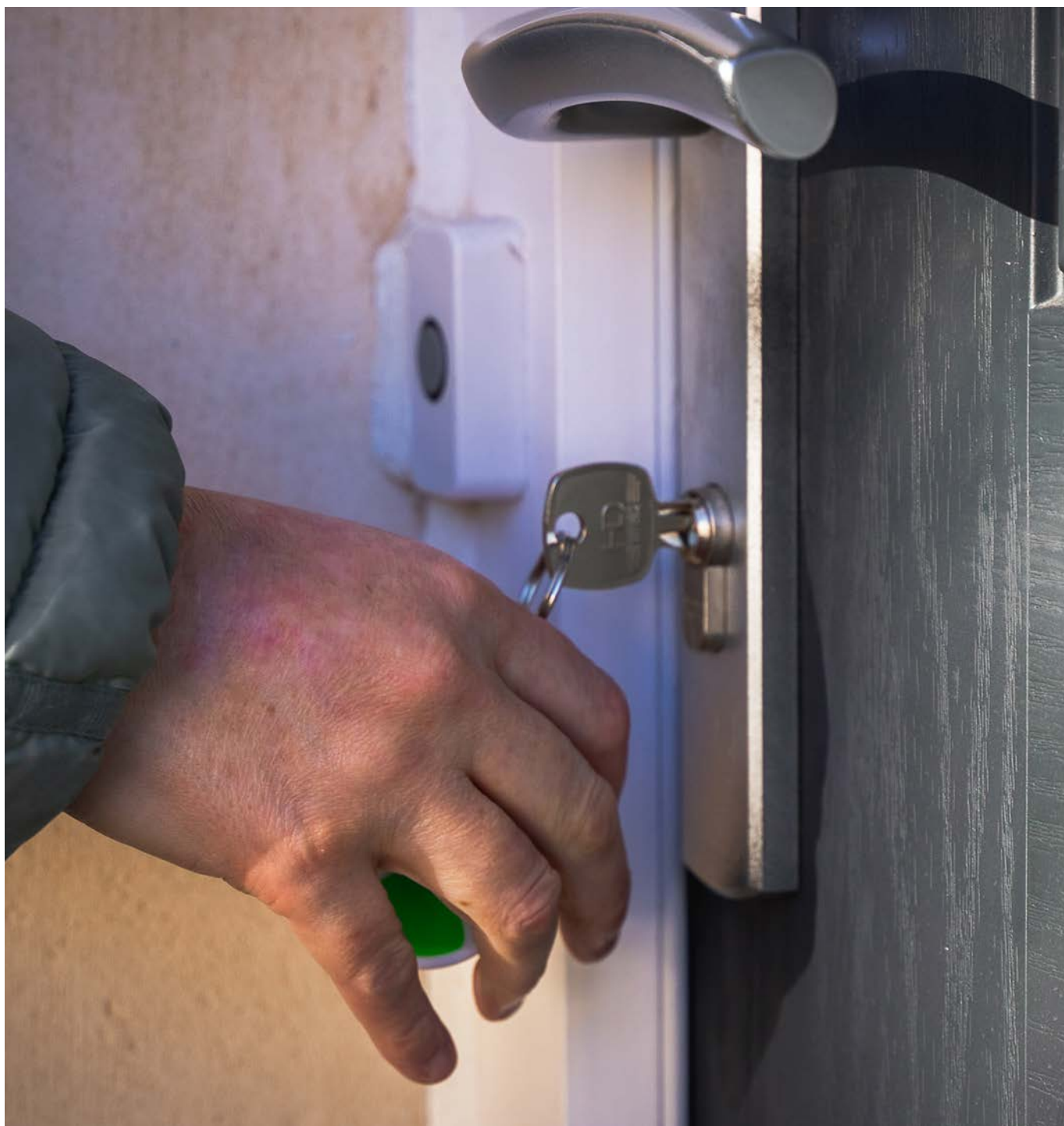




# My Own Front Door

A campaign to uphold the human rights of all adults who have a learning disability in Scotland to live in the home they choose, in the community they choose, close to the people they love by 2023.

An equal society  
for every person  
who has a  
learning disability



**“I want to live in Scotland, near my family,  
I want my own flat, with my own things  
around me. It’s my life, I’m in charge!”**

*Note – all of the stories told in this report are the stories of individuals and families who have approached **ENABLE Scotland**’s charity team in 2021. They reflect real life, current practice, and all represent situations in different local authority areas.*

---

Nova is 44 years old, friendly and fun with a wicked sense of humour. She also has a moderate learning disability, Autism, Tourette syndrome and Epilepsy. All of these conditions impact on Nova's ability to live her life independently. As a child, Nova lived in a residential care setting and as an adult, she moved around various different models of support and location. Most recently, Nova lived in England for several years where she lived in her own flat but was supported by care staff 24-hours a day.

Following a return to the family home in Scotland due to Covid-19, Nova made the decision to move to Scotland permanently in October 2020 to be closer to her family. It was agreed that Nova would live with her sister on a temporary basis until accommodation and support could be arranged.

Whilst social work agreed immediately to a full support package and budget, it was harder to find a place for Nova to live. Options around shared living were offered, as was a care home.

Throughout her life Nova has had many people make decisions for her which were not always the right ones. Fundamentally, Nova wants to live on her own. She has tried living with other people, and she did not like it.

Nova was adamant that this is not what she wanted and her family supported her to speak up for herself. They did not know how to navigate the system and found their way to **ENABLE Scotland's Family Connect** service.

Thanks to a significant amount of advocacy and partnership working across the family, housing and social work, the panel authorised a budget for Nova based on 24-hour support, and a brand new flat close to her family was identified. After 12 long months of wanting to be in her own flat, and the impact on her own family of 24/7 support, Nova now has the keys to her own front door, and is starting 2022 in her own home.



**“Nova unlocked her own front door. We just helped provide the keys.”**

Sarah, Nova's sister

---

All adults who have a learning disability have the right to live in a home they have chosen, in a community they wish to live in, supported by people they choose, and close to the people they love – to unlock their **#OwnFrontDoor**.

But for hundreds of people who have a learning disability in Scotland, this is not the case. Many adults who have a learning disability cannot find the support of sufficient and sustainable quality good enough to assist them to live independently in the community of their choice. This is especially true of people who have a learning disability, autistic people, and those who are described as having complex needs or challenging behaviour.

This has meant many people have to be sent to live where support is available. This can be living on their own, far from what they know, or sometimes in an institutional home setting, whether that is what they want or not.

Many other adults who have a learning disability have been admitted to hospital, either because of physical or mental ill health. Once they are better, too many find that there is no support available to assist them to live independently. This means that many Scottish adults who have learning disabilities today are 'living' in hospital.

**“I am supporting one lady who has now lived in hospital for sixty years.”**

NHS Consultant Psychiatrist, 2021

**“Please help me get my child out of hospital. I just want her home. No one will speak to me because I don’t have ‘guardianship’. I don’t even know what that is, I just want her home. She’s been in there for one and a half years now. She’s 27. They are saying that she is displaying a change in behaviour which means that she cannot be supported to live with me. They don’t understand that this is because she is unhappy and this is her way of communicating that she wants to come home. Please help me.”**

Mother of a young adult who has a learning disability, 2021

This is a human rights emergency. It is a national scandal – hidden in plain sight. Brothers, sisters, sons and daughters; living far from home. Living in hospital. Living in care settings where they are uncomfortable and unhappy. Or putting life on hold because they can’t get the support they need to move out. Far too often, attitudinal challenges also prevail, with a perception that some people just cannot live in a home of their own and will always need a specialist place to be – whereas it is specialist help they need to live in an ordinary place.

Policy initiatives to resolve this in Scotland have been around since the advent of community care. Decades later, whilst there has been significant progress achieved which **ENABLE Scotland** very much welcomes, there are still too many people in delayed discharge or out of area provision indefinitely, with no clear timetable to change.



In the immediate term, this creates the absurdity in the system of ‘two-way traffic’ where on the one hand strenuous efforts are made by some HSCPs to help people to come home, while systematically others are still sending people away. This member-led campaign is timed to ensure the opportunities of the current priority focus are realised in good time, and to raise the public profile of the situation our fellow citizens find themselves in.

We cannot wait any longer for decisive action. People with learning disabilities are being subjected to a level of discrimination that we would not, and do not, expect other groups in our society to bear.

So, how many people in Scotland are in this position? And why do so many people who have a learning disability in Scotland not have keys to their **#OwnFrontDoor?**



## Learning disability in Scotland

- 📍 There are 175,000 people who have a learning disability in Scotland<sup>1</sup>
- 📍 24,000 of those people are known to local authorities<sup>2</sup>

This campaign focuses on those people who have been assessed as requiring social care support to live independently; in particular, those people who are described as having complex needs, or challenging behaviour. There is no accurate public health data available which can truly quantify this population within the context of the general figures above.

**“Far too often a ‘one-size-fits-all’ solution is assumed with little in the way of recognition about what this means for people with learning disabilities or the range of conditions and issues that this includes, nor is there robust data collected to help. This is why we have titled [this population] ‘Scotland’s Invisible People’. Not only are they not visible in public debate, but the support they receive has receded in recent years and this has largely happened under the radar.... there are grave (and valid) concerns that their human rights are being curtailed.”<sup>3</sup>**

<sup>1</sup> Report - *Scotland’s Invisible People* | FAI (fraserofallander.org)

<sup>2</sup> [www.sclid.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf](http://www.sclid.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf)

<sup>3</sup> Report - *Scotland’s Invisible People* | FAI (fraserofallander.org)

<sup>4</sup> [no\\_through\\_road.pdf](#) (mwcscot.org.uk)

<sup>5</sup> *The Same As You?* A review of services for People with Learning Disabilities (Scottish Government, 2000)

---

## The story so far

Over the past 40 years there has been a transformation in service provision for people with learning disabilities in Scotland.

According to the Mental Welfare Commission, *No Through Road*,<sup>4</sup> in 1980 there were 6,500 people with learning disabilities in hospital care, which fell to 2,450 in 1998.

In 2000, the Scottish Government published *The Same As You?* – the first major review of learning disability services for several decades. It set out a 10-year programme of change in health and social care to improve services and support for people with learning disabilities, their families and carers. It recognised that people with learning disabilities should have the same opportunities to live independently with the same choices, control and protection as other Scottish citizens. One of the key recommendations was the closure of long stay hospitals by 2005.

In 2000, *The Same As You?* created the right for everyone who has a learning disability to live in their own homes and communities, following decades of self and group advocacy work led within the learning disability community.

**“Recommendation 12: Health boards should make sure they have plans now for closing all remaining long-stay hospitals for people with learning disabilities by 2005.”<sup>5</sup>**



---

A significant hospital closure programme ensued, which was largely successful, and resulted in most people in that situation being supported to access a place to live in the community of their choice.

The policy and implementation context were strong and large-scale institutions such as Lennox Castle in Greater Glasgow and Gogarburn in Edinburgh were closed by fully focused hospital closure teams.

In 2013/2014, the Social Care (Self Directed Support) (Scotland) Act was introduced which also reaffirmed the rights of people to live in their own home.

Over time however, it has become all too apparent that the social care system at large has not ensured that the promises of *The Same As You* to uphold the human rights of all people who have a learning disability have been kept. As the statutory guidance states:

**“Self-directed support, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one’s own life and which respects the person’s right to participate in society.”**

The next national review of learning disability policy in Scotland was *The Keys to Life*, published in 2013. It recognised that there were a number of individuals who have complex care needs for whom community-based support had broken down, and who were either back in institutional settings, including hospitals, or who had been moved out of area. It made three recommendations (Recommendations 50-52) in relation to those with complex care needs:

- 1 Developing joint discharge agreement protocols for people for whom there is no suitable community placement**
- 2 Looking at how to enable people in out of area placements to be supported nearer their home and family**
- 3 Scoping public sector investment required for high-cost care packages and alternative models of provision**

In 2015, the Scottish Government published the *Keys to Life* Implementation Framework<sup>6</sup>, which also prioritised these actions, and also commissioned a two-year national project to identify the types of support required for individuals who have complex care needs.

In 2016, the Scottish Government published *A Fairer Scotland for Disabled People* as part of its obligations under The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The first of the five ambitions outlined in its delivery plan<sup>7</sup> is ‘*Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation.*’







---

In 2016, the Mental Welfare Commission published *No Through Road*, which identified 58 delayed discharge situations for people who have learning disabilities.

In 2018, the Scottish Government published *Coming Home*<sup>8</sup> – a report it had commissioned on both out of area placements and delayed discharge for people with learning disabilities and complex needs.

## How many people do not have the key to their #OwnFrontDoor?





The *Coming Home* report found that:

-  **705 adults with a learning disability were ‘out of area’ meaning that they do not live in their own community, due to lack of available support**
-  **109 people were identified as priority to return – meaning that they did not want to be where they had been placed**
-  **67 people were living in hospital because no appropriate accommodation and support is unavailable in their community (more than identified by the MWC two years earlier)**
-  **Of this group, 22% had been in hospital for more than 10 years, and 9% between 5-10 years<sup>8i</sup>**

Given that this data did not include returns from Scotland’s largest HSCP, and did not include individuals at risk of placement breakdown, it is very likely that these figures are an underestimate. To date, the Scottish Government has not published information about progress made since that time. However, more recent data from other published sources provides further context:

-  **1,011 adults with learning disabilities are in an out of area placement<sup>9</sup>**

In terms of hospital settings, the latest Inpatient Bed Census showed:

-  **294 adults who have a learning disability or autism are in NHS Scotland inpatient units<sup>10</sup>**
-  **A further 40 adults with learning disabilities or autism are outwith NHS Scotland inpatient units<sup>11</sup>**
-  **16 children/young people who have a diagnosis of autistic spectrum disorder are in NHS Scotland inpatient units<sup>12</sup>**
-  **54 delayed discharges in learning disability specialties, with an average length of delay totalling more than two years<sup>13</sup>**

---

<sup>6</sup> [www.sclid.org.uk/wp-content/uploads/2015/07/The-Keys-to-Life\\_Implementation-Framework-and-Priorities\\_final.pdf](http://www.sclid.org.uk/wp-content/uploads/2015/07/The-Keys-to-Life_Implementation-Framework-and-Priorities_final.pdf)

<sup>7</sup> [www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/pages/6](http://www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/pages/6)

<sup>8</sup> [www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/documents](http://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/documents)

<sup>8i</sup> *Coming Home*, Scottish Government, 2018

<sup>9</sup> [www.sclid.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf](http://www.sclid.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf)

<sup>10</sup> [www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/](http://www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/) (pg 1)

<sup>11</sup> [www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/](http://www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/) (pg 35)

<sup>12</sup> [www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/](http://www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/) (Pg 28)

<sup>13</sup> [www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/](http://www.gov.scot/publications/inpatient-census-2019-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/) (pg 16)



---

## How many more people are at risk?

There are many more who are at risk of being in this position. Young people who want to leave their family home for the first time.

**“My son told social work when he was 18 that he wanted to work towards getting his own place. He was told to bring it up again next year. He is now 32. Still at home. Stuck in his room. He is not living, and I am beside myself with worry.”**

Adults who have lived with their family carers all their lives, mums and dads who became full-time carers and who are now elderly themselves.

**“We know of one lady who used to come to our groups. She stopped turning up and we were worried. We eventually found out that her mother had passed away suddenly and she had been placed in a care home for elderly people. She is in her late forties. She has no family members left. We are now trying to establish who has guardianship to see if we can help, but it is difficult.”**

For people who have complex care and support needs, all too often providers find it difficult to recruit and retain a skilled staff team, particularly when supporting individuals where staff describe their behaviours as very challenging. This leads to support breakdown and the need for urgent alternatives, often when families are at crisis point.

**“The provider has tried everything to recruit good staff in the local area. But my brother has not had a consistent staff team now for some time, and now our elderly mum is not able to be there to pick up the pieces anymore. We live far away, and as a family we are devastated about this. A placement has been found for our brother over 100 miles away from our mum and the community he knows. He loves his local swimming pool, and all the staff know him. This will be heart-breaking for mum, and for my brother, especially just after losing our dad, but we feel we have no choice but to agree. We just need him to be somewhere safe.”**

---

And if suitable community-based support cannot be identified, even far away from their local community, then there is a risk that individuals are admitted to Assessment and Treatment Units. Whilst this is often intended as a short-term intervention to allow time for a more appropriate arrangement to be made, too often, there are challenges in designing and implementing a robust and sustainable support package in the local community of their choosing, in a house that meets their needs, and so the cycle continues. There are 18 hospital units in Scotland for people who have learning disabilities<sup>14</sup> If the individual does not have access to a strong family member or friend advocating on their behalf, it can be very difficult to change this situation.

**“We are deprived of our rights in education, in health and housing, in relationships and family life, in access to work and employment, to equal treatment before the law and in rights to a fair trial and even the right to have legal entity status as citizens.”<sup>15</sup>**



---

## What is the problem?

The Community Care Act and the Hospital Closure Programme 2005 as directed by *The Same As You?* has made assumptions about how care would thereafter be delivered to uphold the human rights of all citizens to not only live in the community of their choice, but to stay there.

Unfortunately, as a consequence of the marketisation of social care, the specialist, values driven infrastructure required to make this a success is simply not there in every community, and there has been little systematic investment in building the infrastructure to support citizens to have a home to call their own, in the community they want to live in.

Local commissioners are in the unfortunate position of not being clear on a) how to commission specialist support within the restraints of generic frameworks and specialised accommodation needs and costs, and b) having no way of testing confidence in the local provider market fitness to practice at this level of complexity.

The *Independent Review of Adult Social Care* recognised this recently, and recommended that:

**“Provision should...be made at national level for support for people whose needs are very complex or highly specialist.”<sup>16</sup>**

In terms of accountability, there has been no requirement nationally or locally to monitor the human rights of this population. The Mental Welfare Commission *No Through Road* report in 2016, and the *Coming Home* report in 2018 are the only recent examples of monitoring.

In contrast, the Care Quality Commission in England published a report *Out of Sight – Who Cares?* in 2020, which identified the population in this position and made 17 recommendations. A follow up report was published in 2021<sup>17</sup>, outlining continued concern and evidence of the population of people in institutional settings, delayed discharge, and subject to chemical and physical restraint. A further follow up inspection process is expected in 2022.<sup>18</sup>

Advocacy support is not available to all at the point of need, and there is no requirement to ensure or evidence that person-centred planning has taken place.

---

<sup>14</sup> [www.mwscot.org.uk/sites/default/files/2019-06/no\\_through\\_road.pdf](http://www.mwscot.org.uk/sites/default/files/2019-06/no_through_road.pdf)

<sup>15</sup> [Learning/intellectual disability and autism: transformation plan - gov.scot \(www.gov.scot\)](http://www.gov.scot/learning/intellectual-disability-and-autism-transformation-plan)

<sup>16</sup> [independent-review-adult-care-scotland \(1\).pdf](#)

<sup>17</sup> [Restraint, segregation and seclusion review: Progress report | Care Quality Commission \(cqc.org.uk\)](#)

<sup>18</sup> [Out of Sight – who cares? \(cqc.org.uk\)](#)

<sup>19</sup> [Backing for Feeley Review recommendations - gov.scot \(www.gov.scot\)](#)

---

## David's story

David is 18 years old. He has a diagnosis of Autism, ADHD and a learning disability, and has lived in his family home with his mum, dad and his twin sister all his life. David can display behaviour which others can view as challenging and can harm himself and others. He requires routine and consistency. David has been assessed as eligible for social care support, and accesses the support of social care staff for a number of hours per week to do the things he enjoys in his local community like going to the library and the shops. Until recently, this has worked well for him and for the family.

Due to ill health, and David's changing needs and behaviours as he has grown into an adult, his family reached a crisis point in terms of the support available to him. Equally, as a young man transitioning to adulthood, David, like all young people, is desperate to live an independent life in his own home and has dreams for the future. He is close to his family and wants to be near them. His family want him to be near them too. He is only 18.

The social work department agreed that it would be possible for David to move out of his family home and agreed that to enable him to live successfully in his tenancy, his current support needed to be reviewed. It was established that a 24-hour care and support package would be required, and the budget was identified.

Due to the family's health crisis, his social worker quickly to identify a proposal. The family were contacted with the good news that a placement had been identified for David – over 400 miles away from his family home in a private sector run residential centre in the South of England.

David's family sought support to advocate for an alternative, all the while battling their own medical challenges. The next option offered to David was his own tenancy in a different local authority area, more than 35 miles from his family home, in a community which he is not connected to. Despite this, the family thought that this was better than the previous offer, and David was excited. Unfortunately, due to the lack of appropriate person-centred planning, it became evident that this solution did not meet David's needs. David felt completely let down as did his family.

After 6 months of specialist advocacy support, including the completion of a housing application form, a suitable property has become available for David in the same town as his family, and the social work team is now engaging in a person-centred planning process to build the support around this opportunity to ensure that it is successful and sustainable.

# Why are things not changing?

Across all of the various reports, policy documents and direct lived experiences available to **ENABLE Scotland** in the development of this campaign, it can be summarised that the key problems are:

## Perception of risk

As outlined in the 2021 report, *A New Way Home*:<sup>19</sup>

“It is an uncomfortable truth that the public perception of people with learning disability and challenging behaviour is a negative one: their disabilities, in and of themselves, cause them to be misunderstood, undervalued, viewed as different; the behaviours they display create fear and anxiety, a perception of irrational violence, and a desire that they should be kept at a distance; in turn, the segregation and institutionalisation that often follow merely add to the associated fear and stigma.

It is also important to assert that the risks their behaviours pose to themselves and to others are risks that can be managed in local, community settings. There is nothing intrinsic to their behaviour, or the risks this behaviour creates, which implies they are better managed in large institutions, far from home – indeed the opposite is true. Nor is it acceptable to argue that the large institutions are required in order to manage the behaviours of a small number of people who are said to be exceptions to this rule.”



---

## Data

The Fraser of Allander Institute recently published research which identified this population as Scotland's Invisible People:

**“The lack of robust data available for people with learning disabilities is difficult to reconcile with government ambitions to improve their lives and it makes effective-evidence based policy making almost impossible. It also makes it hard to gauge whether things are improving overall, or getting worse, over time.”<sup>21</sup>**

Within the context of people who have learning disabilities and complex support needs, population level data does not seem to be informing local housing or commissioning strategies to ensure that all people who want to stay in their home community can do so. By the time an individual presents to social work as requiring care and support, it is often at crisis point, as in David's story outlined above. This is not conducive to strategic planning and commissioning practice.

At local and national level, it is also not permitting accountability, meaning that people are lost or stuck in a system with no impetus to move.

## Planning

As a result of this, interventions are often made at crisis point, which rarely creates the circumstances for robust person-centred planning and investment in sustainable local solutions, nor the robust preparatory or transition work required to successfully sustain a placement.

As in some of the stories shared in this report, family carers also provide a significant amount of support to maintain the right of the person they love to continue to live in the community of their choice.

**“The support given by unpaid carers [of people with learning disabilities] is often overlooked and undervalued. We surveyed unpaid carers of adults with a learning disability and found that on average, the support delivered by each unpaid carer in our sample would have cost the taxpayer £114,000 per year to deliver equivalent care.”<sup>22</sup>**

## Availability of specialist social care support

The provision of social care support for people who have a learning disability and complex care and support needs requires skilled, committed and values-driven social care practitioners. In light of the well documented recruitment challenges facing the social care market in recent times, the attraction and retention of staff within this context is a significant challenge.

One of the reasons so many people end up in hospital or out of area is placement breakdown. Beyond access to a consistent and skilled workforce, providers have no guidance or national framework to work within, and commissioners similarly don't have access to guidance or support on what/how to commission at this level. This is a key barrier in the development of sustainable community-based support in Scotland.



---

## Advocacy

Once a person is in a situation where they are in ATU for a long time or sent to a community far away from where they would normally live, it can be very difficult to speak up for your rights to come home, and to coordinate the changes in the system around you or your loved one to make that happen:

“For people associated with these levels of exclusion, confusion and perceived risk it may become difficult to even begin to envisage what a positive future might look like.”<sup>23</sup>

## Capacity

Reasons of reduced intellectual capacity are also used to justify the practice of making choices and decisions for people with challenging behaviour.

“It is important to realise that “legal capacity” is not the same thing as decision-making capacity. A person’s decision-making capacity relates to their ability to make decisions about things that affect their life. To have decision-making capacity means that the person can understand a decision, the available choices, the consequences of any decision they make and can communicate this decision. “Legal capacity” on the other hand is the ability to hold rights and to make decisions that are respected and capable of being enforced under the law (e.g. signing contracts and agreeing to medical care and treatment).”<sup>24</sup>

A recent Mental Welfare Commission report *Authority to Discharge* (2021)<sup>25</sup> found that there appears to be inconsistent limited understanding or application of the correct approach to establishing and enabling capacity for people who have learning disabilities and complex support needs within decision making about where they live.

## Recent Progress

Since the publication of *Coming Home*, ENABLE Scotland has consistently called for action at national and local level to make strategic interventions in the health and social care system to urgently give people access to the right to their **#OwnFrontDoor**.

During the summer of 2020, in the midst of the Covid-19 pandemic, COSLA and the Scottish Government commissioned a **Short Life Working Group** tasked with producing recommendations to move individuals out of inappropriate long term delayed discharge arrangements, where **ENABLE Scotland** has been an active contributor.

We understand the final report from this **Short Life Working Group** is due to be published soon; however, interim recommendations for the group were accepted by the Scottish Government and COSLA in February 2021<sup>18ii</sup> as part of immediate plans to deliver on recommendations of Derek Feeley’s *Independent Review of Adult Social Care*, namely: The fund has a three year implementation timeline; however, has not yet been accompanied by detailed guidance for Commissioners.<sup>26</sup>

- 🗳️ **The introduction of a centrally held, dynamic register of individuals who are in, or at risk of, a delayed discharge situation, and;**
- 🗳️ **A £20m Community Living Change Fund to redesign services for people who have complex needs including learning disabilities and autism, to avoid out of area and delayed discharge for people who have learning disabilities and complex needs.**

---

Work is also ongoing to support the social care workforce to access improved training in positive support strategies in the provision of support via the PBS Community of Practice.<sup>27</sup>

## Early Impact of the Community Living Change Fund

In the Summer of 2021, **ENABLE Scotland** had informal discussions with 10 HSCPs across Scotland about their plans for the **Coming Home** population in light of the introduction of the Community Living Change Fund. These discussions were motivated by ensuring that priority was being given to progressing early action for the population of people who were out of area or in delayed discharge. Whilst not collated formally, the observations, as a result of these conversations, are worth capturing.

It is clear that the Community Living Change Fund has multiple applications across the country. Some areas are using it to fund work to assess the local **Coming Home** population need; others are using it to help fund property adaptations to support with the cost of bringing individuals back to their home authority.

Commissioners are very keen to progress but often face challenges around procurement and the restrictions that framework-based commissioning bring – one of the key issues they need to explore is assessing the fitness of the provider to operate at this level of complexity. Often, there are providers on the local framework who do not have the practice background and specialist governance arrangements in place to plan, design, implement and sustain a successful package of support for an individual to live locally. This presents a risk in terms of placement breakdown, and is also presenting in some areas commissioning multi bed units, which are undoubtedly institutional settings.

Lack of suitable and available housing stock is also a barrier for many, and it is an issue that is perceived as requiring a longer-term alignment with strategic housing plans. There is some evidence of innovative work across housing associations and other registered social landlords, but there is an acknowledgement that funding of this will be a longer-term challenge – the housing benefit accessed by the individual for example may not be enough to cover the costs of the type of specialist tenancy required. Some commissioners are responding by inviting providers to identify and provide accommodation as part of the tendering process, which thereafter inextricably links the support provider to the tenancy, eroding the choice and control of the individual should any elements of their care and support change.

Whilst the Community Living Change Fund is a very welcome step forward, given the complexity of need, there is an acknowledgement that this is not a lot of money per HSCP area, per person. Whilst in theory this process should be leading to resource transfer, the reality is that the sharp end is being met from social care budgets, and the budget from the NHS does not travel.

---

<sup>19</sup> [www.centreforwelfarereform.org/uploads/attachment/752/a-new-way-home-scotland.pdf](http://www.centreforwelfarereform.org/uploads/attachment/752/a-new-way-home-scotland.pdf)

<sup>20</sup> Mansell, J (2007) Services for people with learning disabilities and challenging behaviour or mental health needs. London. Department of Health (Cited in [www.centreforwelfarereform.org/uploads/attachment/752/a-new-way-home-scotland.pdf](http://www.centreforwelfarereform.org/uploads/attachment/752/a-new-way-home-scotland.pdf))

<sup>21</sup> [2020-09-25-Scotlands-Invisible-People.pdf](http://2020-09-25-Scotlands-Invisible-People.pdf) (fraserofallander.org)

<sup>22</sup> Learning disabilities and the value of unpaid care | FAI (fraserofallander.org)

<sup>23</sup> A New Way Home (Scottish Edition) (centreforwelfarereform.org)

<sup>24</sup> [www.centreforwelfarereform.org/uploads/attachment/752/a-new-way-home-scotland.pdf](http://www.centreforwelfarereform.org/uploads/attachment/752/a-new-way-home-scotland.pdf)

<sup>25</sup> Moves from hospitals to care homes during the pandemic – new report finds wider concerns over adherence to the law | Mental Welfare Commission for Scotland (mwscot.org.uk) [learning-intellectual-disability-autism-towards-transformation\(3\).pdf](http://learning-intellectual-disability-autism-towards-transformation(3).pdf)

<sup>26</sup> [learning-intellectual-disability-autism-towards-transformation\(3\).pdf](http://learning-intellectual-disability-autism-towards-transformation(3).pdf)

<sup>27</sup> [www.sclد.org.uk/positive-behaviour-support-pbs/](http://www.sclد.org.uk/positive-behaviour-support-pbs/)



---

# Now is the Time to Act

**ENABLE Scotland** believes that further decisive action is now required to end the human rights emergency faced by individuals in this position and their families. **ENABLE Scotland** believes that the keys to unlocking their **#OwnFrontDoor** is in our hands. Building on the positive progress of the **Short Life Working Group**, we believe that there are two significant opportunities which will sustain the change for good:

 **A National Care Service**

 **A new Commissioner for People who have Learning Disabilities and Autistic People.**

## National Care Service

The Scottish Government is currently scoping a new National Care Service for Scotland. Within the context of informing and designing the National Care Service, the Independent Review of ASC has recommended further that:

**“Provision should also be made at national level for support for people whose needs are very complex or highly specialist. This will provide people with greater levels of support and allow for the cost to be absorbed nationally.”<sup>28</sup>**

There is a clear opportunity for action in the immediate term to influence the shape of this provision as it will be enshrined in the National Care Service moving forward.

## A New Commissioner for People who have Learning Disabilities and Autistic People

Secondly, the Scottish Government has committed:

**“To uphold and protect the rights of people with autism or learning/ intellectual disabilities, we will take forward a Learning Disability, Autism and Neurodiversity Bill, with scoping work carried out in 2021-22. We will also provide an independent advocate for people to secure the protections of such a law, through a Learning Disabilities, Autism and Neurodiversity Commissioner.”<sup>29</sup>**

The experiences of this population should both inform the scoping of, and benefit from, the function of the Commissioner and the legislation to be developed over the course of the coming parliamentary session.

But the human rights of people in hospital, or in an area they don't want to be in, cannot wait.

---

<sup>28</sup> Learning disabilities and the value of unpaid care | FAI ([fraserofallander.org](http://fraserofallander.org))

<sup>29</sup> [fairer-greener-scotland-programme-government-2021-22 \(1\).pdf](#)

---

# #MyOwnFrontDoor

The campaign for every person who has a learning disability to have their human rights upheld by having access to their #OwnFrontDoor calls on the Scottish Government, NHS and COSLA to work together to use the following keys to unlock the system:

## **Key 1: Close ATU beds and end practice of Scottish citizens being sent out of country**

As with any other citizen, a person who has a learning disability who has a mental health support emergency may require inpatient treatment. However, the continued existence of dedicated ATUs for people who have a learning disability means that they continue to be an option.

Inevitably, as an intervention which is intended to be temporary by design, this increases traumatic transitions for people who have a learning disability. #MyOwnFrontDoor calls on the Scottish Government and HSCPs to work to close ATU beds for people who have a learning disability by 2024.

In parallel, work must be undertaken to ensure that people who have a learning disability who are also experiencing a mental health emergency have equal access to specialist assessment, treatment and support.

In addition, strong early direction to HSCPs that the practice of sending Scottish citizens out of Scotland must end by 2023 is required to avoid an increase in the numbers of people who are in this position and to inform strategic commissioning and planning at local community and national level.





## Key 2: With immediate effect, implement a **Community First** principle for the commissioning of support for all adults and children who have a learning disability in Scotland

This must ensure that the choice and control around which community to live in rests with the individual. In order to maximise the impact of the Community Living Change Fund, strong early guidance to HSCP commissioners is required to make clear that **commissioning solutions must not involve institutional, multi-bed units**.

Building on the health and social care principle of **Home First** which has emerged from the pandemic in relation to care home settings, a guiding principle of **Community First** must be adopted by commissioners in the immediate term, and end the practice of any individual being required to move out of the community and neighbourhood that they want to live in.

Beyond the right of choice and control for individuals about who they choose to share their home with, there are inherent risks in living within institutional settings. There has been well documented abuse linked with these types of services, for example Winterbourne View and, more recently, Whorlton Hall in England, which happened 8 years apart. Living in unsuitable environments increases the use of restrictive practices such as restraint, seclusion, and inappropriate use of psychotropic medication.

“We have known for a long time that for each person living in an institutional setting there is an equivalent person, with similar characteristics, living well in the community.” (Baker & Urquhart, 1987) <sup>30</sup>



## Key 3: Invest nationally in a **Specialist Providers Network** to improve local coverage accessible in every neighbourhood

One of the biggest challenges in delivering an equitable offer of high quality, human rights driven community-based care and support for any person who has a learning disability and complex needs, wherever they choose to live, is the availability of skilled and consistent social care.

Building on the **Feeley Review** recommendations, a dedicated, specialist group of providers should be assembled as a network who have national coverage, are assessed as having fitness to practice for this population, and are funded to be part of this network to ensure sustainable reward and frontline specialist training and support. Their role will be to enable progress quickly for the individuals identified as priority to return. This must not be a closed group and opportunities for other providers, who are sufficiently invested and have the necessary competency and capability, to join over time should be actively encouraged and supported in order to ensure Scotland wide, locally based coverage. As per the **Feeley Review** recommendation, this approach would ‘allow for the [additional] cost to be absorbed nationally’ and connect with other complementary nationally managed funding streams such as the ILF.



#### **Key 4: Maintain a National At-Risk Register and ensure that everyone identified on this in 2021/22 has a plan in place by 2023 to come home to the community of their choice**

Building on the good work already started via the *Coming Home* report, the Scottish Government and COSLA must now work to collate and maintain a register of all people who are a) in delayed discharge; b) out of area and who do not want to be; and c) who are at risk of placement breakdown. At local level, this register must inform local commissioning and planning practice. At national level, it must be monitored to ensure accountability around a reduction in the number of people in this position.

The *Keys to Life* strategy first acknowledged that there was a need to address this issue in 2013. It is critical that a clear direction now is given that a plan must be in place for every person on this register to move to the community of their choice by 2023.



#### **Key 5: Create a National Community Living Panel to ensure oversight and accountability of decision making about individual placements**

Aligned to the at-risk register and given the often complex circumstances surrounding advocacy, capacity, and the need for awareness of person-centred planning and the impact of the reduction of restrictive practice on an individual's presentation, an independent expert panel must be convened to support and monitor decision making, ensuring that the voice of the individual is guiding the plan.

There is a precedent for this practice within the deprivation of liberty decision making process in line with the Mental Health (Care and Treatment) Act 2003, and the Children's Panel process as defined in the Children's Hearings (Scotland) Act 2011. This function should also be able to link individuals and families to appropriate and independent advocacy agencies to support the process.



Together, these actions taken now will demonstrate the potential of a National Care Service for this population and demonstrate a potential critical role for a Commissioner for people who have learning disabilities and autistic people.

Taken urgently and consistently, they will provide the keys to unlocking **#MyOwnFrontDoor** for every person who has a learning disability in Scotland, now and for generations to come.



# Unlock #MyOwnFrontDoor

## Join our movement for change and get involved!

- Visit** – [www.enable.org.uk/myownfrontdoor](http://www.enable.org.uk/myownfrontdoor)
- Act** – write to your MSP about the campaign by downloading our standard letter – it's easy!
- Share** – follow us on Twitter, Facebook and Instagram and share your support for the campaign using [#MyOwnFrontDoor](#) and [#CommunityFirst](#)
- Tell us your story** – are you an individual who desperately wants the keys to your own front door? Are you a family carer fighting for the rights of your loved one to come home? Are you a commissioner frustrated by the lack of local solutions available to you? We want to keep the national conversation going - complete our survey and let us know your experiences:
- Join** – our Family Connect seminars to find out more about your rights. Call 0800 303 0228 or email [FamilyConnect@enable.org.uk](mailto:FamilyConnect@enable.org.uk)
- Download** – **ENABLE Talks** to keep campaigning to hear about other families who have experienced the issues raised by [#MyOwnFrontDoor](#). Available wherever you get your podcasts!
- Text** – To donate £5, please text **ENABLE** to 70480  
To donate £10, please text **ENABLE** to 70490
- #MyOwnFrontDoor**

Texts cost £5 or £10 plus one standard rate message and you will be signing up to hear more from us. ENABLE Scotland will receive £4.70 or £9.40 of all donations and 100% of any Gift Aid.

## Be PART of it!

Four ways for people to join the ENABLE family:



Member



Supporter



Branch



Donor



# MEMBER

visit [www.enable.org.uk/membership](http://www.enable.org.uk/membership)

**ENABLE Scotland**  
INSPIRE House  
3 Renshaw Place  
Eurocentral  
North Lanarkshire  
ML1 4UF

**Contact:**  
0300 0200 101  
[enabledirect@enable.org.uk](mailto:enabledirect@enable.org.uk)  
[www.enable.org.uk](http://www.enable.org.uk)

[@ENABLEScotland/](#) [ENABLEScotland](#) [ENABLEScotland](#) [@ENABLEScotland](#)