Membership SLWG

Jane O'Donnell, Convention of Scottish Local Authorities (COSLA) (Joint Chair of SLWG)

David Williams, Scottish Government (Joint Chair)

Cleland Sneddon, Society of Local Authority Chief Executives (SOLACE)

Hugh McAloon, Scottish Government

Julie Murray, Chief Officer East Renfrewshire & member of Integration Joint Board Chief Officers (IJB CO) Network group

Duncan McIntyre, Midlothian Council,
on behalf of Social Work Scotland

Clare Thomas, COSLA (Co-chair workstream 1)

Brian Slater, Scottish Government, (Co-chair workstream 1)

Gillian Barclay, Scottish Government, (Chair workstream 2)

COSLA and Scottish Government Officials

Workstream 1

Clare Thomas, COSLA (Co-chair)

Brain Slater, Scottish Government (Co-chair)

Joyce Campbell, Scotland Excel

Alex Stephen, Aberdeen City Health and Social Care Partnership (HSCP)

COSLA and Scottish Government Officials

Appendix Five

Workstream 2

Gillian Barclay, Scottish Government (Chair)

Dr Anne MacDonald, University of Glasgow

Charlie MacMillan, Scottish Commission for people with Learning Disabilities (SCLD)

Andy Kerr (Piper Group)

Austen Smyth, Richmond Fellowship

Dr Ron Culley, Quarriers

Kate Sainsbury, Parent carer

Dr Eleanor Brewster, Royal College Psychiatrists

Tony Cain, Association of Local Authority Chief Housing Officers (ALACHO)

Dr Elita Smiley, NHS Greater Glasgow and Clyde/East Renfrewshire HSCP

Tom Kelly, NHS Greater Glasgow and Clyde/East Renfrewshire HSCP

Jane Mackie, Moray HSCP

Isla McGlade, NHS Grampian

Anne Armstrong, Scottish Government

Arlene Johnstone, NHS Highland

Clare Thomas, COSLA

Brain Slater, Scottish Government

COSLA and Scottish Government Officials

Membership of Register Subgroup

Angela Henderson, Scottish Learning Disabilities Observatory

Dr Anne MacDonald, University of Glasgow

Arlene Johnstone, NHS Highland

Austen Smyth, The Richmond Fellowship Scotland

Tom Kelly, NHS Greater Glasgow and Clyde
Scottish Government Official

Scottish Government
Riaghaltas na h-Alba
gov.scot

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Any enquiries regarding this publication should be sent to us at
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