

SHRC

Scottish
Human Rights
Commission



“Tick Tock...”

A human rights assessment of
progress from institutionalisation
to independent living in Scotland

January 2025

The Scottish Human Rights Commission was established by the Scottish Commission for Human Rights Act 2006, and formed in 2008. The Commission is the National Human Rights Institution for Scotland and is independent of the Scottish Government and Parliament in the exercise of its functions. The Commission has a general duty to promote human rights and a series of specific powers to protect human rights for everyone in Scotland.

This report is issued under sections 3(1) and 4 of the Scottish Commission for Human Rights Act 2006. It measures human rights progress in moving from institutions to independent living in Scotland under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities.

www.scottishhumanrights.com

Our title is a quote from a mother of a person who has learning disabilities and is autistic, reminding us that while we await progress, people continue to live in institutions without choice and control.

Contents

Foreword	4	9. Empowerment	49
Executive Summary	6	10. Living arrangements	51
Overall findings	6	11. Involvement in deciding where to live	52
Our research approach	6	Broader indicators	53
Key findings	7	12. Access to support services	53
Data	8	13. Transferability of support services	54
Progress	8	14. Eligibility for community support services	54
Hidden Populations	8	15. User control	55
Human Rights Based Approach	9	16. Informal support	55
Recommendations	9	17. Access to justice	56
What will happen next	11	A human rights based approach?	57
Snapshot analysis of progress to implement the Coming Home Plan against UNCRPD Article 19 indicators	12	Data	58
About this research	18	Recommendations	59
UNCRPD Article 19 – Living independently and being included in the community	18	Urgent action	59
Methodology	18	Accountability	59
Our Project Group	18	Human rights measurement	60
Language	19	Publishing information on how money is spent	60
Deinstitutionalisation in Scotland	20	Forensic patients	61
What is the Coming Home Implementation Plan about?	21	Law reform	62
What is an institution?	22	A wider deinstitutionalisation plan	63
Key data summary	23	Better use of human rights	64
The Legal Framework	25	Remedies, reparations and redress	64
The UN Convention on the Rights of Persons with Disabilities (CRPD)	26	Conclusion	65
European Convention on Human Rights	28	Annex 1: Human rights indicators	67
Domestic Legal Framework	30	Article 19: Cross-cutting provisions	67
How we did this research	31	Article 19(a): Living arrangements	74
Baseline Indicators	31	Article 19(b): Support services	77
Assessment	32	Annex 2: About the Commission	83
What human rights measurement is	32	Who we are	83
Our findings	34	Annex 3: Methodology	84
1. Action plan and strategies of the State	34	Development of indicators	84
2. Disabled persons organisations’ involvement	36	Project Reference Group and Measuring Change Group of Human Rights Defenders	84
3. Institutions	38	Commissioned Research Approach	85
4. Training	43	Data sources	85
5. Complaints	44	Factchecking Processes	86
6. Monitoring	46	Evidence Analysis	86
7. Quality standards	47	Challenges and Limitations	86
8. Awareness of Support Services	48	Annex 4: Project Group	87
		Annex 5: Measuring Change Project – Human Rights Defenders	88

Foreword

Scotland’s journey from housing people with learning disabilities and/or who are autistic in institutional care, towards enabling them to live independent lives in the community, has a long history. In previous eras, people with learning disabilities and/or who are autistic were medicalised and treated as having defects which had to be hidden away from society. Now, there is more universal recognition they have the same human rights as everyone else, and are part of the diversity of humanity. These are not treatable ‘conditions’, although people may require lifelong support and it is the role of the State to make sure that is provided.

However, our systems of care still bear the legacy of previous attitudes. While large-scale institutions have been closed, a population of people deemed too complex to be able to live independently remains stuck in hospitals when there is no need for medical care, or in placements far away from home.

“Institutionalisation is when you go into a hospital or a care environment and... you don’t get back out again. Time goes on and there is no end date in sight, and it is very sad because it is not a way to live.”

Human Rights Defender

The Scottish Government has previously recognised the urgency of this unacceptable situation and the Coming Home Implementation Plan made a clear commitment in 2022 to “greatly reduce” these inappropriate placements by March 2024. It recognised clear failures to uphold the human rights of people held in institutions and set out to use a human rights-based approach to change that. Applying detailed human rights standards would ensure that approach means something – not merely statements of good intention but specific and measurable actions.

At the Scottish Human Rights Commission, we have examined and measured the work of Coming Home in detail through the lens of human rights standards. It is troubling to find that little progress has been made and clear failures to uphold human rights continue. Money that was set aside to facilitate independent living sits in budgets unspent and, equally of concern, it appears these dedicated resources have been spent in ways that do not align with human rights expectations. It is also disappointing to find the potential of stated good intentions has evaporated and commitments to a human rights-based approach have not been used in a meaningful way to make sure this work delivers for people with learning disabilities and/or who are autistic.

What results is a failure to uphold the right to independent living in terms of Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD).

Beyond Article 19 CRPD, the European Convention on Human Rights (ECHR), already enshrined in domestic law, establishes strict criteria for detention. The failure of the State to provide social care support should not be considered appropriate criteria for admission and sustained detention. Allowing the detention of people with learning disabilities and/or who are autistic without therapeutic benefit places the Scottish Government at risk of breaches of the ECHR. There may be people in this position in Scotland right now.

We have provided a framework of human rights measurement based on internationally recognised best practice, for duty bearers to apply and to identify what is needed to ensure the right to independent living is a reality for the population affected by Coming Home. Our hope is that duty bearers, advocates, and the Scottish Parliament will now utilise this framework to make transparent progress to realise the right to independent living.

We will continue to monitor this situation and use our limited powers to push for change, including encouraging other duty bearers to act.

We encourage all human rights defenders to use the findings of this research report, the framework and the toolkit we have published alongside to challenge inadequate progress where they see it.

Through understanding the true meaning of institutionalisation, articulated by the Convention on the Rights of Persons with Disabilities, it becomes clear that there are

likely to be many other populations across Scotland who require attention. They may not be living in the most obvious forms of institutions, but unless people have real choice and control over their living arrangements and day to day activities, they are not being permitted their right to independent living.

The Scottish Government must keep focussed on progress and reform, and utilise the human rights framework provided in this report to demonstrate compliance with the right to independent living.

Until this situation is remedied, people will continue to suffer the harms of institutionalisation, both people stuck in inappropriate placements, and their families from whom they are separated. The severity of these impacts must be recognised, and we have recommended a suite of actions based on human rights standards that must be taken to make up for these continuing harms.

Independent living is not a luxury. It is a basic right which we must all expect and demand. No one is too complex to live independently. Many people who were previously thought to need institutional care now live full lives in the community. The rest should not have to wait.




Executive Summary

66 Scotland’s existing structures, policies and interventions are currently inadequate in relation to realising a human rights-based process of deinstitutionalisation. It is clear that people continue to live in accommodation that is institutional, inappropriate, and not in the area that they would call home. The Coming Home Implementation Plan itself would not, if implemented in full, fulfil the terms or vision of Article 19 of the CRPD. Furthermore, the key interventions proposed in the Coming Home Implementation Plan have not been fully implemented.¹ **99**

Overall findings

The State has not adopted a human rights framework to deliver and monitor community-based support which delivers the right to independent living in Scotland. There is a lack of transparency and monitoring to ensure actions taken in relation to people with learning disabilities and/or who are autistic meet human rights requirements. It would also appear that the allocation and spend of resources has not been informed by a human rights budgeting approach that would respect, protect, and fulfil international treaty obligations, specifically those enshrined in Article 19 of the UN CRPD.

The law must recognise and protect the right of disabled people to make decisions about their own lives and the support they receive. It is clear that legislative intervention in Scotland is required to protect the right to independent living in Scots Law, to reform frameworks which permit the detention of people with learning disabilities and/or who are autistic, and to provide independent oversight of the individual situations of those remaining in inappropriate placements.

Our research approach

This project set out to measure progress in moving people from institutional living to independent living, in line with human rights standards set out in detail by the UN Convention on the Rights of Persons with Disabilities (CRPD). It focused on the situation of people with learning disabilities and/or who are autistic who have been recognised as being in inappropriate hospital or out of area placements. The Scottish Government’s plan to remedy this, the Coming Home Implementation Plan, ran from February 2022 until March 2024.

To inform our assessment, we commissioned research using a set of human rights indicators to measure progress made in the realisation of the right to independent living as set out in Article 19 CRPD, in relation to those affected by the Coming Home Implementation Plan. Our methodology is set out in [Annex 3](#).

The research approach used indicators developed by the European Union Agency on Fundamental Rights (FRA), an independent centre of reference and excellence for promoting and protecting human rights in

the EU. In 2018, FRA carried out a project to collect and analyse comparable data on the transition from institutional care to community-based support in the 28 EU Member States.²

One of the central aims of the research was to develop and populate these existing human rights indicators to enable an assessment of whether Article 19 of the CRPD was being fulfilled. These indicators are rigorously developed and well tested and we have used them as the basis for our human rights measurement. Small adaptations have been made to fit them to the Scottish context and to narrow the focus to those within the scope of Coming Home.

A full set of the indicators used is published in [Annex 1](#). It is our hope that duty bearers will now use this framework to guide their progress towards fulfilling the right to independent living for those people impacted by this policy area. We have provided a summary snapshot of our analysis against these indicators as Table 1 below.

Our research consisted of two phases:

1. Development of a completed set of indicators, and identification of available evidence and gaps in evidence against them, based on data available up to 31 May 2024;
2. An assessment of the particular steps taken during the course of the Coming Home Implementation Plan, exploring available data and highlighting data that could be used to measure progress against the Plan, or with some change, could evolve to measure progress.

To arrive at our findings, we have analysed that evidence, together with the lived experience of people impacted by the policy via a Project Reference Group, compared

this against the requirements of Article 19 of the UNCRPD, and identified where key gaps in implementation arise. Our Project Group comprised people from a range of backgrounds, including Disabled People’s Organisations and people with lived experience of the issues, as well as third sector organisations – including one provider of social care, and one representing the collective community of people with learning disabilities.

It should be noted that the Commission does not have formal powers of investigation and cannot compel information from public authorities. Our research therefore must rely on published data, which was confirmed through a series of interviews with duty bearers to inform our final assessment. The Scottish Government has also been given the opportunity to check the publicly available data used to inform our assessment prior to publication.

The research prepared for the Commission by Professor Jo Ferrie and Dr Paul Pearson is published alongside this report to inform any deeper understanding required of our analysis.

Key findings

Overall, we have found a clear gulf between the rhetoric of taking a human rights-based approach, and the reality of putting that into practice.

We have found many significant and concerning gaps in the progress of the Coming Home Implementation Plan which fall short of CRPD guidance and, in some areas, indicate a failure to comply with basic requirements. This means that the situation currently faced by people with learning disabilities and/or who are autistic affected by that Plan fails to comply with the right to independent living.

Data

As a starting point, we found that it is not possible to measure progress accurately across the full set of human rights requirements due to significant gaps in the data available.

The basic concept of institutional living is not reflected in the data gathered, and there is no overarching measurement of those still living in institutions. This falls short of the minimum core requirements of the right to independent living, which a country needs to comply with at all times and in all circumstances, regardless of their resources or the overall conditions of the country. This information is essential in order to develop any plan for deinstitutionalisation, or to assess its progress.

It has, however, been possible to identify a broad spread of associated data which can be pieced together to answer some of the human rights indicators. It does give us clear indications of the progress that has taken place within the timeframe of the Coming Home Implementation Plan and highlights clear gaps in implementation. A summary of our analysis of key gaps is provided as Table 1.

Progress

The evidence shows that, despite commitments, the target to “greatly reduce” the numbers of people affected by March 2024 has not been met. There has been little change in the number of people still living in institutions who should have been positively affected by the Coming Home Implementation Plan. There is no clear plan from the Scottish Government after the expiry of the Coming Home Implementation Plan on 31st March 2024.

People continue to spend many years on learning disability units. Furthermore, people continue to be admitted for reason of

“learning disability” which raises additional questions about compliance with the European Convention on Human Rights, which does not permit detention on the basis of learning disability unless there is a clear therapeutic purpose.

Public funding was made available by the Scottish Government to Health and Social Care Partnerships on 5th February 2021, in the form of a £20 million Community Living Change Fund to be used over a three year period (2021-2024). Our analysis of the publicly available information as at May 2024, tracked £14 million of that fund, of which the vast majority – £12,634,881 – was unspent going into the final year of the fund. Again, there is no clarity on the funds available after the expiry of the Plan.

Information on the use of funds was difficult to source, demonstrating a lack of transparency and accountability both towards disabled people and in the use of public funds. Of the money that can be identified as spent, we are particularly concerned about examples of expenditure which ought to have been allocated directly to independent living appearing to be used instead to refurbish and repurpose institutional settings. This would be in direct contravention of the requirements of the right to independent living.

Hidden Populations

There are also hidden populations significantly affected by institutionalisation. People housed in forensic learning disability services also spend many years in hospital, however they were not included in the Coming Home Implementation Plan. More interrogation of the situation of this population is urgently required.

Autistic people are also hard to find in the data, much of which only specifies people with learning disabilities. This level of disaggregation is important in order to ensure deinstitutionalisation processes capture all those affected and are suitably tailored to the needs of those affected.

Human Rights Based Approach

Although the Coming Home Implementation Plan claims to take a human rights-based approach, we have found little meaningful engagement with human rights standards throughout the action taken, for example, in guidance around the use of the fund and accountability for how that fund was spent.

The State has not adopted a human rights framework to deliver and monitor community-based support which delivers the right to independent living. It would also appear that the allocation and spend of resources has not been informed by a human rights budgeting approach that would respect, protect, and fulfil international treaty obligations. There is a lack of transparency and monitoring to ensure actions taken in relation to people with learning disabilities and/or who are autistic meet human rights requirements.

The law must recognise and protect the right of disabled people to make decisions about their own lives and the support they receive. It is clear that legislative intervention in Scotland is required to protect the right to independent living in Scots Law, to reform frameworks which permit the detention of people with learning disabilities and/or who are autistic, and to provide independent oversight of the individual situations of those remaining in inappropriate placements.

Recommendations

On the basis of our findings, the Commission makes the following recommendations grounded in the CRPD Committee guidelines to address areas where our research identifies significant gaps between human rights standards on deinstitutionalisation and the measurable progress made under the Coming Home Implementation Plan.



Urgent action

The Scottish Government should urgently develop a fresh action plan to deliver the outstanding commitment of Coming Home. It must be concretely grounded in the CRPD Committee’s guidelines and address all components of deinstitutionalisation, including mechanisms of redress.



Accountability

We recommend that the Scottish Government designate an independent mechanism to monitor progress on achieving deinstitutionalisation under a new action plan. The mechanism should ensure the meaningful participation of disabled people, especially people who have experienced institutionalisation.



Human rights measurement

We recommend that the Scottish Government employ measurable human rights indicators and concrete benchmarks in all further work on Coming Home, forensic patients and deinstitutionalisation.

We recommend that regulators and data collection agencies ensure their measurement and data frameworks explicitly reflect human rights requirements. In particular, they should ensure that institutional care, as defined by CRPD, is identifiable.



Publishing information on how money is spent

We recommend that the Scottish Government publish an account of how the Community Living Change Fund was spent in all Health and Social Care Partnerships across the funded period 2021-2024. This should include what the fund was spent on and identify whether the areas in which it was spent constitute independent living support services in terms of CRPD guidance.

We recommend that this evidence is scrutinised by Audit Scotland and/or the Public Audit Committee in 2025



Forensic patients

We recommend that a specific plan of action be made to identify and address the situation of forensic patients who have been excluded from the scope of the Coming Home Implementation Plan. The plan should be grounded in the CRPD Committee’s deinstitutionalisation guidelines and respond to the recommendations of the Barron review.



Law reform

We recommend that the Scottish Government outline, within three months of this report, a clear timeline for the replacement of Mental Health (Care & Treatment) (Scotland) Act 2003 with updated legislation which complies with CRPD.

We recommend that the Scottish Government urgently clarifies its intention around incorporating CRPD, particularly Article 19 in its ongoing work to develop a Human Rights Bill to introduce in the next session of the Scottish Parliament, and propose the strongest possibly duty, within the limits of devolved competence, for public authorities to comply with the right to independent living.

We recommend that the Scottish Government identify, by Summer 2025, the quickest legislative vehicle to establish a National Support Panel with statutory powers.



A wider deinstitutionalisation plan

We recommend that the Scottish Government immediately commence development of a concrete action plan to replace any institutionalised settings with independent living support services across all settings in Scotland. Planning should comply with the CRPD Committee’s guidelines on deinstitutionalisation.



Better use of human rights

The Scottish Government should publicly commit to following all guidance issued by the CRPD Committee in ongoing work on this area. In particular, it should commit to follow the CRPD Committee’s Guidelines on Deinstitutionalisation.



Remedies, reparations and redress

The Scottish Government should scope a set of mechanisms to provide all components of remedies, reparations and redress outlined by the CRPD Committee’s Guidelines on Deinstitutionalisation. Scoping should take place by the end of this Parliamentary session (2026) with a clear timeline for implementation thereafter.

Beyond these key findings, our research has raised further considerations in respect of rights enshrined in the ECHR, protected in law by the Human Rights Act 1998. The impact of failing to uphold the right to independent living is leading to the State being at risk of breaching its obligations under the ECHR, namely the right to liberty, the right to private and family life and, potentially, the prohibition on inhuman and degrading

treatment. Evidence that people are still being admitted to hospital for the reason ‘learning disability’ raises questions about compliance with ECHR standards in light of the Court’s clarification that learning disability is not a sufficient basis for detention unless there is a clear therapeutic purpose. This is of concern to the Commission.

What will happen next

We will share our findings with the Scottish Government and seek its commitment to implementing our recommendations. We will also share this report with Disabled People’s Organisations in Scotland.

Alongside this report, we have worked with human rights defenders to produce a resource *Measuring Change on Ending Institutionalisation in Scotland: A Toolkit for Human Rights Defenders*. This resource provides guidance for people affected by the issue, families and advocates to support them to use human rights to navigate their way to independent living. Details of the Measuring Change Project can be found at Annex 5.

We will share this report with a range of bodies to inform their own monitoring. This includes:

- The Equalities, Human Rights and Civil Justice Committee of the Scottish Parliament
- The Mental Welfare Commission
- The Care Inspectorate
- Audit Scotland

- The Committee on the Rights of Persons with Disabilities
- The UN Special Rapporteur on the rights of persons with disabilities
- The Fundamental Rights Agency
- Our partners in the UK Independent Mechanism for the Convention on the Rights of Persons with Disabilities
- Our partner members of the National Preventive Mechanism in Scotland

The Scottish Human Rights Commission will produce factsheets to turn the findings of this report into guides for concrete action, and advice for individuals and families, fulfilling our education mandate. We will also seek to embed human rights measurement and human rights budget analysis in our monitoring activity.




Our Strategic Plan 2024-28 identifies both places of detention and the rights of specially protected groups as areas of focus. The Commission will continue to monitor progress towards deinstitutionalisation and take further action to pursue the implementation of our recommendations.



Snapshot analysis of progress to implement the Coming Home Plan against UNCRPD Article 19 indicators*



(*Using the the EU Agency for Fundamental Rights Measurement Framework)




The following table uses the Article 19 indicators at [Annex 1](#), summarising detailed analysis provided in the main report. The framework presents a core tool to support duty bearers to assess their own compliance with the human rights provisions in focus in this report.





Assessments are categorised as:





-  **red** – significant gaps indicated in meeting CRPD requirements
-  **amber** – CRPD requirements partially met
-  **green** – CRPD requirements fully met



Summary of indicators	Key gaps in implementation	Assessment
Action plan and strategies		
<p>How strong is the Coming Home Implementation Plan on human rights requirements?</p> <p>How much money has been made available to make the plan happen?</p> <p>Have the targets in the plan been met?</p>	<p>While there was an action plan up to March 2024, its targets have not been met. The Plan expired in March 2024 and there is no current action plan on deinstitutionalisation for the target group.</p> <p>Funds were allocated towards moving people to the community, but the vast majority do not appear to have been spent.</p>	
Disabled persons organisations involvement		
<p>How involved are disabled people in the work around Coming Home?</p> <p>Does this include people with learning disabilities and/or who are autistic who have been affected by institutionalisation?</p> <p>How much budget has been made available to involve disabled people?</p>	<p>There is poor information on the extent of involvement of DPOs and, particularly, those with experience of institutional living. While funding is provided to one DPO to facilitate people living in hospital to share their lived experience and expertise to inform the Coming Home work, DPO members do not feel that their views are listened to or reflected in decision-making.</p> <p>A group of 24 DPOs have expressed concern about the level of involvement of disabled people.</p>	

Summary of indicators	Key gaps in implementation	Assessment
Institutions		
<p>Has the Scottish Government said it will not put any more people with learning disabilities and/or who are autistic in institutions?</p> <p>How many people with learning disabilities and/or who are autistic have been moved out of institutions?</p>	<p>The Coming Home Implementation Plan does not explicitly state that institutions will be closed, nor that no new admissions will happen.</p> <p>Coming Home implementation has not led to “greatly reducing” the numbers of people living in institutions.</p> <p>The length of time people are staying in institutions appears to be getting worse for people on learning disability units.</p> <p>People continue to be admitted solely for “learning disability” rather than clinical need, running against the zero-tolerance vision of Coming Home implementation and raising questions of ECHR compliance.</p> <p>Data does not clearly identify institutional living, making it difficult to be clear whether any progress is being made in abolishing it. The absence of consistent data does not meet the minimum core of the right to independent living.</p> <p>There is evidence of spend and planned spend of funds which ought to have been spent on independent living being used to refurbish and repurpose institutional settings.</p>	
Training		
<p>Do people responsible for delivering independent living have training on the Convention on the Rights of Persons with Disabilities?</p> <p>Are disabled people involved in the design and delivery of training?</p> <p>Is there a requirement that staff of institutions must be retrained before working in community-based services and has this happened?</p>	<p>We found no evidence of CRPD being incorporated in any training for those working on Coming Home implementation or responsible for delivering independent living.</p> <p>We found no evidence of retraining of institutional staff.</p> <p>We found no evidence of disabled people being involved in training in this area.</p>	

Summary of indicators	Key gaps in implementation	Assessment
Complaints		
<p>Are there independent processes people can use to challenge barriers that interfere with their right to live independently – both in courts and outside of courts?</p> <p>How many complaints have been made?</p> <p>Is there support for making complaints? Are there efforts to make sure people are aware of how to use complaints processes?</p>	<p>At present, no specific mechanism exists to allow people to challenge the barriers that prevent them moving from institutions to the community. Potential mechanisms have been suggested but are far from being implemented.</p>	
Monitoring		
<p>Are services checked regularly to make sure they protect people’s human rights?</p> <p>Are people with learning disabilities and/or who are autistic involved?</p> <p>Are monitoring reports published in accessible formats?</p>	<p>Recommendations of the Mental Welfare Commission which would affect learning disability inpatient units, are not legally enforceable.</p> <p>We found no evidence of routine involvement of disabled people and DPOs as part of the monitoring process.</p> <p>Reports are not published in accessible formats</p> <p>There is no clear monitoring process of the Coming Home Implementation Plan</p>	
Quality standards		
<p>Are there legally enforceable standards about how care and support is provided?</p> <p>Do these standards make sure people’s human rights are protected?</p> <p>How many service providers have been found in breach of quality standards?</p>	<p>Health and Social Care Standards are not legally enforceable by individuals</p> <p>CRPD requirements could be more explicitly outlined in quality standards</p>	

Summary of indicators	Key gaps in implementation	Assessment
Awareness of support services		
<p>Is there information or programmes provided to make sure people with learning disabilities and/or who are autistic know about services that can help them live independently?</p>	<p>We found no evidence of State efforts to ensure empowerment of those affected by Coming Home, such as accessible materials on independent living for people living in hospital or clear information about what to do if someone’s rights are not being upheld.</p>	
<p>How much money is spent on this and how many people have taken part in programmes?</p>	<p>There are known gaps in the provision of independent advocacy for people with learning disabilities and/or who are autistic.</p>	
Empowerment		
<p>Are there programmes and budgets in place to support people with learning disabilities and/or who are autistic to build up skills required to live independently?</p>	<p>We found no evidence of plans to facilitate and financially support disabled people and families affected by institutionalisation. Peer support initiated by the Scottish Government focuses on professionals only.</p>	
Living arrangements		
<p>Does the law say people with learning disabilities and/or who are autistic have a right to choose where to live and who they live with?</p>	<p>The law does not protect the right to choose where to live and with whom. Various laws which apply to people with learning disabilities and/or who are autistic currently permit this right to be restricted.</p>	
<p>Are there laws that might stop disabled people choosing where to live and who they live with?</p>	<p>Whilst a £20m Community Living Change Fund was made available by the Scottish Government to progress action in 2021-2024, it is not possible to fully assess what has been spent in every area, and how many people have directly benefited.</p>	
<p>How much budget has been allocated to provide living arrangements in the community and how many people do now live in the community?</p>		
Involvement in deciding where to live		
<p>Does the law make sure people can make decisions about where they live and with who?</p>	<p>We found no published evidence of particular processes to ensure the process of moving out of institutions is based on the will and preference of the individual.</p>	
<p>Do people with learning disabilities and/or who are autistic get support to make that choice?</p>	<p>Support for decision-making and adequate respect for the will and preference of the individual are outstanding matters to be addressed in mental health and capacity laws.</p>	
<p>Is their choice listened to?</p>		

Summary of indicators	Key gaps in implementation	Assessment
Access to support services		
<p>What kind of support is there to live independently? Is it provided for in law?</p> <p>Does it cover everything disabled people need to live at home?</p> <p>Do carers get support services?</p>	<p>Given our findings in relation to use of the Community Living Change Fund, evidence of how comprehensive mapping of services is taking place should be made available.</p>	
Transferability of support services		
<p>Can people move their support to other parts of the country?</p>	<p>Data relating to how many people have requested transfer or whether transfers have been permitted or refused should be gathered and published.</p>	
Eligibility for community support services		
<p>Are there legal restrictions on eligibility to receive community support services?</p> <p>What criteria are they based on?</p> <p>Can they be challenged and how many are overturned?</p>	<p>Research on eligibility criteria and their application in practice is beyond the scope of this research.</p> <p>It should also be considered what the criteria are for determining that a person can no longer live in the community because their support needs are considered too high, however, this is outwith the scope of this research.</p>	
User control		
<p>Does the law say that decisions about how support is provided are made by people with learning disabilities and/or who are autistic themselves?</p> <p>Does it provide that carers can also do this for their own support?</p>	<p>It is beyond the scope of our research to assess the implementation of Self-Directed Support; however, a range of independent reports have identified a significant implementation gap.</p> <p>A group of 24 DPOs have pointed out that “There is no reference [in the Coming Home Implementation Plan] to independent advocacy, supported decision-making or Self-Directed Support, key mechanisms for supporting choice and control for those drawing on social care support.”³</p>	

Summary of indicators	Key gaps in implementation	Assessment
Informal support		
<p>Does the law recognise informal supports in the community?</p> <p>How much budget and training are provided to informal supports?</p>	<p>Informal community support is legally recognised through the Carers (Scotland) Act 2016, and the Social Care (Self-directed Support)(Scotland) Act 2013.</p> <p>We did not find data relating to this indicator. It is beyond the scope of our research to assess the extent to which this is provided in practice, or how much it emphasises the requirements of CRPD.</p>	
Access to justice		
<p>Have apologies, truth and reconciliation, public awareness-raising, compensation and guarantees that institutionalisation will not happen again taken place?</p>	<p>None of the reparations, remedies or redress required by CRPD have been established either in relation to the Coming Home Implementation Plan or the previous hospital closure programmes undertaken in Scotland.</p>	

About this research

UNCRPD Article 19 – Living independently and being included in the community

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.

Methodology

A full overview of the research methodology is provided at [Annex 3](#).

Our Project Group

We were supported throughout this work by a Project Group of individuals with significant expertise in the issues. We sought representation from Disabled People’s Organisations and people with lived experience of the issues, as well as third sector organisations with a track record of work in this area. They represent:

- Disabled People’s Organisations;
- People with lived experience of learning disabilities and/or who are autistic;
- Families of people who have experienced institutionalisation;
- Third sector organisations who support people with learning disabilities and/or who are autistic;
- Independent Advocacy;
- Academic expertise in disability studies and activism.

Our Project Group has shaped the development of this project and our conclusions and have contributed the wide expertise they bring in relation to the reality of the issues facing people with learning disabilities and/or who are autistic. This report includes some of their reflections on the issues our research found, reflecting their own views. We are very grateful to them for their contributions to this work.

Details of the constitution and role of the Project Group are outlined at [Annex 4](#).

Language

BB An othering process happens within the health and social care system. Learning disabled and/or autistic sons, daughters, brothers, sisters and loved ones are defined by their worst experience of distress, fear and dislocation. They become known as complex. Families know better. They know who their loved one is and all they can be, if they are listened to and receive the right support. GG

Project Group Member, civil society

- People with learning disabilities and/or who are autistic:** The Coming Home Report uses the term “people with learning disabilities and complex support needs” to define the group who the report affects. Our research is based around this term as it allows for as much consistency as possible when looking for data. Our Project Group guided us to use the term “people with learning disabilities and/or who are autistic” when talking about those affected. These are the terms that people themselves prefer, as they do not see themselves as “complex” or as having needs which are too difficult to meet.
- Social model of disability:** This report is grounded in the social model of disability as enshrined in the CRPD. It views disability as being caused by barriers in society, which interact with long-term physical, mental, intellectual or sensory impairments to hinder full and effective participation in society. We recognise that people self-define in a number of ways. When referring to CRPD, we will use the terms “persons with disabilities” (the words of the Convention) or “disabled people” (the term commonly accepted in Scotland).
- Independent living:** The meaning of this term has been explained by the UN Committee on the Rights of Persons with Disabilities. It means that “individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights. These activities are linked to the development of a person’s identity and personality: where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual’s autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities”¹⁴

Deinstitutionalisation in Scotland

66 It has been almost 20 years. People come, people go, yet I stay and wait. 99

Voices from hospital (People First)⁵

Attitudes towards people with learning disabilities and/or who are autistic have changed significantly over the centuries. CRPD cemented a shift in the view of disability, from one which looked at medical “deficiencies” to the social model which recognises that people are disabled by the failure of society to account for their difference and provide adequate support.

Human rights standards enshrine the idea that disabled people, including people with learning disabilities and/or who are autistic, have the same human rights as everyone else and are entitled to live in their communities with appropriate support to enable them to live freely, with choice and control.

Throughout the 20th century, asylums, hospitals and other institutions housed both adults and children with learning disabilities segregating them, often permanently, from society for what was perceived to be their own good and the protection of society. Large-scale institutions existed across Scotland, such as Lennox Castle, housing almost 1000 individuals, Gogarburn, and the Royal Scottish National Hospital. In 1970, there were about 8,500 patients with learning disabilities in long-stay institutions.⁶ From at least 1970, disability rights campaigners pushed for the closure of long-stay hospitals leading to a concerted period of hospital closures in the 1990s and 2000s. In 2000, the

then Scottish Executive’s learning disability policy ‘*The same as you?*’ included a key recommendation that all the remaining long-stay hospitals should close by March 2005 retaining only a small number of places for people with learning disabilities who required assessment and treatment or those on statutory orders.

However, despite progress, by 2005 this target had not been met and there were still eight hospitals or units open providing long-stay beds to 165 residents.⁷ In addition, some long-term residents remained in assessment and treatment units or nursing homes without adequate discharge plans.⁸

Following the concerted effort by the State towards long-stay hospital closure whereby the majority of people with learning disabilities in long-stay hospitals did move into the community, a number of available hospital beds remain, most of which are intended for assessment and treatment purposes. The right to independent living does not permit either long or short-term placements in an institution.

Reports by the Mental Welfare Commission (2016) and commissioned by the Scottish Government (2018) have highlighted that, for many people with learning disabilities and/or who are autistic, human rights are denied. They disclosed significant numbers of people

who are stuck in hospitals despite being assessed as no longer needing to be there. These delays were shown to last many years. In 2018, the Coming Home Report showed that more than 22 per cent of people in institutions had been in hospital for more than ten years, and another 9 per cent for five to ten years.⁹ It also recognised that this is “fundamentally a human rights issue and must be addressed with the urgency which that context indicates”.

The persistence of the issue in Scotland is a significant human rights concern which we have raised with UN human rights bodies.¹⁰

What is the Coming Home Implementation Plan about?

The issue of delays in discharging people with learning disabilities and/or who are autistic has been highlighted for many years, including by the reports of the Mental Welfare Commission and Dr Anne MacDonald on behalf of the Scottish Government.

The Scottish Government published its implementation plan (‘the Coming Home Implementation Plan’) in 2022 setting a deadline of **March 2024** to implement its changes. The Coming Home Implementation Plan makes an explicit commitment to taking a human rights-based approach and to ensuring the Scottish Government is meeting its obligations under CRPD. It is this Plan and the progress that has been made that we set out to explore.

The Coming Home Implementation Plan focused on the need to move people on from institutions which are “unsuitable” or “inappropriate” which the Scottish



Government explains as those which do not reflect the individual’s choice of community they want to live in.¹¹ This definition brings into focus the right to independent living, addressing the need to move away from institutional care towards supported community-based living for all disabled people. In our report, the Commission has therefore focused on measuring this particular human right – **the right to independent living articulated by Article 19 CRPD.**

What is an institution?

BB Institutionalisation is when you go into a hospital environment or a care environment and basically you don't get back out again. Time goes on and there is no end date in sight, and it is very sad because it is not a way to live. 99

Human Rights Defender, Measuring Change
Project Reference Group

BB A lot of people with autism or learning disabilities are currently living in hospital settings, in secure settings – in institutions and that is where they live. They are not able to be discharged because there is no appropriate care in the community and no social accommodation for them. 99

Human Rights Defender, Measuring Change
Project Reference Group

It is important to begin with a shared understanding of what an institution is, as defined by human rights. The CRPD Committee have explained the aspects that define an institution.¹² They are not defined by their size or the type of building but rather by the loss of personal choice and autonomy as a result of certain life and living arrangements being imposed. The key elements are:

- Little choice over who you live with and who supports you
- Isolation and separation from the community
- Lack of control over day-to-day decisions
- Lack of choice over who you live with
- Rigidity of routine regardless of will and preferences
- Identical activities in the same place for a group of individuals
- Supervision of living arrangements
- A paternalistic approach in service provision
- A disproportionate number of disabled people living in the same environment

It can be thought of as any place where you are forced to be because you are disabled, even if it is for “care” or “treatment”. This may be in a setting where you are placed with other disabled people but not “even individual homes can be called independent living arrangements if they have other defining elements of institutions”.¹³

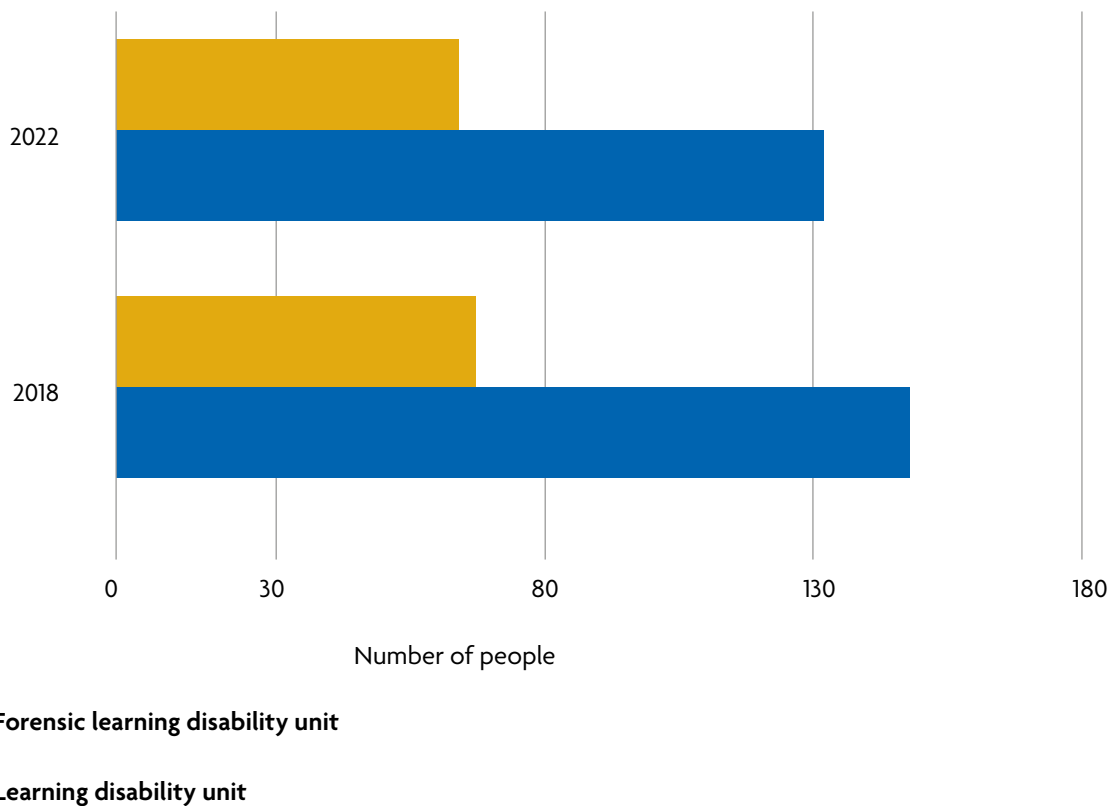
Institutions include¹⁴:

- Social care institutions
- Psychiatric institutions
- Long-stay hospitals
- Nursing homes
- Forensic psychiatric settings
- Settings located “in the community” where service providers set a routine and deny autonomy

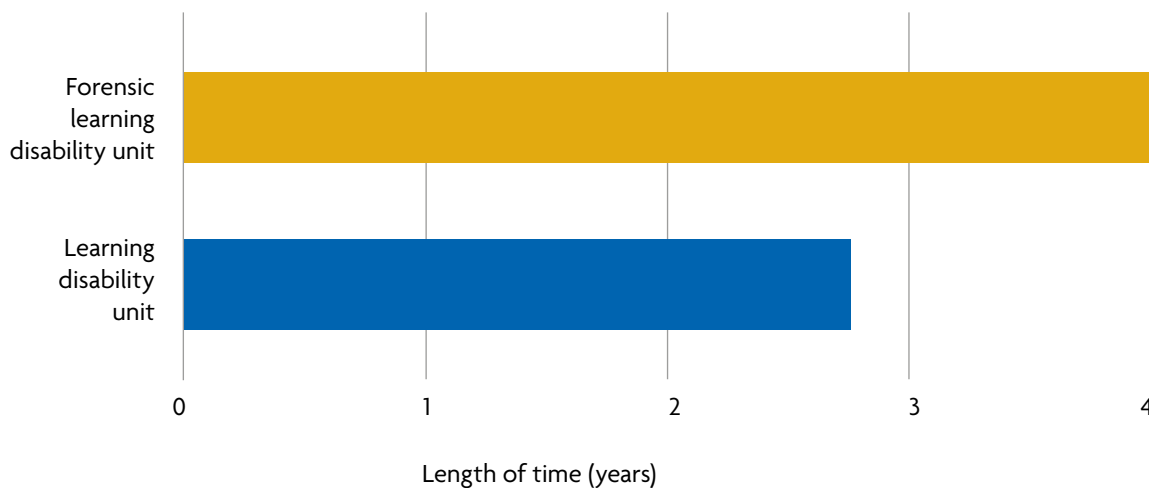
There are many places in Scotland that would be considered institutions. While we are focusing on those affecting the Coming Home population, this report provides the basis to assess and plan for moving people on from institutions of any type across Scotland. In terms of CRPD, this is an obligation of immediate priority for all settings.

Key data summary

Number of people in ‘learning disability beds’ by Year and Type of Facility



Average length of stay over 5 years of data



This data is taken from a range of sources including data from the Care Inspectorate, NHS Delayed Discharge data and the Scottish Government’s Mental Health Inpatient Census 2022¹⁵

- While there has been an overall reduction in the number of building based adult social care services with multiple occupants (between 2 and 150 occupants) between 2021/22 and 2024, **the number of services that provide multiple beds suitable for adults with a learning disability and/or autism has risen** during this period (345 today up from 323 in 21/22)
- One third of these services were **required to improve provision** by the Care Inspectorate¹⁶
- It is difficult to identify people who have a learning disability and/or who are autistic in general delayed discharge data, however, there is **no improvement over time** in the length of time discharges are delayed
- There were fewer people in ‘learning disability beds’ in hospital wards in 2022 (64 in forensic learning disability and 132 in learning disability units) compared with 2018 (67 in forensic learning disability and 148 in learning disability units), but there is **no great reduction in numbers**.
- Over a 5-year period, the average time a person spends in a learning disability unit is **2.76 years**. The single year average in 2022 was **4.28 years**.
- Over a 5-year period, the average time a person spends in a forensic learning disability unit is **4.01 years**. The single year average in 2022 was **3.82 years**.
- The number of people admitted to NHS inpatient care for reason of ‘learning disability’ has dropped from 140 people in 2016 to 65 people in 2022 but **remains above the zero expected** if people were no longer being admitted for “learning disability” according to the vision of the Coming Home Implementation Plan.
- The number of patients treated outwith Scotland but funded by NHS Scotland has **remained the same** since 2016 (33) 2022 (33) although there were rises and subsequent reductions in intervening years.
- **Autistic people** are not visible across a number of these data sources.

The Legal Framework

Institutional care affects a wide range of human rights. People in institutions may face the following situations which engage their human rights¹⁷:

- Restrictions on their ability to see their family (the right to private and family life)

“The health and social care system aims to help people with learning disabilities and/or who are autistic and their families. For too many individuals and families the system, however, does not feel safe. Particularly those whose loved ones live in institutions. Families fight for their rights to be respected, protected and upheld. It is a fight that takes a terrible toll, one that the system fails to adequately address.”

Project Group Member, civil society

- Restrictions on their freedom to make day-to-day decisions including, what to eat, what to wear, what activities they do (the right to private and family life)

“I have no privacy or peace. All doors and windows are locked. I have no choice when to eat.”

Voices from hospital (People First) 18

- Restraint and seclusion (the prohibition of torture, inhuman or degrading treatment and the right to private and family life)

“My son is haunted by traumatic incidents of restraint from institutionalisation. ‘All fall down!’ he says, pale and tense with fear, when he remembers what happened to him and others on the ward. Seeing somebody fall is enough to trigger this. Trauma interacts with his underlying profound brain injuries, making him more vulnerable, making caring harder.”

Project Group Member, parent

- Decisions made by others which override their will and preferences, including forced medication and treatment (right to legal capacity)

“I am told that I am not allowed to use the internet. I am not told why. If I question things I am told I am being ‘difficult’. If I get upset, I am told I am being ‘challenging’, and I might get a jag.”

Voices from hospital (People First)¹⁹

- Deprivation of liberty (right to liberty)

“I have to live with people I don’t get on with. I have to live somewhere that I don’t want to be, so I have learned not to speak out.”

Voices from hospital (People First)²⁰

The UN Convention on the Rights of Persons with Disabilities (CRPD)

The United Kingdom, including Scotland, has signed up to the UN Convention on the Rights of Persons with Disabilities (CRPD). This means that the Scottish Government is under a duty to implement CRPD to ensure it fulfils its obligations towards disabled people.

For a time, the Scottish Government was proposing to incorporate CRPD into Scots law via its Human Rights Bill, providing a legal framework to implement CRPD and consequences for failing to do so, which are currently lacking.

The Committee on the Rights of Persons with Disabilities (the CRPD Committee), which monitors CRPD, issues General Comments which explain the content of specific rights and the obligations they contain. While General Comments and guidelines from the Committee are not legally binding, they are the authoritative interpretation of the standards of CRPD. The CRPD Committee has continually highlighted the importance of replacing institutional care with community support as central to those obligations.

BB Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed. Resources are invested in institutions instead of developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalisation, isolation and segregation. **99**

United Nations Committee on the Rights of Persons with Disabilities, General Comment No.5 (2017) on living independently and being included in the community para ¹²¹

Deinstitutionalisation means the process of moving people out of institutions into community living, where they are able to enjoy their right to independent living as protected by Article 19 CRPD. The CRPD Committee has emphasised that “[t]o respect the rights of persons with disabilities under article 19 means that States parties need to phase out institutionalisation.”²² They state that there is no justification for continuing institutionalisation, including that community services are lacking or that pilot projects or law reform are needed before immediate action is taken.²³ States are allowed to decide **how** to replace institutions but not **whether to**.

A human rights-based approach is only meaningful if it is grounded in the specific human rights standards that apply to the situation. In this case, we can be very clear about what human rights require of deinstitutionalisation and what it looks like to truly realise the human rights of those affected. The CRPD Committee has outlined both a detailed explanation of the right to

independent living²⁴ and a set of guidelines detailing the specific actions needed to end institutionalisation.²⁵ These standards include:

- A commitment to building no new institutions, and to admitting no new residents when others leave
- Processes of deinstitutionalisation led by disabled people, with priority given to those affected by institutionalisation
- Prioritising the development of high quality, individualised support, and inclusive services in the community without delay
- Prohibiting investment in institutions and directing funding to community support
- The right for disabled people to control their own housing by entering rental or ownership agreements
- Adequate financial, social and other support for family members where a person chooses to have them provide support
- Recognition in law of the right to live independently and be included in the community
- Investment in peer support, self-advocacy, and other support networks, including disabled persons’ organisations and centres for independent living

- Preparations for leaving the institution customised to each individual
- Access to justice, through formal apologies, automatic compensation, rehabilitation and truth commissions which promote understanding of the full scope of harm caused to past and present survivors.

Closely related to Article 19 CRPD is the requirement to ensure equal recognition before the law under Article 12 CRPD.²⁶ This requires the State to ensure that disabled people have the right to make their own decisions, including on where and with whom they live, and to have their will and preferences respected. Disabled people must be provided with support for decision-making and their will and preferences must be respected. States must focus on providing support for decision-making and not permit decisions to be made by others on their behalf (substitute decision-making).

Guidance from the CRPD Committee should form the basis of any plans by the State to achieve deinstitutionalisation. They articulate exactly what components we need to look for to establish whether a human rights-based approach is being taken in practice. Throughout this report we explain in detail the human rights standards set out by the CRPD Committee and explore the extent to which they have been delivered in practice.

European Convention on Human Rights

Although deinstitutionalisation is not explicitly required by the European Convention on Human Rights (ECHR), the European Court of Human Rights (“the Court”) has dealt with many cases concerning detention in institutions. While continuing to accept that some circumstances may justify detention and overriding a person’s wishes, the Court closely scrutinises the safeguards around this and has, in recent years, highlighted the importance of taking into account the person’s rights, will and preferences. It has also increased the scrutiny required to ensure that detention truly serves a therapeutic purpose throughout a person’s treatment, in order for it to remain justified.

These cases involve:

- The right to liberty (Article 5 ECHR)
- The right to private and family life (Article 8 ECHR)
- The prohibition of torture, inhuman or degrading treatment (Article 3 ECHR)

These rights are protected in law via the Human Rights Act 1998. Many of those within the scope of Coming Home and in the forensic mental health system will be subject to measures of detention which must continuously ensure they meet these criteria. Any failure to do so may be subject to legal challenge.

Right to liberty (Article 5 ECHR)

The right to liberty does permit the detention of people of “unsound mind” (a term which is significantly out of date), but only in the following circumstances:

- The individual must reliably be shown to be of “unsound mind”;
- The mental disorder must be serious

enough to require compulsory detention;

- The detention only remains valid as long as the “disorder” continues at the necessary level of seriousness.²⁷

Detention is not justified just because it is said to be in a person’s “best interests”, and proper checks and authorisation must be given to ensure it is absolutely necessary to deprive a person of their liberty.²⁸ The individual’s consent or lack of consent to the arrangement is crucial and there must be compelling reasons to justify overriding the individual’s wishes. The fact that a person is deemed to have impaired capacity does not necessarily mean he or she is unable to understand and consent to their situation.²⁹

The case of *Rooman v Belgium*³⁰ in 2019 increased the scrutiny on the appropriateness of the treatment actually provided, in order to justify detention. The case was brought by a Belgian prisoner detained in a “social-protection facility.” The Court found his right to liberty and the prohibition of inhuman and degrading treatment had both been violated by the failure to provide psychiatric and psychological treatment in the facility in which he was detained. They made clear that individuals “are entitled to be provided with a suitable medical environment accompanied by real therapeutic measures, with a view to preparing them for their eventual release”. If this is not the case, then their detention will no longer be justified.

This case highlights the importance of scrutinising the actual therapeutic benefit a person is receiving from remaining in hospital, without which, a violation of their right to liberty is likely. It has been described as “remarkably difficult in the face of this decision to see the basis upon which the majority of those with learning disability/autism can sensibly be said to lawfully be deprived of their liberty in ATUs [Assessment and Treatment Units] or psychiatric hospitals

(whether this is under the framework of [mental health or incapacity law]), as it would appear difficult to see the basis upon which such institutions can be said to be appropriate.”³¹ Similar questions arise in Scotland.

Right to private and family life (Article 8 ECHR)

The right to private and family life protects the right to make decisions about your own life, including where you live, with whom, and your day-to-day routine. This right can be restricted where it is found to be necessary to achieve a legitimate aim, such as protection from risks to yourself or others, and proportionate (the least restriction necessary). States must provide adequate safeguards to ensure that people are able to participate in the process and that the process is sufficiently individualised to meet their unique needs.³²

When considering the choice of place of residence for a person with learning disabilities and/or who are autistic, the key question the Court looks at is whether a fair balance has been struck between respect for the dignity and self-determination of the individual and protecting and safeguarding his or her interests, especially where the individual’s capacities or situation place him or her in a particularly vulnerable position.³³ The Court will look at how strong the procedure and safeguards are that led to the person’s wishes being overridden. They must ensure that the individual’s rights, will and preferences are taken into account and that they have sufficient opportunity to participate and be heard.

The prohibition of torture, inhuman or degrading treatment (Article 3 ECHR)

In order to prevent inhuman and degrading treatment, the conditions a person is detained in must be suitable for their needs. The Court requires particular scrutiny for detainees who are vulnerable because of ‘mental disorder’. The place where a person is detained must provide proper treatment or they must be transferred to somewhere that can.³⁴

The Court recently looked at the situation of a 15-year-old person with a perceived “mild intellectual disability”, in the words of the Court, in a psychiatric hospital.³⁵ Both his placement and his extended stay in hospital were found to be partly because there was no alternative care available to him. The Court confirmed that learning disability cannot be an acceptable reason to detain someone, unless it has a “therapeutic purpose”. This means that a person can only be detained in hospital if it is to provide medical care and treatment which continues to be necessary during their stay. The Court found that the whole circumstances of the case (including the fact that he was given antipsychotic medication, placed in an adult ward, his discharge being delayed, combined with his age, learning disability and the absence of parental care) amounted to inhuman and degrading treatment, in breach of Article 3 ECHR. Although this case took place in Moldova and depended on many specific factors, it highlights a number of factors which must be intensely scrutinised to make sure the detention of people with learning disabilities does not violate their human rights.

Domestic Legal Framework

The legal framework in Scotland provides a set of procedural safeguards that aim to address the requirements of the European Convention on Human Rights. These are set out in the

- Mental Health (Care & Treatment) (Scotland) Act 2003
- Adults with Incapacity (Scotland) Act 2000

Both pieces of legislation have been subject to criticism and review of their inadequate support for decision-making and failure to keep pace with international human rights developments. The Scottish Mental Health Law Review (2023) (the Scott Review)³⁶ provides the most comprehensive analysis of the changes needed in order to keep pace with modern human rights requirements. The Independent Review of Learning Disability and Autism in the Mental Health Act (the Rome Review) (2019) examined the changes needed to properly protect the human rights of people with learning disabilities and/or who are autistic. Our report is written against this backdrop of the recognised need for the Scottish legal framework to evolve beyond its current state.

The Social Care (Self-Directed Support) (Scotland) Act 2013, properly employed, also provides a framework for the delivery of independent living by enabling choice and control over a person’s budget and support arrangements. We comment on the use of Self-Directed Support in practice in our findings.

The Scottish Government had committed to bring forward a Human Rights Bill incorporating CRPD (among other human rights treaties) before 2026, however, a Bill will not likely be brought forward until at least the next Parliamentary session. The proposed Learning Disability, Autism and Neurodivergence Bill also faces an uncertain future. While the Scottish Government committed to publish a draft Bill for consultation, there is no schedule for it to progress through Parliament. Our position on the potential of these proposed Bills in relation to the findings from this research is presented in the later section on recommendations.

How we did this research

Further detail on our methodology can be found in [Annex 3](#).

Baseline Indicators

Human rights are universal for everyone. . The Commission is part of the international human rights system monitoring human rights in countries across the world, and we have looked at what tools have been developed in other parts of the world.

The Fundamental Rights Agency (FRA) is the European Union’s independent centre for excellence for promoting and protecting human rights in the European Union. The FRA has created indicators that can be used to measure progress in realising Article 19 of the UNCRPD, the right to independent living and inclusion in the community. These indicators are human rights broken down into individual elements. The FRA indicators provide questions to help assess if all disabled people can live independently in their country. The indicators include the following areas for measurement:

- Commitment to the Convention on the Rights of Persons with Disabilities.
- Action plan for transition from institutional care to community-based support.
- Involvement of disabled people and their organisations in developing laws and policies that affect them.
- Impact of non-discrimination legislation on disabled people.
- Quality standards for public and private service providers.
- Training on the Convention on the Rights of Persons with Disabilities is required by law.
- Awareness of support provision.

- Empowerment programmes for disabled people.
- Monitoring of public and private services for disabled people.
- Availability of complaints and redress.
- Living arrangements available for disabled people.
- Involvement of disabled people in deciding where to live.
- Access to support services.
- Transfer of support services across different local areas.
- Eligibility for community support services.
- Control of disabled people in choosing their support.
- Availability of adaptations to homes for disabled people.
- Availability of informal support.
- Availability and adaptations of community services and facilities.

In 2018, FRA carried out a project to collect and analyse comparable data on the transition from institutional care to community-based support in the 28 EU Member States.³⁷

One of the central aims of the FRA project was to develop and populate human rights indicators to enable the assessment of whether Article 19 of the CRPD was being fulfilled. These indicators are rigorously developed and well tested and we have used them as the basis for our human rights measurement. Small adaptations have been made to fit them to the Scottish context and to narrow the focus to those within the scope of Coming Home. The indicators have been tested on data from the UK and remain a robust way to measure the right to independent living, regardless of national context.

Assessment

We commissioned research to undertake **human rights measurement** of a set of indicators measuring progress in realisation of Article 19 CRPD in relation to those affected by the Coming Home Implementation Plan. We adopted the indicators developed by the Fundamental Rights Agency for measurement of Article 19 CRPD. We made minor amendments to the indicators to take account of the domestic context, the specific focus of the Coming Home Implementation Plan and subsequent clarifications provided by the CRPD Committee’s guidelines on deinstitutionalisation.

A full set of the indicators used in this project is published in [Annex 1](#). We suggest that duty bearers may now utilise these to inform their own work from here.

The Commission’s baseline research, by Professor Jo Ferrie & Dr Paul Pearson, is published alongside this report.³⁸ The research includes data available up to 31 May 2024.

The research employed a mixed-methods approach. This involved the analysis of a range of publicly available data sets, with the aim of measuring the deinstitutionalisation process. This approach was supplemented with interviews throughout the research process with key stakeholders including duty bearers, researchers and representatives of third sector organisations.

Further detail on the research methodology can be found in [Annex 3](#).

What human rights measurement is

Human rights measurement is a way of checking how well human rights are being realised in real life.³⁹ It takes the ideas of human rights and turns them into things we can look for and count. It shows what is being done and what is not being done. It tells us what is missing along on the way to making sure our human rights are realised in real life.

Human rights measurement assesses not only what efforts or discussions have happened on a particular issue, but also what specific commitments have been made, and what actual outcomes have been achieved. This approach aims to assess the gap between rhetoric and reality by looking at all the steps that are required to realise human rights – a State must not only commit to addressing a problem, but also make continuous efforts to do so, and make sure that those efforts achieve real results for rights holders.

Human rights measurement looks at three levels: **Structure – Process – Outcome**.

Structure – this looks at the concrete **commitments** made by the State in the legal, policy and institutional framework.

- Commitment to international human rights law
- Legislation in place
- Policies, strategies, action plans, guidelines, adopted
- Institutional framework
- Complaint and support mechanisms exist

Process – this looks at the **efforts** towards addressing the issue

- Budgetary allocations
- Implementation of policies, strategies, action plans, guidelines etc.
- Effectiveness of complaint and support mechanisms

Outcome – this looks at the actual **results** delivered

- Actual awareness of rights
- Actual impact of policies and other measures
- Actual occurrence of violations

Human rights measurement can be developed into a series of measurable indicators which track progress over time.

Why human rights are measured

Measuring human rights gives you evidence and facts. When human rights are not measured, it is hard to be sure if they have been delivered. This means people can have different opinions and important things can be forgotten.

Human rights measurement looks beyond what people say, to what is really happening. It does this based on facts, not opinions.

How human rights are measured

Human rights laws tell us what our human rights are. They are often short statements but there are lots of parts that have to be put together to make up those rights. Human rights courts and the United Nations have set out a lot of detail about all the parts that make up our human rights.

We can break the parts of human rights into pieces to allow for measurement of more specific actions and outcomes. We call these pieces **indicators**. We can look at each of these indicators and check it against what is happening in real life.

What human rights measurement tells you

Human rights measurement will tell you which parts of human rights are being respected or fulfilled. It will tell you which parts are missing. It will also tell you when there isn't any information to be able to say what is happening.

What it will not tell you

Human rights measurement will not tell you what people's lives are really like and how they feel about what is happening to them. This is also an important part of the whole picture of human rights; however, it would be measured in different ways.

Human rights measurement only gives you a picture at one point in time. It works best when it is used again and again over time.

Our findings

We wanted to find out what had happened since the Coming Home Report was published in 2018 and what the evidence could tell us about how much progress is being made to end institutionalisation for people with learning disabilities and/or who are autistic.

Each heading and set of questions are taken from the UNCRPD indicators at [Annex 1](#), based on the Fundamental Rights Agency framework. We begin by summarising what the indicators are looking for in the context of the Coming Home Implementation Plan. We then look at the specific requirements set out by CRPD, and, lastly, at what the evidence identified by our researchers was able to tell us about whether they are being met. The evidence accessed through our research, when measured against CRPD, identifies many gaps – both in whether progress is being made in a way that meets human rights standards, and in the information available to be able to assess this.

The findings of our work suggest that Scotland’s existing structures, policies and interventions are currently inadequate in relation to realising a human rights-based process of deinstitutionalisation. It is clear that people continue to live in accommodation that is institutional, inappropriate, and not in the area that they would call home. The Coming Home Implementation Plan itself would not even if implemented in full, fulfil the terms or vision of Article 19 of the CRPD. Furthermore, the key interventions proposed in the Coming Home Implementation Plan have not been fully implemented.⁴⁰

Details of the research methodology are at [Annex 3](#). Where we state that “we found no evidence” of a given indicator, we mean

that it was not able to be identified through the research methods employed and within publicly available evidence. Scottish Government have been given an opportunity to identify any evidence missed and minor clarifications have been added as a result. We acknowledge the possibility that evidence may yet exist although this would illustrate the difficulty in identifying such information. The Commission does not have the power to compel information from public authorities.

1. Action plan and strategies of the State

How strong is the Coming Home Implementation Plan on human rights requirements?

How much money has been made available to make the Plan happen?

Have the targets in the Plan been met?

What is required

The right to independent living requires that governments immediately begin planning, together with disabled people, to replace institutions with independent living support services.⁴¹ Plans must be detailed, explaining the time they will take, benchmarks along the way, and what resources are needed.⁴² All of this must be monitored to ensure it is delivered.⁴³

What we found

The Coming Home Implementation Plan was published in February 2022 setting out an action plan to “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.”⁴⁴ A target of March 2024 was set out by which time out-of-area residential placements and inappropriate hospital stays were to be “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.” While being clear on its vision, the plan fails to acknowledge legislation or policy that could help it deliver a human rights-based approach. For example, the plan does not refer to or make use of the Social Care (Self-Directed Support) (Scotland) Act 2013 which makes explicit use of human rights.

The target of March 2024 has not been met. Our research found no evidence to show that the number of people in the target group has been “greatly reduced” [see Section 3]. **There is no action plan following the end of the Coming Home Implementation Plan in March 2024.**⁴⁵

The plan was accompanied by a Community Living Change Fund of £20 million which was allocated from February 2021 to March 2024 by the Scottish Government and divided between health and social care authorities across Scotland. The fund was allocated based on a pre-existing standard

formula⁴⁶, rather than the number of people whose situation needed to be addressed in particular areas. This led to at least one local authority (Shetland) being allocated funds although they did not have anyone in an institution in the target group at the time the fund was released.

There is no way to assess the overall impact of the Community Change Fund in achieving deinstitutionalisation. The Scottish Government receives reports monitoring how the money is spent but this information is not publicly available, and so it is difficult to tell how it has been spent. In the absence of publicly available monitoring data, our researchers accessed annual accounts and performance reports to ascertain how and on what the fund has been spent. Our research sampled published accounts from a range of health and social care authorities⁴⁷ and found that there was little spending of this specific Fund recorded within any of the recipient authorities. There was also little evidence in the annual performance reports of these health and social care authorities of the fund being used. The information available only goes up to March 2023, so it does not show whether money was spent between then and March 2024. **It is not clear what funding is or has been available after March 2024.**

Our research was able to trace specified Coming Home funds as designated reserves in the published accounts of three of those health and social care authorities.

Annual accounts showing money sitting in reserve (not spent)⁴⁸

Health and social care authority	2020-2021	2021-2022	2022-2023
East Renfrewshire	£ 295,000	£ 295,000	£ 254,000
Clackmannanshire & Stirling	£ 512,000	£ 512,000	£ 512,000
East Dunbartonshire	£ 350,000*	£ 341,000	£ 341,000

* Figure appears as £0.35m in annual accounts of 2020-21, but is recorded as £341,000 in subsequent accounts without evidence of spend.

Our research also looked at the use of the fund across the country. Allocations of the Fund in the following areas were not identifiable: West Dunbartonshire, Western Isles, Highland, Glasgow City and Edinburgh City. In these areas the Fund may or may not have been spent and we are aware of some spend on initiatives relevant to the Coming Home Implementation Plan within this group (see findings on a particular service development below). Through publicly available information via audited accounts, researchers traced approximately £14 million of the allocated Fund in the accounts across all Health and Social Care Partnerships. These figures show that, from the most recent information available, only £1,433,585 had been spent by March 2023. This means the vast majority – **£12,634,881** – was unspent going into the final year of the fund.

Allocation, amount held in reserve and spending of CLCF⁴⁹

Total Allocation where figures were available	£14,068,466
Total held in reserve as of March 2023	£12,634,881
Total spend of CLCF from available figures as of March 2023	£1,433,585

Key gaps in implementation

- While there was a Scottish Government action plan up to March 2024, its targets have not been met. The plan expired in March 2024 and there is no current action plan on deinstitutionalisation for the target group.
- Funds were allocated towards moving people to the community, but the vast majority do not appear to have been spent.

2. Disabled persons organisations’ involvement

How involved are disabled people in the work around Coming Home?

Does this include people with learning disabilities and/or who are autistic who have been affected by institutionalisation?

How much budget has been made available to involve disabled people?

What is required

One of the central obligations of CRPD is that disabled people must be actively involved when dealing with issues affecting them.⁵⁰ They must be closely involved in deinstitutionalisation processes and governments should give priority to the views of people who have been, or are in, institutions in these processes.⁵¹

What we found

There was little public information on who has been involved in Coming Home processes. The Scottish Government has provided funding for the People First (Scotland) Hospital Advocacy Project since November 2021 and currently provides collective advocacy to people with a learning disability living in six hospital units.⁵² The project offers the opportunity for people living in hospital to share their lived experience and expertise to inform the Coming Home work. Funding this project means citizens living in hospital units have contributed their invaluable, frequently unheard, lived experience. However, members express continued frustration at the lack of progress and lack of change around decision-making processes, both at an individual and strategic level. People First have said:

66 The continuation of the hospital group allows People First development workers to support members to take part in advisory groups and strategic planning groups. The lived experience stories gathered by the hospital group provide much need perspectives and expertise on these panels. However, we do not feel the voice of lived experience is being listened to. We do not see our views reflected in the work that is going on. 99⁵³

Our researchers found evidence of a Coming Home Senior Strategy Group organised by Scottish Government and the Convention of Scottish Local Authorities (COSLA), which has at least one Disabled Person’s Organisation (DPO) as a member. However, because there was little published information on this group, it was unclear who else is involved or how the group contributed to implementation of the plan. While an independent advisory group is reported to exist, and this has been confirmed to us by the Scottish Government as part of a factcheck exercise ahead of publication, the membership and the role of this of this group are not visible to the public.

A group of 24 DPOs wrote to the Scottish Government in 2022, on publication of the Coming Home Implementation Plan, explaining their concern that “there was no involvement of people with learning disabilities and/or who are autistic, or Disabled People’s Organisations in the drafting of this report. There was also very little by way of engagement with family carers, carers’ organisations, or Support Provider representative organisations such as CCPS.”⁵⁴ In response, the Scottish Government cited “stakeholder engagement and scoping work” since publication of the report “with individuals, families and carers with lived experience, clinicians and practitioners, commissioners and organisations across the sector.”⁵⁵

In relation to the Community Living Change Fund, our research found little evidence of what processes involving disabled people were in place to decide how the money should be spent. While the Scottish Government guidance setting principles for use of the Fund specify “Involvement” including participatory processes, our researchers were unable to find any evidence of this in publicly available data. There was one reference to a “community and inpatient redesign group” which was chaired by both “inpatient and community colleagues”, which appears to refer to professional colleagues rather than including people with lived experience or DPOs.

Key gaps in implementation

- There is poor information on the extent of involvement of DPOs and, particularly, those with experience of institutional living. While funding is provided to facilitate the support of Voices from Hospital by a DPO, DPO members do not feel that their views are listened to or reflected.
- A group of 24 DPOs have expressed concern about the level of involvement of disabled people.

3. Institutions

Has the Scottish Government said it will not put any more people with learning disabilities and/or who are autistic in institutions?

How many people with learning disabilities and/or who are autistic have been moved out of institutions?

What is required

The CRPD Committee has been clear that “No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents’ physical safety. Institutions should not be extended, new residents should not enter when others leave...”⁵⁶

According to the CRPD Committee, the commitment to end institutionalisation has three parts:

1. To shut down residential institutions
2. To stop new admissions to residential institutions
3. Not to build new institutions

A move towards ending institutionalisation would show smaller numbers of people living in institutional settings over time, as people moved into the community, and no one was admitted in their place.

What we found

a. Institutional living

The Coming Home Implementation Plan committed the Scottish Government to “greatly reducing” placements which would be considered institutional; however, it stops short of making the three explicit commitments required by this indicator. It

does not explicitly state that institutions will be closed, nor that no new admissions will happen. While institutions remain open, there remains a risk that new people will be admitted. It is not possible from the data to assess whether the numbers of people in institutions from one point in time to the next are the same people or people who have been newly admitted after others leave. In any case, the data does not show any reduction in the number of people living in institutions during the Coming Home implementation period.

It is difficult to be clear about the exact numbers of people living in institutions as none of the available data uses terms like “residential institutions” or defines what is or is not an institutional placement. This information is essential in order to develop any plan for deinstitutionalisation, or to assess its progress. It is also one of the most basic requirements of the right to independent living that that the State must collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions.⁵⁷ These basic requirements (called “minimum core obligations”) are rights which a country needs to comply with at all times and in all circumstances, regardless of their resources or the overall conditions of the country. **The minimum core of Article 19 is not being met in relation to data on institutionalisation.**

Without that clear information, our research explored any data which might tell us about the scale of institutional living.

There is no way to ascertain the exact numbers of people living in institutions as defined by CRPD. However, the data indicated some important information and gaps:

- Care Inspectorate data showing the type and quality of care services in Scotland⁵⁸ shows the number of beds in a care setting but does not give any information

on whether a person is there by choice or able to exercise choice and control over their day-to-day life. 345 adult services provide services for people with learning disabilities and have between 2 and 150 rooms. This shows that even when people have their own rooms, they are living beside many other people, raising the question of whether they may be considered institutions.

- NHS Delayed Discharge Data⁵⁹ shows the numbers of people in hospital who no longer need to be there for medical reasons and are waiting to be discharged. It shows increases in the numbers of people waiting for an appropriate placement overall, but it does not tell us how many of these people have a learning disability and/or are autistic. This information is of limited use, but it does not show any improvement over time in how quickly people are able to move into appropriate placements.
- Dynamic Support Register: The Coming Home Implementation Plan has focused on creating a Dynamic Support Register, which was launched in May 2023. It “record[s] information about people with learning disabilities and complex care needs who are in hospital, who are in out-of-area placements or whose current support arrangements are at risk of breaking down. Integration Authorities report data from their Register to Public Health Scotland (PHS) who analyse and publish this information twice a year.”⁶⁰ This should include people who are institutionalised but, again, it does not use the concept of institutionalisation, limiting the ability to answer the key indicator on who is living in an institution. Our researchers had access to a version of the Register and highlighted where it could have potential to provide clearer information on institutionalisation.⁶¹

The Inpatient Census 2022⁶² provided the most information, and the most concerning indications. It tells us how many people were in NHS care in learning disability units or forensic learning disability units.⁶³

Type of unit	People in NHS care in 2018	People in NHS care in 2022
Learning disability unit	148	132
Forensic learning disability unit	67	64

There are several points to note about this data:

- At the time of our research, there was no information available after 2022, which is a concern when we are trying to understand the impact of Coming Home. The Inpatient Census for 2023 was published in November 2024, outwith the timeframe of our research. Further analysis of the figures and trends would enable further understanding of the state of progress.
- Some of these people may be in hospital for a short period of assessment and treatment, however, placements in these units are exactly the types of admissions that deinstitutionalisation is concerned with and are the numbers we would expect to see “greatly reduced” if the Coming Home Implementation Plan was having an impact.

This data also showed that the numbers of people in care outside Scotland has not significantly reduced (although it has fluctuated). There is therefore no evidence that Coming Home Implementation has been effective in reducing the number of people with a learning disability and/or who are autistic being detained outwith Scotland.

Patients treated outwith but funded by NHS Scotland⁶⁴

Patient Category	2014	2016	2017	2018	2019	2022
Learning disability/autism	35	33	27	65	40	33

Number of people admitted to inpatient facility, NHS Scotland for reason ‘learning disability’, 2016-2022⁶⁵

Reason for Admission	2016	2017	2018	2019	2022
Learning disability	140	131	112	107	65

The data also shows the length of time people are staying in NHS wards although there are some years missing.⁶⁶ The numbers here undoubtedly indicate long-term admissions and institutional living. They show both very concerning lengths of stay and even more concerning increases in how long people with learning disabilities are spending in hospital. The data covered by our research does not go beyond 2022, however, that period should have been impacted by Coming Home implementation.

- Over a 5-year period, the average time a person spends in a learning disability unit is **2.76 years**. The single year average in 2022 was **4.28 years**.
- Over a 5-year period, the average time a person spends in a forensic learning disability unit is **4.01 years**. The single year average in 2022, it was still **3.82 years**.

We also see that many people are still being admitted to hospital for reason of “learning disability”. Learning disability is listed as a reason (other reasons are therapeutic/clinical crisis; diagnostic; rehabilitation; self-inflicted injury; other type of psychiatric admission; no additional detail).

Admission on the basis of learning disability runs counter to the declaration by Professor Sir Gregor Smith, the Chief Medical Officer, in the foreword of the Coming Home Implementation Plan that people should only be admitted to inpatient services for a clear clinical reason. According to the Scottish Government, expressions of behaviours perceived as challenging, with no identified clinical need, are “not an appropriate reason to admit people to inpatient assessment and treatment services.”⁶⁷ The Coming Home Implementation Report also makes a core commitment to “a zero-tolerance approach to inappropriate placements for people with learning disabilities.”⁶⁸ While there is a trend towards lower numbers year on year, in 2022 the value should have been zero, if people were no longer being admitted for “learning disability” according to the vision. **This also raises questions about compliance with ECHR standards in light of the Court’s clarification that learning disability is not a sufficient basis for detention unless there is a clear therapeutic purpose.**⁶⁹

Key gaps in implementation:

- The Coming Home Implementation Plan does not explicitly state that institutions will be closed, nor that no new admissions will happen.
- Coming Home implementation has not led to “greatly reducing” the numbers of people living in institutions.
- The length of time people are staying in institutions appears to be getting worse for people on learning disability units.
- People continue to be admitted solely for “learning disability” rather than clinical need, running against the zero-tolerance vision of Coming Home implementation and raising questions of ECHR compliance.
- Data does not clearly identify institutional living, making it difficult to be clear whether any progress is being made in abolishing it. The absence of consistent data does not meet the minimum core of the right to independent living.

b. How the Community Living Change Fund has been used

Both pieces of direction from the CRPD Committee are explicit about the use of funds

“Investments in institutions, including renovation, should be prohibited...State parties should stop using public funds for the construction and renovation of institutions.”⁷⁰

There was very little information available about exactly how the small amount of money spent from the Community Living

Change Fund was used, however, findings on what data is available indicate real concerns as to whether this key requirement is being complied with.

In one authority, evidence was found of proposed use of the fund to purchase and refurbish vacant NHS multi bed accommodation.⁷¹ More recent publicly available documents provided detail of the purchasing, rationale and plans for this,⁷² including an update on longstanding plans to resettle people with a learning disability who have been resident in the authority’s “last remaining NHS longer stay unit.” According to this report, the identified building had previously been used, as a longer stay unit before being closed in 2017. In 2021, having been vacant since its closure, it was purchased and has since undergone refurbishment. A service provider has been appointed and was scheduled to open in March 2024. These plans, part of a resettlement strategy, were “further enhanced with the publication of the Scottish Government Coming Home Implementation Report 2022, and the £20 million fund to take forward redesign across Scotland.”⁷³ Whilst we were not able to ascertain the level of spend, we are able to confirm that it was purchased and redesigned using at least part of the share of the CLCF.⁷⁴

Documents refer to the refurbishment as providing “an enhanced community living service for adults with a learning disability” in preference to previous plans to commission a 15-person specialist care home for this client group.⁷⁵ The description of an enhanced community living service is

“An enhanced community living service for people with a learning disability aims to provide an intermediate bridge in service provision between those people assessed as suitable for discharge from NHS hospital care, but for whom existing community

accommodation is at present unlikely to be a suitable or sustainable option. We acknowledge that for some individuals who will be transferring to the new service from NHS long stay beds, the prospect of discharge to a lower tier community service may be unlikely. Notwithstanding that, the ethos of the new service will very much be to support individuals to reach a stage when a more independent form of community provision can be considered.”⁷⁶

While this is referred to as “a community-based alternative to long stay hospital admission”, this arrangement prompts questions as to whether it complies with independent living in line with Article 19:

- Repurposing a former institution requires particular scrutiny as to whether it represents a different form of institutionalisation. It would only be acceptable if it complied with all aspects of independent living, ensuring self-chosen support and choice and control in all aspects of daily living.
- The information indicates that this is a placement which is a step down from hospital but only an “intermediate bridge” to community living.

- The lack of definition of institutions in Scotland means that it is not possible to ascertain whether this particular unit is or is not an institution. The information suggests that it falls short of independent living and thus represents a contravention of CRPD guidelines.

In addition, one other area referenced the fund in their 2020-21 report stating that “We had also planned to meet some refurbishment costs for work within our Learning Disability in-patient units, however this work was delayed at the start of the pandemic; this work is now on hold and will be incorporated as part of the work supported by the Community Living Change Fund”⁷⁷. This refurbishment would clearly be in contravention of CRPD direction.

Key gaps in implementation:

- There is evidence of spend and planned spend of funds which ought to have been spent on independent living being used to refurbish and repurpose institutional settings.

4. Training

Do people responsible for delivering independent living have training on the Convention on the Rights of Persons with Disabilities?

Are disabled people involved in the design and delivery of training?

Is there a requirement that staff of institutions must be retrained before working in community-based services and has this happened?

on the right to independent living. This may contribute to use of the fund in probable contravention of the requirements of Article 19 CRPD.

Our research found no evidence of a requirement for institutional staff to retrain or of this having happened. The Care Inspectorate will identify the lack of or poor training, in general, as a breach of their standards and, when they do, call for frequent and regular training opportunities. However, our research found no evidence that this covers CRPD or the specific need to retrain between working in institutional and community settings.

What is required

Personnel working in services for disabled people, including staff providing support, decision-makers and civil servants monitoring services must be adequately trained on independent living.⁷⁸

What we found

We did not identify any specific training on CRPD, mandatory or otherwise, being routinely provided for those responsible for delivering independent living in relation to Coming Home. They also did not find any evidence of disabled people being involved in designing or delivering training.

Training may exist but evidence was difficult to find. Guidance around Self-Directed Support says that authorities should provide training on human rights-based approaches but, without evidence, it is not possible to ascertain either whether this training is being routinely delivered or whether it has any specific focus on CRPD. While we see guidance to authorities to take a human rights-based approach in using the Community Living Change Fund, our research highlights that this is not supported by any particular human rights training or guidance

Key gaps in implementation

- We found no evidence of CRPD being incorporated in any training for those working on Coming Home implementation or responsible for delivering independent living.
- We found no evidence of retraining of institutional staff.
- We found no evidence of disabled people being involved in training in this area.

5. Complaints

Are there independent processes people can use to challenge barriers that interfere with their right to live independently – both in courts and outside of courts?

How many complaints have been made?

Is there support for making complaints? Are there efforts to make sure people are aware of how to use complaints processes?

What is required

States must ensure access to justice and provide legal aid and appropriate legal advice, remedies and support for people who want to enforce their right to independence living.⁷⁹ They should provide pathways to seek redress and accountability which are individualised, accessible, effective, prompt and participatory.⁸⁰

What we found

The broader issues of access to complaints mechanisms in relation to social care are outwith the scope of this research; however, it is an area of ongoing interest to the Commission.

In relation to the group of people affected by Coming Home, the Scottish Government acknowledges that “[t]here is not currently a way for people with learning disabilities and complex care needs who are facing inappropriate hospital stays or out-of-area placements to have their case reviewed by experts”.⁸¹

The Coming Home Implementation Plan recommended that a National Support Panel, be created. Options for this are still being scoped and it is not yet in place. Consultation on the proposal set out three options, only one of which would provide a basis in law for the Panel to look at individual cases. Proposals outline that “[t]his type of Panel would require the powers to:

- review individual data;
- require information and evidence from public bodies; and,
- make recommendations, potentially with consequences for non-compliance.”⁸²

There is therefore potential for a new mechanism to be created for this group of people which meets the CRPD criteria; however, at present, no such mechanism exists, and another option might be chosen. In any case, the Learning Disabilities, Autism and Neurodivergence Bill, which may have offered a route to create such a mechanism, has no clear timetable for introduction, and the Scottish Government has confirmed that it will not be progressed in the current session of Parliament.

People who are detained in hospital have some mechanisms of challenge open to them through the Mental Health Tribunal for Scotland (the Tribunal). The Tribunal decides on applications for compulsory treatment and carries out periodic reviews of people receiving compulsory treatment. While they can make a finding which specifies community care and other services (called ‘recorded matters’⁸³), they cannot enforce the provision of community services to individuals. The Scottish Mental Health Law Review (the Scott Review) commented on the weaknesses in recorded matters in relation to moving people with learning disabilities out of hospital:

“In 2020, the [Mental Welfare Commission] raised concerns about how effective this power was. When looking at the experience of people with learning disabilities in hospital they found a lot of people whose discharge was delayed. They also found a small number of examples where the Tribunal had made a ‘recorded matter’ about this. However, it did not always make a difference. A Tribunal in 2014 made a ‘recorded matter’ to identify accommodation and support for someone within six months. This had still not been done when they checked on it six years later.”⁸⁴

The Scott Review recommended that recorded matters be strengthened so that the Tribunal can enforce them, in order to protect the individual’s human rights.⁸⁵ This is not identified as one of the priority actions being taken forward by Scottish Government in response to the Review.

Key gaps in implementation

- At present, no specific mechanism exists to allow people to challenge the barriers that prevent them moving from institutions to the community. Potential mechanisms have been suggested but are far from being implemented.

6. Monitoring

Are services checked regularly to make sure they protect people’s human rights?

Are people with learning disabilities and/or who are autistic involved?

Are monitoring reports published in accessible formats?

What is required

States must have bodies which monitor existing institutions and residential services, with the participation of disabled people.⁸⁶

Deinstitutionalisation processes should, at all stages, be monitored by bodies which provide accountability, transparency and the protection and promotion of human rights. They must include meaningful participation of disabled people, particularly those who have experienced institutionalisation.⁸⁷

What we found

The Care Inspectorate inspect registered care services including those providing care and support to people with learning disabilities and/or who are autistic. Their work is independent of government and service providers. Monitoring occurs every second or third year, though providers found to have breached standards may be subject to more frequent review. They publish their findings publicly, but not in easy read formats. They make recommendations for improvement and can, ultimately, carry out legal enforcement action. Our research found no evidence that disabled people and DPOs are part of the monitoring process.

The Mental Welfare Commission carry out monitoring by local visits to people who are being treated or cared for in local services, such as a particular hospital ward, a local care home, local supported accommodation, the State Hospital or a prison. They publish reports after each of these visits and make recommendations for change when necessary. They are independent of government and service providers. The frequency of visits is not set out in law. Their recommendations are not legally enforceable. Our research found no evidence that disabled people and DPOs are part of the monitoring process.

There is no clear monitoring process of the Coming Home Implementation Plan which meets the requirements of accountability, transparency or the meaningful involvement of disabled people.

Key gaps in implementation

- Recommendations of the Mental Welfare Commission, which would affect learning disability inpatient units, are not legally enforceable.
- We found no evidence of routine involvement of disabled people and DPOs as part of the monitoring process.
- Reports are not published in accessible formats.
- There is no clear monitoring process of the Coming Home Implementation Plan.

7. Quality standards

Are there legally enforceable standards about how care and support is provided?

Do these standards make sure people’s human rights are protected?

How many service providers have been found in breach of quality standards?

What is required

Disability support services must be available, accessible, acceptable, affordable and adaptable to disabled people.⁸⁸ All support services must be designed and delivered to support living within the community and to support full inclusion within the community.⁸⁹ States should make sure that all support services are based on ethical regulatory frameworks that reflect CRPD requirements.⁹⁰

What we found

The Health and Social Care Standards⁹¹ outline quality standards for public and private service providers. These standards are “taken into account by the Care Inspectorate, Healthcare Improvement Scotland and other scrutiny bodies in relation to inspections, and registration, of health and care services”⁹², however they are not legally enforceable in themselves i.e. a person cannot bring a legal claim if they believe a standard has been breached.

The standards cover all aspects of care provided in residential support from support and choice around medication, to fulfilling community living. The standards do, in some ways take a human rights approach, though no reference to the CRPD was found. Their standards include choice, participation, relationship building and meaningful integration explicitly, and Care Inspectors have required remedial action from service providers when evidence of these principles is not found. Care Inspectorate data could, however, explicitly use human rights generally, and Article 19 specifically, to transparently show the progress made.

In 2024, Care Inspectorate data showed 117 relevant services were required to improve provision in at least one area. This figure was 189 in 2022/23 and in 279 2021/22 giving a total of 585 since 2021.⁹³ It cannot be determined from the data whether people with learning disabilities and/or who are autistic were actually in residence during this monitoring, rather that the service was one which could have people with learning disabilities and/or who are autistic in residence.

Key gaps in implementation

- Health and Social Care Standards are not legally enforceable by individuals.
- CRPD requirements could be more explicitly outlined in quality standards.

8. Awareness of Support Services

Is there information or are programmes provided to make sure people with learning disabilities and/or who are autistic know about services that can help them live independently?

How much money is spent on this and how many people have taken part in programmes?

What is required

States should inform disabled people about their right to live independently and be included in the community in ways they can understand and provide training which empowers people to learn how to enforce their rights.⁹⁴

What we found

Our research could not find evidence or data against this indicator in relation specifically to those affected by Coming Home. We did not find evidence of, for example, accessible materials for people living in hospital about their right to independent living and necessary support, or clear information about what to do if someone’s rights are not being upheld.

Broader information, advice and advocacy related to independent living is provided in a range of ways:

- The Social Care (Self-directed Support) (Scotland) Act 2013 provides that Local Authorities have a duty “where it considers it appropriate to do so, to provide information about organisations and individuals who can provide independent advocacy services.”⁹⁵

- The Support in the Right Direction Fund provides local independent support, information, advice and advocacy around self-directed support, in line with Scottish Government’s Self-Directed Support Improvement Plan 2023-27.⁹⁶ 33 organisations across Scotland share £9.2 million of funding from the Scottish Government across a three-year period.
- DPOs, including Centres for Inclusive Living, provide information, advice, support and learning about independent living, many of which receive some Scottish Government funding.
- Independent advocacy is set out in law as a right for those coming within the definition of “mental disorder” in the Mental Health (Care & Treatment) (Scotland) Act 2003, which would include people with learning disabilities and/or who are autistic.⁹⁷ However, the Rome Review and the Scottish Independent Advocacy Alliance have both highlighted that this does not always happen in practice, with significant gaps in provision for these groups.⁹⁸

Key gaps in implementation

- We found no evidence of State efforts to ensure empowerment of those affected by Coming Home, such as accessible materials on independent living for people living in hospital or clear information about what to do if someone’s rights are not being upheld.
- There are known gaps in the provision of independent advocacy for people with learning disabilities and/or who are autistic.

9. Empowerment

Are there programmes and budgets in place to support with learning disabilities and/or who are autistic to build up skills required to live independently?

What is required

States should recognise that people who have not been allowed to make decisions about their living situation may not initially feel comfortable with being invited to live independently and should aim to help them overcome any barriers they experience in moving to the community.⁹⁹ A range of preparations for living in the community should be provided, including:


- Being provided with adequate time and opportunities to prepare physically and emotionally for living in the community
- Being respected as survivors to whom reparations are due, and being provided with information about and opportunities to participate fully in the planning and implementation of deinstitutionalisation, truth commissions and reparations [see further in the section on Access to Justice]
- Being offered a wide range of experiences in the community in preparation for leaving the institution, to help build their experience, strengths, social skills and life skills, remove fears and gain positive experiences of living independently
- Receiving information about housing options, transport, work and employment, individualised funding.¹⁰⁰

States should invest in peer support, self-advocacy, circles of support and other support networks – including organisations of

persons with disabilities, particularly those of survivors of institutionalisation – and centres for independent living. States parties should encourage the creation of such support networks, provide financial support and fund access to and the design of training in human rights, advocacy and crisis support.¹⁰¹

What we found

Our research could not find evidence against this indicator. Self-directed support guidance mentions “early planning for transitions” to ensure that “people are given the help and support they need to plan for, and adjust to, new phases of their lives”.¹⁰² There is no publicly available evidence of any programmes designed to provide this for this particular population aligned to the Coming Home Implementation Plan, and we are unable to establish the extent to which it happens or if it covers the particular requirements of the CRPD guidelines.

BB Within the Coming Home workstream, peer support was accepted as a way of sharing good practice. It emerged this was intended for professionals only. Having established a model of good practice myself, based on learning from other families, and other sources, I proposed a Peer Support group for people who use services, their families and supporters, facilitated by a government-funded secretariat. Our issues are distinct. 

Project Group Member, parent

The Scottish Government is taking forward plans to establish a Practitioner Support Network “to provide an informal group for people to share best practice”.¹⁰³ However, this is aimed at professionals and we can find no plans to facilitate and financially support peer support for disabled people and families affected by institutionalisation. Peer support networks of disabled people already exist in Scotland but our research found no evidence of efforts to facilitate and support them to provide peer support in the delivery of the Coming Home Implementation Plan.

Key gaps in implementation

- We found no evidence of plans to facilitate and financially support disabled people and families affected by institutionalisation. Peer support initiated by the Scottish Government focuses on professionals only.

10. Living arrangements

Does the law say people with learning disabilities and/or who are autistic have a right to choose where to live and who they live with?

Are there laws that might stop disabled people choosing where to live and who they live with?

How much budget has been allocated to provide living arrangements in the community and how many people do now live in the community?

What is required

The right to choose where to live and who to live with must be protected in law immediately.¹⁰⁴ States must change any laws, policies or practices which prevent this.¹⁰⁵ People must be able to choose support services based on their personal requirements and preferences.¹⁰⁶

What we found

The right to independent living is not currently enshrined in Scots Law. The Scottish Government has postponed plans to bring forward a Human Rights Bill which incorporates CRPD. The plans outlined to date would not require public authorities to comply with its provisions.¹⁰⁷

The Social Care (Self-Directed Support) (Scotland) Act 2003 provides a legislative route for people to choose how to direct their support to live independently. However, its implementation has been challenging. The Health, Social Care and Sport Committee has found that implementation of Self-Directed Support has been hampered by a range of factors, concluding that “the current

underlying system of social care delivery based on individual assessment, eligibility and transactional care contracts is incompatible with the principles of SDS.”¹⁰⁸

BB Scotland needs to incorporate the CRPD in full. Although not sufficient on its own, full incorporation would nevertheless provide a solid ground for driving deinstitutionalisation forward. The treaty requires the provision of accessible and affordable housing in the community, adequate personal assistance, peer support, and the development of supported decision-making systems as alternatives to substitute decision making. **99**

Project Group Member, academic

People can be placed in institutions by means of both the Mental Health (Care & Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000, which can override a person’s right to choose where and with whom to live. Restrictions are linked to the existence of a “mental disorder”, which includes learning disability and autism in the current definition.¹⁰⁹ While this has been the subject of debate and recommendations from both the Independent Review of Learning Disability and Autism in the Mental Health Act (the Rome Review) and the Scott Review, no change to the law has been confirmed.

Our findings on the money made available and the number of people now living in the community are reported at Section 1.

Key gaps in implementation

- The law does not protect the right to choose where to live and with whom. Various laws which apply to people with learning disabilities and/or who are autistic currently allow this right to be restricted.

11. Involvement in deciding where to live

Does the law make sure people can make decisions about where they live and with who?

Do people with learning disabilities and/or who are autistic get support to make that choice?

Is their choice listened to?

What is required

Disabled people must have the equal right to have choice and control over their own lives by choosing where, with whom and how they want to live and to receive support along with their will and preferences. They must be provided with support for decision-making if they need it. Their will and preferences must be respected and not overridden by others.¹¹⁰

What we found

66 So much of the Coming Home implementation work is about putting more processes and systems in place rather than working with someone to support them to express their will and preference and making it happen. 99

Project Group Member, Human Rights Defender

Supported decision-making has been recognised as in need of urgent development. The Scott Review highlighted the need to develop a comprehensive scheme of supported decision-making as a lynchpin of reforming mental health and incapacity laws.¹¹¹ Supporting decision-making and strengthening access to Independent Advocacy has been identified by the Scottish Government as a priority action following the Scott Review. The Scottish Government has committed to “map existing practices and next steps by end 2024.”¹¹² Until these practices are

developed and law reform takes place, mental health and incapacity laws allow for people’s decisions about where they live and with whom, to be overridden.

The Mission Statement of the Coming Home Implementation Plan highlights that decisions must be based on “individual and family choices” and that a placement away from a person’s home area is inappropriate if it does not “reflect the individual’s choice of community they want to live in”. It does not come with a legal obligation.

For people who are affected by Coming Home, our research could find no evidence of a specific protocol or process to be used which would ensure choice was available. Our researchers enquired about the existence of a mechanism of choice, based around the person’s will and preference, such as a pathway used to support people to choose where to live on leaving an institution, or to change arrangements if they do not meet their will and preference. They were not provided with any such mechanism, nor were they able to identify one.

The Social Care (Self-directed Support) (Scotland) Act 2013 ought to provide a framework for a process of decision-making led by the individual however it is unclear how this is being used in the process of moving people out of institutions.

Key gaps in implementation

- We found no evidence of specific procedures to ensure the process of moving out of institutions is based on the will and preference of the individual.
- Support for decision-making and adequate respect for the will and preference of the individual are outstanding matters to be addressed in mental health and capacity laws

Broader indicators

Some of the indicators look at broad issues in relation to the provision of all the components necessary to ensure independent living in the community. The original Coming Home report identified systemic issues such as the importance of developing commissioning and service planning, identifying suitable housing options and recruitment and retention issues in the social care workforce. These issues are recognised across the social care landscape and were explored in the Independent Review of Adult Social Care in Scotland (the Feeley Review).¹¹³ Proposals for a National Care Service were intended to provide a new approach to social care. This could develop a national approach to address these systemic issues, however, to date, the Bill provides little detail on the extent to which it will do so, and is unlikely to proceed as planned in the current session of Parliament.

It was beyond the scope of this research to explore these wider issues with the provision of social care; however, we have highlighted what CRPD requires of them and any information of particular importance in relation to the Coming Home Implementation Plan and those affected by it.

12. Access to support services

What kind of support is there to live independently? Is it provided for in law?

Does it cover everything disabled people need to live at home?

Do carers get support services?

What is required

Disability support services must be available, accessible, acceptable, affordable and adaptable to disabled people.¹¹⁴ Access to support services should not be limited by “supply” and there should be the option of designing new forms of support.¹¹⁵ Deinstitutionalisation processes should comprehensively map existing community-based services and identify where there is a need to develop new services.¹¹⁶

What we found

There is a legal framework for the provision of supports in the community, including the Social Care (Self-directed Support)(Scotland) Act 2013.

Our research did not find evidence of a comprehensive mapping exercise of community-based services which identifies key gaps for people described in the Coming Home Implementation Plan. Development of community-based support was delegated to health and social care authorities as part of the Community Living Change Fund. Processes for mapping will therefore vary across authorities.

Use of the Fund is reported on at Section 1.

Key gaps emerging:

- Given our findings in relation to use of the Community Living Change Fund, evidence of how comprehensive mapping of services is taking place should be made available.

13. Transferability of support services

Can people move their support to other parts of the country?

What is required

People must have the same amount of choice and control over their lives as other members of the community. Person-led support means that support services must be controlled by the disabled person, including deciding where they live and receive support services.¹¹⁷

This includes the ability to decide to change support services in accordance with their will and preferences.

What we found

Our research could not find data relating to how many people have requested transfer or whether transfers have been permitted or refused. This information should be gathered and published.

14. Eligibility for community support services

Are there legal restrictions on eligibility to receive community support services?

What criteria are they based on?

Can they be challenged and how many are overturned?

What is required

Eligibility for community support services should focus on the requirements of the person to overcome barriers in society rather than their impairment.¹¹⁸ No one should be excluded from being able to receive community support because of the kind and amount of support services required i.e. that their needs are too high.¹¹⁹

What we found

Research on eligibility criteria and their application in practice is beyond the scope of this research. All those who require to be discharged from hospital under the Coming Home Implementation Plan are identified as having a high level of “need” and would therefore be likely to qualify under eligibility criteria. It should also be considered what the criteria are for determining that a person can no longer live in the community because their support needs are considered too high, however, this is outwith the scope of this research.

15. User control

Does the law say that decisions about how support is provided are made by people with learning disabilities and/or who are autistic themselves?

Does it provide that carers can also do this for their own support?

What is required

A person-centred process should be used to identify the range of support that a person may need to live independently, using self-assessment tools. Medical professionals should not have higher status in assessments or any decision-making power over disabled people.¹²⁰

What we found

The law does recognise the rights of disabled people and carers to determine their own support in the Social Care (Self-directed Support)(Scotland) Act 2013 and the Carers (Scotland) Act 2016.

It is beyond the scope of our research to assess how this operates in practice, however, a group of 24 DPOs have pointed out that “There is no reference [in the Coming Home Implementation Plan] to independent advocacy, supported decision-making or Self-Directed Support, key mechanisms for supporting choice and control for those drawing on social care support.”¹²¹

A range of independent reports have identified significant issues in the implementation of Self-Directed Support in practice.¹²² Most recently, the Scottish Parliament’s Health, Social Care and Sport Committee carried out post-legislative scrutiny and found that implementation of

Self-Directed Support has been hampered by a range of factors, concluding that “the current underlying system of social care delivery based on individual assessment, eligibility and transactional care contracts is incompatible with the principles of SDS.”¹²³

16. Informal support

Does the law recognise informal supports in the community?

How much budget and training are provided to informal supports?

What is required

Disabled people can choose that the support they have for living independently is provided informally, for example, by families, support persons and peer support.¹²⁴ It does not have to be provided by a formal service. States should recognise these types of support and provide training and support for them to exercise their role in a way that respects the will and preferences of the disabled person themselves.¹²⁵

What we found

Informal community support is legally recognised through the Carers (Scotland) Act 2016, and the Social Care (Self-directed Support)(Scotland) Act 2013. They provide a framework to assess and provide the support needed for carers, including information and advice.

Our research did not find data relating to this indicator. It is beyond the scope of our research to assess the extent to which this is provided in practice, or how much it emphasises the requirements of CRPD.

17. Access to justice

Have apologies, truth and reconciliation, public awareness-raising, compensation and guarantees that institutionalisation will not happen again taken place?

66 The traumatic impact of institutionalisation is life-long and should never be underestimated. Serious consideration must be given by the Scottish Government to a truth process (as detailed in the CRPD) for people with learning disabilities and their families. Their lives have been badly scarred by society’s failure to respond to their needs appropriately. This must be addressed at the highest levels and their stories must be heard. **99**

Project Group Member, civil society

Our findings show the lack of progress for many in being supported to live independently in the community. The impact of ongoing institutionalisation on those who have had to experience it – people with learning disabilities and/or who are autistic and their families – must be recognised. Since the indicators we have used were developed, the CRPD Committee’s Guidelines have provided additional detail of the steps needed to right the wrongs caused by institutionalisation, by providing remedies, reparations and redress.¹²⁶ They require Governments, working with disabled people, to provide:

- A mechanism for redress, which would identify and raise awareness about the harm caused by all forms of institutionalisation and recommend changes in law and policy;
- Ways for disabled people to seek redress and reparations, including rehabilitation;
- A mechanism to provide formal apologies to survivors of institutionalisation, negotiated with people who have experienced it;
- Automatic compensation to survivors for damage caused;
- Guarantees that institutionalisation will not happen to people again;
- Truth commissions to investigate and promote public understanding of all forms of institutionalisation and the harm caused.

Key gaps in implementation

- None of the required reparations, remedies or redress have been established either in relation to the Coming Home Implementation Plan or the previous hospital closure programmes undertaken in Scotland.

A human rights based approach?

There are many places where the implementation of Coming Home reveals an absence of human rights standards. While there is repeated discussion of taking a human rights-based approach, in the Coming Home Implementation Plan and in the Guidance on use of the Community Living Change Fund, including mention of the Article 19 Right to Independent Living, there is no detail on what this requires. This report has now provided a framework to apply.

Unfortunately, this is not merely a question of missing words in a policy document. We see this play out in several ways – in an absence of information about who is even in an institution, in the lack of evidence of participation in processes by survivors of institutionalisation and, most concerning, in the spend of funds which should be used to end institutions instead being used to refurbish or repurpose institutions. This demonstrates why it is essential, when talking about human rights, not to stop at the general term, but to be specific about which rights to focus on and, crucially, what they require and what they prohibit. This is what is required to meaningfully guide duty bearers and individuals alike in their decision-making.

In the Coming Home Implementation Plan, the Scottish Government identify the PANEL principles – Participation, Accountability, Non-discrimination, Empowerment and Legality – as the basis for a human rights-based approach. There are gaps across all these areas on the work of Coming Home, however the principles of Accountability and Legality stand out as particularly lacking. This is not uncommon, however, the failures

identified demonstrate how important it is that work is grounded in concrete human rights standards, specifically the CRPD Committee’s guidance on independent living and deinstitutionalisation (Legality). They also demonstrate the importance of monitoring and accountability when standards are not being upheld.

Our findings on the use of the Community Living Change Fund reflect the importance of employing human rights budgeting as part of a human rights-based approach. Human rights budgeting uses human rights standards and principles to develop a budget.¹²⁷ In this context, it would ensure that the Community Living Change Fund was accompanied by clear direction about how it would be spent in a way that advances CRPD requirements. It would also analyse and provide accountability for how the money was, in fact, spent. The Commission has produced information on this, available on the [Human Rights Budget Work](#) page of our website at www.scottishhumanrights.com.

Data

The exercise of human rights measurement has been severely restricted by the data available, none of which is aligned with human rights indicators.

The lack of definition of what are or are not institutional living arrangements means that it is not even possible, at this stage, to be clear about the starting point for deinstitutionalisation plans. Without this data, any exercise in addressing deinstitutionalisation is hampered from the start. This gap also falls short of basic minimum core requirements of the right to independent living which require the State to collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions.

The research we commissioned identifies a number of areas in which existing data could be improved to better reflect human rights issues and to enable easier measurement. In particular, it highlights the lack of transparency and accessibility of information regarding the Community Living Change Fund. In summary, our research recommends that:

“There is a clear need for increased transparency of data relating to the deinstitutionalisation process, and of the people who continue to be impacted. This data should be collected and published using defined human rights indicators. The use of public funds to support this process should be made transparent, and again be measured using human rights indicators.”¹²⁸

Some of the available data specifies whether it concerns people with learning disabilities, but **autistic people are much harder to identify**. For example, it is not possible to clearly identify autistic people among the

data on hospital admissions and length of stay. While there may be people with learning disabilities who are also autistic, this level of disaggregation is important in order to ensure deinstitutionalisation processes are suitably tailored to the needs of those affected and is supported by the requirements of Article 31 CRPD.¹²⁹

BB Autistic people are overly represented in these settings, although the extent is not known, and many are undiagnosed due to diagnostic overshadowing and a lack of current autism understanding. Needs are often not met, with communication and stress responses misinterpreted. These behaviours are then “treated” inappropriately by over-medicating and/or behavioural interventions based on neurotypical norms to make others’ lives easier, rather than what is important for meeting rights and a good life for the autistic person. **99**

Project Group member, parent

Recommendations

The Commission is empowered by our legislation to review and recommend changes to any area of the law of Scotland, or any policies or practices of any Scottish public authorities.¹³⁰

Our recommendations are grounded in the CRPD Committee guidelines and address areas where our research identifies significant gaps between human rights standards on deinstitutionalisation and the measurable progress made under the Coming Home Implementation Plan.



Urgent action

The Scottish Government should urgently develop a fresh action plan to deliver the outstanding commitment of Coming Home. It must be concretely grounded in the CRPD Committee’s guidelines and address all components of deinstitutionalisation, including mechanisms of redress.

The deadline set by the Coming Home Implementation Plan passed many months ago. It is clear that the Mission Statement has not been delivered. We cannot identify any material change in remedying the issue of people who become stuck in hospital when what they need is independent support in the community. This was, and remains, unacceptable. We know that the Scottish Government has expressed the same sentiment, but the situation cannot be allowed to continue. A new plan is urgently needed. This time, it must be grounded in the CRPD requirements on independent

living if it is to avoid the same mistakes. It must address each component of the right to independent living and the requirements of deinstitutionalisation. It must take action to provide access to justice to survivors of institutionalisation by providing the mechanisms of redress outlined by the CRPD guidelines.



Accountability

We recommend that the Scottish Government designate an independent mechanism to monitor progress on achieving deinstitutionalisation under a new action plan. The mechanism should ensure the meaningful participation of disabled people, especially people who have experienced institutionalisation.

Our research highlights a lack of accountability in ensuring that the goal set by Scottish Government in the Coming Home Implementation Plan was met, that the Community Living Change Fund met its goals and that it did not invest in institutional care. There is no clear actor responsible for ensuring that any of the work met its stated intention of taking a human rights-based approach or adhered to the clear standards applicable under Article 19 CRPD.

Monitoring could be carried out by an existing independent monitoring body or by a mechanism established for this particular function. However constructed, it must ensure that disabled people and those affected by institutionalisation are fully embedded in its operation.



Human rights measurement

We recommend that the Scottish Government employ measurable human rights indicators and concrete benchmarks in all further work on Coming Home, forensic patients and deinstitutionalisation.

We recommend that regulators and data collection agencies ensure their measurement and data frameworks explicitly reflect human rights requirements. In particular, they should ensure that institutional care, as defined by CRPD, is identifiable.

Human rights measurement is essential in order to effectively implement deinstitutionalisation measures. Tracking progress will assist the Scottish Government and other duty bearers to be transparent, demonstrate a meaningful commitment to human rights, and identify gaps. It will also assist rights holders to be empowered to participate in processes and to have confidence in the Scottish Government's actions.

Both work to address deinstitutionalisation and monitoring of that work by regulators must clearly identify where institutional care is or may be taking place to enable closer scrutiny and planning to address outstanding human rights breaches.



Publishing information on how money is spent

We recommend that the Scottish Government publish an account of how the Community Living Change Fund was spent in all Health and Social Care Partnerships across the funded period 2021-2024. This should include what the fund was spent on and identify whether the areas in which it was spent constitute independent living support services in terms of CRPD guidance.

We recommend that this evidence is scrutinised by Audit Scotland and/or the Public Audit Committee in 2025.

The lack of transparency in relation to the Community Living Change Fund is very concerning, especially as it appears that some of the spend has been in contravention of CRPD guidelines. There are limitations to our data collection which mean that there may have been further spend which we were unable to uncover. Publication by the Scottish Government would demonstrate its commitment to being accountable to disabled people and upholding a human rights based approach.

Commitments to develop and implement a human rights budgeting approach to raising, allocating, and spending public money are essential at all levels of government and public accountability.

A human rights budgeting approach, as advocated for by the Commission, and committed to by the Scottish Government, actioned through our membership of and recommendations from the Equality and Human Rights Budgets Advisory Group, must underpin the raising, allocation, and evaluation of spend of public resources. Without a clear understanding of the

obligation to comply with rights realisation built into public finance decision making, policy objectives will continue to be undermined, and the everyday rights of people disregarded, especially those most marginalised such as people with learning disabilities and/or who are autistic.



Forensic patients

We recommend that a specific plan of action be made to identify and address the situation of forensic patients who have been excluded from the scope of the Coming Home Implementation Plan. The plan should be grounded in the CRPD Committee’s deinstitutionalisation guidelines and respond to the recommendations of the Barron review.

The Coming Home Implementation Plan does not cover people who are in forensic learning disability services, however, we know that this group face disproportionately long periods of time in secure forensic settings and are sometimes placed in conditions of greater security than are required to manage their risks.¹³¹ These issues were acknowledged by the Barron Review in 2021, which made a series of recommendations about how to address the excessive lengths of time for accommodation or support

packages to support discharge of forensic patients. It made specific recommendations about how to address the particular needs of people with learning disabilities and recommended a needs assessment to ensure appropriate support for people with “neurodevelopmental disorders”. These recommendations have not been implemented. People in forensic settings are subject to the highest degree of restrictions on their human rights and their situation must be scrutinised and addressed with a corresponding level of priority.

“All existing evidence and approved public policy are agreed that no good outcome is achieved for any person with autism and challenging behaviour, including those with forensic histories, through prolonged detention in psychiatric facilities (the use of which should be restricted to short-term, focussed periods of treatment). Not only is it therefore deeply troubling that such people continue to be detained in The State Hospital without limit of time, but their additional exclusion from the processes associated with the Coming Home report is without any credible or humane rationale.”

Project Group Member, social care expert



Law reform

We recommend that the Scottish Government outline, within three months of this report, a clear timeline for the replacement of the Mental Health (Care & Treatment) (Scotland) Act 2003 with updated legislation which complies with CRPD.

We recommend that the Scottish Government urgently clarifies its intention around incorporating CRPD, particularly Article 19 in its ongoing work to develop a Human Rights Bill to introduce in the next session of the Scottish Parliament, and propose the strongest possibly duty, within the limits of devolved competence, for public authorities to comply with the right to independent living.

We recommend that the Scottish Government identify, by Summer 2025, the quickest legislative vehicle to establish a National Support Panel with statutory powers.

There are three significant weaknesses in the legal framework which limit the realisation of the right to independent living for people with learning disabilities and/or who are autistic. First, the right itself, in terms of Article 19 CRPD is not enforceable in law, resulting in people having very few routes to challenge their situation when they become stuck in hospital. The Scottish Government

must urgently consider routes to remedy this, within the limits of devolved competence, ensuring that the right to independent living is accompanied by the strongest possible duty, namely a duty to **comply**.

Secondly, mental health and incapacity law, as it stands, permits the detention of people with learning disabilities and/or who are autistic, by reason of learning disability. It also fails to provide the structures to ensure supported decision-making is the foundation for all decisions about the lives of people with learning disabilities and/or who are autistic. This has been explored in detail by the Scottish Mental Health Law Review and a law reform programme is underway. We accept that the Scottish Government has committed to reach a position on the definition of mental disorder e.g. whether ‘learning disability’ should be removed, by some time in 2024. However, the key exercise of replacing existing mental health law with a CRPD compliant model is envisaged as a long-term project stretching past 2029.¹³² Our research suggests a much greater degree of urgency.

Thirdly, there is a lack of oversight of the individual situations of people stuck in hospital. The National Support Panel recommended by the Coming Home Implementation Plan could, with the requisite powers, provide this scrutiny. There are various vehicles for this, including in the proposed Learning Disability, Autism and Neurodivergence Bill, the proposed Human Rights Bill and the proposals for a Disability Commissioner.

All of these pieces of legislation are either uncertain, postponed or will take many years. The priority should be to take clear and purposeful action **soon**, therefore we call on the Scottish Government to address these gaps in the law to the greatest extent possible as each piece of legislation makes its way to Parliament.

“If the Scottish Government are serious about their Coming Home commitment, they need to urgently remove learning disability from the definition of ‘mental disorder’ and establish a full system of Supported Decision-Making to give us choice and control over our own life. Detaining us because of a failure to support us in the community is a breach of our human rights and a breach of the United Nations Convention on the Rights of Persons with Disabilities.”

Project Group Member, Human Rights Defender



A wider deinstitutionalisation plan

We recommend that the Scottish Government immediately commence development of a concrete action plan to replace any institutionalised settings with independent living support services across all settings in Scotland. Planning should comply with the CRPD Committee’s guidelines on deinstitutionalisation.

Article 19 applies to all institutions and the requirement is for the State to have a deinstitutionalisation plan covering all institutions. Our research shows a lack of focus on identifying and measuring institutionalisation, where it is not even possible to clearly identify what is and is not considered an institution. This shows that Scotland is falling far short of the requirements of Article 19.

“Deinstitutionalisation in Scotland should not stop at delayed discharges and remote placements. Institutionalisation of disabled people in small institutions, boarding schools, nursing homes and the like should also be tackled. None of these forms of institutional care is compliant with the CRPD.”

Project Group Member, academic



Better use of human rights

The Scottish Government should publicly commit to following all guidance issued by the CRPD Committee in ongoing work on this area. In particular, it should commit to follow the CRPD Committee’s Guidelines on Deinstitutionalisation.

A human rights-based approach means embedding human rights in all areas of law, policy and practice. Each of our recommendations identify steps that must be explicitly grounded in human rights standards. It is crucial that all action in this area spells out in detail the implications of human rights standards and how they are being employed. As work to progress the Learning Disability, Autism and Neurodivergence Bill continues to be explored, it should make explicit reference to CRPD, in particular to General Comments and guidance from the Committee. It is there that concrete requirements can be found which can ensure the work adheres to each specific step required to uphold human rights.



Remedies, reparations and redress

The Scottish Government should scope a set of mechanisms to provide all components of remedies, reparations and redress outlined by the CRPD Committee’s Guidelines on Deinstitutionalisation. Scoping should take place by the end of this Parliamentary session (2026) with a clear timeline for implementation thereafter.

The harms caused by institutionalisation in Scotland, both past and present, have not been addressed in the terms set out by the CRPD Committee. Apologies, truth and reconciliation, public awareness-raising, compensation and guarantees that institutionalisation will not happen again have not taken place.

Conclusion

66 Historically, Scotland has consistently failed children and adults with learning disabilities and this shameful legacy has yet to be addressed. Until relatively recently, institutionalisation was the default option for people with learning disabilities, despite it leaving them vulnerable to abuse and its complete inability to meet their fundamental human rights.

Whilst significant progress has been made over the last 30 years to close our large institutions, this report demonstrates that far too many people with learning disabilities in Scotland are subject to inappropriate hospitalisation and institutionalisation. In fact, we have not learned the lessons from the past and we persist in building and funding institutions in Scotland despite the lack of evidence of any positive outcomes for people. Institutionalisation is detention.



Project Group Member, civil society

Human rights measurement asks us to assess the commitment of the State, its efforts and, crucially, its results. It is clear that the Coming Home Implementation Plan began with a clear commitment to remedying the serious human rights concerns affecting people with learning disabilities and/or who are autistic who found themselves stuck in hospital. There is evidence of efforts in some of the areas required, such as budget allocated to realise the commitment, in the Community Living Change Fund. However, as we delve into many of the other efforts required, we find that they are lacking. We see this in the failure to meet the target committed to, in the lack of follow-up on the use of the Community Living Change Fund, in the lack of CRPD training provided to personnel working in this area. Moreover, when we examine results, we find a distressing lack of change. The numbers of people still forced to live in institutions and the excessive amount of

time they spend there do not seem to have materially improved. However, a look across the gaps we have identified demonstrates all that is still needed to provide the building blocks of making a real and permanent shift from institutions to independent living.

We set out to discover if it was possible to find out what had happened during the Coming Home Implementation Plan using a clear means of measurement, namely human rights measurement. The frustrating answer is that it is not possible to carry out full measurement based on the available information. We have identified failures to meet even the minimum core requirements of the right to independent living by collecting data on who lives in institutions, the basis on which any plan must be built.

Even so, our research demonstrates that employing human rights measurement,

even partially, provides clear evidence of the gap between rhetoric and reality. It also demonstrates the potential of using clear indicators to underpin work to deliver people’s human rights. While we welcome commitments from duty bearers to take a human rights-based approach, the value of the approach is stripped of meaning if it does not concretely engage with what human rights standards say must be done. A framework of indicators and measurement can help to redress this balance and provide Scottish Government and all duty bearers with a clear outline of what good looks like, and how to know when they have achieved it.

We have now provided this, and encourage the Scottish Government and all actors, particularly duty bearers, to use it to plan and measure change. We will continue to monitor this as part of our monitoring role under CRPD and ensure that progress is reported into the UN CRPD Committee to assess Scotland’s implementation of human rights.

We have also made recommendations in respect of the scope and scale of the programme of work required.

Of particular concern is activity we have evidenced which indicates direct violations of Article 19 CRPD, and also serious concerns about potential violations of ECHR obligations enshrined in the Human Rights Act 1998. Whilst this is outwith the scope of this research and may be the focus of further work from the Commission, it points to the need for urgent law reform to remove the opportunity for ‘lawful’ detention that is a result of the state’s inability to provide community-based support, rather than genuine clinical need. European case law is increasingly clear on this point, and we would encourage the Scottish Government to consider urgent action, to prevent the need for individuals to bring their own legal challenge.

Annex 1: Human rights indicators

The human rights indicators used for this research were adapted from those developed by the European Union Agency on Fundamental Rights (FRA).¹³³ Duty bearers are now invited to use this Framework to guide a human rights based approach to ending institutionalisation in Scotland.

All indicators are to be applied to the specific cohort of people who fall within the scope of the Coming Home work. This is defined as: “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.”¹³⁴ The indicators are therefore to be measured for that group, rather than for disabled people as a whole.

Article 19: Cross-cutting provisions

Article 19 can be approached as an overarching goal of the CRPD. Reflecting this, these indicators draw on other key themes of the Convention, with a specific focus on different elements of participation and the extent to which persons with disabilities are involved in decision-making processes.

Action plans/ strategies

Structural indicators	Process indicators	Outcome indicators
Does the State have a strategy/action plan in place which includes measures for the transition from institutional care to community-based support?	How much budget has been allocated, annually since 2018, for the implementation of the strategy/action plan?	N/A
Do the measures take a human rights approach (with reference to the CRPD Committee’s guidelines on deinstitutionalisation (2022))?	Have the targets in the strategy/action plan been met?	
Does the strategy/action plan set out particular actions for specific age groups? (if so, which?)		
Does the strategy/action plan set out concrete targets and a timeframe in which they are to be met?		
Is there a mechanism in place to monitor the implementation of the strategy/action plan?		

Disabled persons organisations (DPO) involvement

Structural indicators	Process indicators	Outcome indicators
<p>Does the State have mechanisms in place to ensure the consultation and involvement of persons with disabilities, irrespective of age and type of impairment, and through DPOs, in the:</p> <ul style="list-style-type: none"> • design, • development, and • implementation and monitoring <p>of laws and policies relating to Coming Home?</p>	<p>How many DPOs have been consulted and involved in the design, development, and implementation and monitoring of laws and policies which affect them, annually since 2018?</p> <p>Of the disabled persons and DPOs involved,</p> <ul style="list-style-type: none"> • How many have direct experience of leaving institutions/are survivors of institutionalisation? <p><i>Provide information by age, race, type of impairment and gender</i></p> <p>How much budget has been available, annually since 2018, to ensure the consultation and involvement of persons with disabilities, through DPOs, in the design, development, and implementation and monitoring of laws and policies which affect them?</p>	<p>N/A</p>

Quality standards

Structural indicators	Process indicators	Outcome indicators
<p>Are there legally enforceable quality standards for public and private service providers, providing care, treatment or support either in hospital or in the community?</p> <ul style="list-style-type: none"> • What service areas do these standards cover for example, health, social care, protection from violence etc.? • Are there guidelines on how to enforce quality standards for public and private providers of specialised and general services? <p>Do the guidelines take a human rights approach (refer to the CRPD)?</p>	<p>How many DPOs have been consulted and involved in the design, development and implementation of quality standards, annually since 2018?</p>	<p>N/A</p>
<p>Are there independent mechanisms in place to monitor the implementation of quality standards?</p>	<p>How many DPOs have been consulted and involved in monitoring the implementation of quality standards, annually since 2018?</p> <p>How many service providers have been found in breach of quality standards annually since 2018?</p>	<p>N/A</p>

Training/Retraining

Structural indicators	Process indicators	Outcome indicators
<p>Is training on the CRPD required by law for the following personnel working in the Coming Home sphere:</p> <ul style="list-style-type: none"> • public officials, • social workers, • health professionals, • education professionals, and • other service providers? <p><i>Is it mandatory?</i></p> <p>Is training on the CRPD integrated into professional training courses/curricula for providers of specialised and general services?</p> <p><i>Is it mandatory?</i></p>	<p>How many:</p> <ul style="list-style-type: none"> • Public officials • Social workers • health workers, • education workers, and • other service providers <p>working in the Coming Home sphere, have undergone training on the CRPD, annually since 2018?</p> <p>Are persons with disabilities, including children, and DPOs involved in the:</p> <ul style="list-style-type: none"> • design, and • provision <p>of training?</p>	<p>N/A</p>
<p>Is there a requirement for staff of residential institutions to undergo retraining prior to working in community-based services?</p> <p><i>Is it mandatory?</i></p>	<p>How many staff of residential institutions have undergone training prior to working in community-based services, annually since 2018?</p>	<p>N/A</p>
<p>Is training on the CRPD available for informal carers?</p>	<p>How many informal carers have undergone training on the CRPD, annually since 2018?</p>	<p>N/A</p>

Awareness of support/services

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal requirement that information about public and private support services to live independently is accessible to persons with disabilities, irrespective of age and impairment?</p>	<p>N/A</p>	<p>N/A</p>
<p>Are there measures or programmes in place to increase persons with disabilities’ awareness of available support and services to live independently, irrespective of age and impairment?</p>	<p>How much budget has been allocated, annually since 2018, to measures and programmes to increase persons with disabilities’ awareness of available support and services to live independently?</p> <p>Are DPOs involved in the:</p> <ul style="list-style-type: none"> • development • delivery <p>of these measures and programmes?</p>	<p>How many persons with disabilities have taken part in such trainings/programmes?</p> <p><i>Provide information by age, race, type of impairment and gender</i></p>
<p>Are there measures or programmes in place to increase the awareness of service providers about the right of persons with disabilities to live independently, irrespective of age and impairment?</p>	<p>How much budget has been allocated, annually since 2018, to measures and programmes to increase the awareness of service providers about the right of persons with disabilities to live independently?</p> <p>Are DPOs involved in the:</p> <ul style="list-style-type: none"> • development • delivery <p>of these measures and programmes?</p>	<p>N/A</p>

Empowerment

Structural indicators	Process indicators	Outcome indicators
Are there programmes in place to support persons with disabilities to build up skills required to live independently	How much budget has been allocated, annually since 2018, to organisations which support persons with disabilities to develop independent living skills?	How many persons with disabilities have received support to develop independent living skills, annually since 2018?
Is peer support/counselling by and for persons with disabilities recognised in legislation?	How many persons with disabilities act as peer supporters/counsellors, annually since 2018?	N/A

Monitoring

Structural indicators	Process indicators	Outcome indicators
<p>Is monitoring of publicly and privately provided services for persons, including children, with disabilities provided for in law?</p> <ul style="list-style-type: none"> • Does the legal provision stipulate how often monitoring must take place? • Is the monitoring independent of government and service providers? • Is there a legal requirement to make monitoring reports and other information publicly available? • Are the recommendations of the monitoring mechanisms legally enforceable? • Are there mechanisms in place to ensure the involvement of persons with disabilities, irrespective of age and impairment, and DPOs in the monitoring process? 	<p>How many DPOs have been involved in the monitoring of publicly and privately provided services for persons with disabilities?</p> <p>Are the monitoring reports published, including in accessible formats?</p>	N/A

Complaints/Redress

Structural indicators	Process indicators	Outcome indicators
<p>Are there independent judicial and/or non-judicial mechanisms and remedies that persons with disabilities can use to challenge barriers to exercising the right to live independently?</p> <ul style="list-style-type: none"> • Are all persons with disabilities legally able to directly access these mechanisms and remedies, irrespective of legal capacity status? • Is there a duty to provide procedural and age-appropriate accommodations in all stages of the complaints process? 	<p>How many complaints have been received by judicial and/or non-judicial complaints mechanisms and remedies annually, since 2018, regarding barriers to exercising the right to independent living?</p> <ul style="list-style-type: none"> • How many of these cases were considered admissible? <p><i>Provide information on type of complaint for example, type of impairment, age, living arrangements, support services, general services</i></p> <p>Is support available to persons with disabilities who may wish to use judicial and/or non-judicial complaints mechanisms and remedies addressing barriers to exercising the right to live independently?</p> <ul style="list-style-type: none"> • Support includes: advocacy services, legal aid, peer support etc. <p>Is information on judicial and/or non-judicial complaint mechanisms and remedies accessible to persons with disabilities, irrespective of age and type of impairment?</p>	<p>N/A</p>
<p>Are there measures in place to increase persons with disabilities’ awareness of judicial and/or non-judicial complaints mechanisms and remedies addressing barriers to exercising the right to live independently?</p>	<p>How much budget has been allocated, annually since 2018, to measures to increase awareness of judicial and/or non-judicial complaints mechanisms and remedies addressing barriers to exercising the right to live independently?</p>	<p>How many persons with disabilities have participated, annually since 2018, in awareness-raising programmes on judicial and/or non-judicial complaint mechanisms and remedies?</p>

Article 19(a): Living arrangements

Article 19 (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

These indicators focus on the principles of ‘on an equal basis’ and ‘opportunity to choose’, while also taking into account questions of accessibility and affordability.

Living arrangements

Structural indicators	Process indicators	Outcome indicators
<p>Are there legal provisions recognising the right of persons with disabilities, irrespective of age and impairment, to choose their place of residence and where and with whom they want to live on an equal basis with others?</p> <ul style="list-style-type: none"> • Are there legal restrictions on the right of persons with disabilities to choose where and with whom to live? • Are the restrictions linked to age or impairment? <p><i>Provide information by type of impairment, level of support needs, age, gender</i></p>	<p>How much budget has been allocated, annually since 2018, for providing living arrangements in the community?</p>	<p>What is the proportion, annually since 2018, of persons with learning disabilities and/or who are autistic living in:</p> <ul style="list-style-type: none"> • private households • social housing <p>compared to the general population?</p> <p><i>Provide information by type of impairment, level of support needs, age, gender</i></p>

Institutions

Structural indicators	Process indicators	Outcome indicators
<p>Are there legal provisions that allow for involuntary admission to institutions on the basis of the existence of an impairment?</p> <ul style="list-style-type: none"> • Are these provisions tied to age or type of impairment? 		<p>How many people have been involuntarily admitted into institutions annually since 2018?</p> <p><i>Provide information by type of impairment, level of support needs, age, gender</i></p>
<p>Has the State committed to:</p> <ul style="list-style-type: none"> • Shut down residential institutions? • Stop new admissions to residential institutions? • Not to build new residential institutions? <p><i>Provide information on the source of the commitment i.e. in law or policy</i></p>	<p>How much budget has been allocated, annually since 2018, to support persons with disabilities, irrespective of age or impairment, to move from an institutional setting to a living arrangement of their choice?</p>	<p>How many persons with disabilities were living in residential institutions annually since 2018?</p> <p><i>Provide information by type of impairment, level of support needs, age, gender</i></p>
<p>Is there a defined legal limit on the maximum number of users that could be accommodated in a particular type of institution?</p> <ul style="list-style-type: none"> • Does the limit vary according to age or type of impairment? 		<p>How many places were there in residential institutions annually since 2018?</p> <p><i>Provide information by type of impairment, level of support needs, age, gender</i></p> <p>How many persons with disabilities have been admitted to residential institutions annually since 2018?</p> <p><i>Provide information by type of impairment, level of support needs, age, gender</i></p>

Involvement in deciding where to live

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal obligation to consult persons with disabilities, irrespective of age and impairment, in decisions about their place of residence and where and with whom they want to live on equal basis with others?</p> <ul style="list-style-type: none"> • Is support available for persons with disabilities to choose where and with whom to live? <p>Are mechanisms in place to ensure that the person’s will and preferences are taken into account in deciding where and with whom to live, irrespective of age and type of impairment?</p>	N/A	N/A

Article 19(b): Support services

Article 19 (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

Support, choice and control, and inclusion and participation are the core elements of Article 19(b). These aspects are reflected throughout the indicators.

Access to support services

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision setting out a right for persons with disabilities, irrespective of age and type of impairment, to receive community support services to live independently?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> • personal assistance; • residential; • in-home; • others (informal support, peer support, day care, voluntary work, etc.) • number of hours provided; • type of services; • spheres of life (that is, in-home, access to leisure and cultural activities, access to medical services, employment, education etc.) 	<p>How much budget has been allocated, annually since 2018, for community support services to live independently?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> • personal assistance; • residential; • in-home; • others (informal support, peer support, day care, voluntary work etc.)? <p><i>Provide information by type of support service</i></p>	<p>How many persons with disabilities were using some type of community support service to live independently, annually since 2018?</p> <p><i>Provide information by type of support service, type of impairment, level of support needs, age, gender</i></p>

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision setting out a right for informal carers of persons with disabilities to receive support services, irrespective of type of impairment?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> • family support (counselling, respite care, early intervention); • residential; • in-home; • others (informal support, peer support, day care etc.) <p>Does the legal provision specify the scope of support services? For example:</p> <ul style="list-style-type: none"> • number of hours provided; • type of services; • spheres of life (that is, in-home, access to leisure and cultural activities, access to medical services, employment, education etc.) 	<p>How much budget has been allocated, annually since 2018, for informal carers of persons with disabilities?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> • family support (counselling, respite care, early intervention); • residential; • in-home; • others (informal support, peer support, day care etc.) <p><i>Provide information by: type of support service</i></p>	<p>How many informal carers of persons with disabilities received some type of family support services, annually since 2018?</p> <p><i>Provide information by: type of support service, type of impairment, level of support needs, gender</i></p>
<p>Is there a legal provision setting out a right for persons with disabilities, irrespective of age and impairment, to receive personal budgets/direct payments?</p> <p>Does the legal provision setting out personal budgets/direct payments specify the scope of services that can be purchased, for example:</p> <ul style="list-style-type: none"> • number of hours provided; • type of services; • spheres of life. 	<p>How much budget has been allocated, annually since 2018, for personal budgets/direct payments?</p>	<p>How many persons with disabilities received personal budgets/direct payments, annually since 2018?</p> <p><i>Provide information by: type of impairment, level of support needs, gender</i></p>

Transferability of support services

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision allowing for community support services to be transferred across different administrative regions?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> • personal assistance; • residential; • in-home; • others (informal support, peer support, day care, voluntary work, etc.) <p>Can personal budgets/direct payments be transferred across different administrative regions?</p>	<p>Are the procedures for requesting transferring of community support services accessible for all persons with disabilities, irrespective of age and impairment?</p> <p>Is assistance in completing administrative requirements available during the process of requesting transferring of support?</p>	<p>How many persons with disabilities have requested, annually since 2018, transfer of community support services to a different administrative region?</p> <p>How many of these requests have resulted in support services being transferred?</p>
<p>Is there a legal provision allowing for support services for informal carers of persons with disabilities to be transferred across different administrative regions?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> • family support (counselling, respite care, early intervention); • residential; • in-home; • others (informal support, peer support, day care etc.) 	<p>N/A</p>	<p>How many informal carers of persons with disabilities have requested, annually since 2018, transfer of support services to a different administrative region?</p> <p>How many of these requests have resulted in support services being transferred?</p>

Eligibility for community support services

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision that stipulates restrictions on eligibility for community support services based on certain criteria?</p> <p>What are the criteria? Criteria include: age, type of impairment, degree of impairment, family situation, income level.</p> <p>Do the same criteria apply for different types of support? Types of support service include:</p> <ul style="list-style-type: none"> • personal assistance; • residential; • family support (counselling, respite care, early intervention); • in-home; • others (informal support, peer support, day care, voluntary work, etc.) <p>Does the legal provision allow eligibility decisions to be challenged?</p> <p>Does the legal provision specify how regularly eligibility should be reviewed?</p>	<p>N/A</p>	<p>How many decisions regarding eligibility for support have been challenged, annually since 2018?</p> <p>How many of these have been overturned?</p>

User Control

Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision providing that persons with disabilities, irrespective of age and type of impairment can choose:</p> <ul style="list-style-type: none"> • type of support service provided; • extent of support provided; • provider of support service; • changes in the support? <p>Types of support service include:</p> <ul style="list-style-type: none"> • personal assistance; • residential; • in-home; others (informal support, peer support, day care, voluntary work, etc.) <p>Are there mechanisms in place to ensure the person’s will and preferences, irrespective of age and type of impairment, are taken into account in choosing:</p> <ul style="list-style-type: none"> • type of support service provided; • extent of support provided; • provider of support service; • changes in the support? 	<p>Does the procedure for providing community support services include self-assessment of needs, irrespective of age and type of impairment?</p> <p>Is information about different types of services and quality of services provided in accessible formats?</p>	<p>N/A</p>

Informal support

Structural indicators	Process indicators	Outcome indicators
<p>Are informal community support services legally recognised as a type of support?</p> <p>Types of informal support services include:</p> <ul style="list-style-type: none"> • care for children with disabilities; • caring for elderly or other family members with support needs; • voluntary work 	<p>How much budget has been allocated, annually since 2018, to informal support services?</p> <p>Is training available for providers of informal community support services for persons with disabilities?</p>	<p>N/A</p>

Annex 2: About the Commission

Who we are

The Scottish Human Rights Commission (the Commission) is the National Human Rights Institution for Scotland.

We are an independent, expert body that works with and for the people of Scotland; we monitor, listen, speak up for all our rights and respond when things go wrong. We are a public body created by the Scottish Commission for Human Rights Act 2006 to protect and promote the human rights of all people in Scotland. We have carried out this research under sections 3 and 4 of our Act, which empower us to conduct research and to monitor laws, policies and practices in any area.

The Commission is also part of the international human rights system. It is accredited by the United Nations as its trusted organisation to provide impartial evidence on the enjoyment of human rights in Scotland. The Commission is independent of Government. We are accountable to the people of Scotland via the Scottish Parliament.

The Commission is also part of UKIM, the independent national monitoring mechanism set up under the Convention on the Rights of Persons with Disabilities (CRPD)¹³⁵ to promote, protect and monitor implementation of the Convention. In relation to the process of moving from institutions to independent living, it is our role to ensure accountability, transparency and the protection and promotion of human rights, including by offering recommendations on best practices.¹³⁶ The Equality and Human Rights Commission, the National Human Rights Institution for England and Wales, has carried out work on this issue in their jurisdiction.

Annex 3: Methodology

This Annex outlines the approach and processes used in this project to assess Scotland’s progress in implementing the Coming Home Implementation Plan under Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). It explains both the methodology—the overarching framework and rationale guiding the research—and the methods, the specific tools and techniques used to gather and analyse data.

The methodology was rooted in a mixed-methods approach, chosen to provide a holistic analysis that combined qualitative and quantitative data. This approach was informed by internationally recognised human rights indicators, participatory input from individuals with lived experience and Disabled People’s Organisations (DPOs), and a commitment to transparency and inclusivity.

The methods used to implement this approach included:

- **Desk-based analysis** of publicly available data from sources such as Public Health Scotland and the Care Inspectorate.
- **Interviews** with key stakeholders, including duty bearers, researchers, and experts, to gather qualitative insights.
- **Factchecking** processes to ensure data accuracy and cross-reference findings with official sources.

Combining this methodological approach with these robust methods, has enabled this project to deliver a reliable and actionable assessment of Scotland’s efforts to meet its human rights obligations under Article 19 CRPD. Below, we detail the steps taken to ensure comprehensive and reliable findings.

Development of indicators

We began by adapting the Fundamental Rights Agency’s indicators for measuring Article 19 of the CRPD. These indicators, originally developed to assess progress on independent living across the EU, were tailored to reflect Scotland’s specific context and the scope of the Coming Home Implementation Plan. This adaptation ensured our analysis was rigorous and relevant. The complete set of indicators used in this study is provided in [Annex 1](#).

Project Reference Group and Measuring Change Group of Human Rights Defenders

These groups provided an essential participatory approach to our work, and we are very grateful to all of the individuals who worked with us on this project. The role and constitution of these groups is explained at [Annex 4](#) and [Annex 5](#).

The Project Reference Group played a central role in shaping this research. Comprised of individuals with lived experience, representatives from Disabled People’s Organisations (DPOs), and third-sector experts, the group provided invaluable guidance. Their input ensured that the research process was informed by those most affected by institutionalisation, contributing directly to the focus and interpretation of findings.

Commissioned Research Approach

Independent researchers, Professor Jo Ferrie & Dr Paul Pearson, were commissioned to undertake this research following a public Invitation to Quote process.

As neither the Commission nor our researchers is able to exercise powers to compel that information be provided to us, the research relied on publicly available data from sources such as Public Health Scotland, the Scottish Commission for People with Learning Disabilities, and statutory and third-sector organisations. Interviews with duty bearers, researchers, and experts were conducted to complement this desk-based analysis, ensuring a thorough exploration of the issues and challenges within the Coming Home Implementation Plan. The Scottish Government also provided the research team with a copy of the Dynamic Support Register.

Publicly available commentary on data lay outwith the scope of the project though attempts were made to incorporate as much as possible where direct and explicit reference to the Coming Home Implementation Plan was established (for example, the Stakeholder Submission on Common Concerns¹³⁷). Their aim in evaluating this data, was to determine to what extent the data a) evidenced successful implementation of the Coming Home Implementation Plan and b) evidenced that Article 19 of the CRPD was being upheld in practice for adults with learning disabilities and/or autism.

Data sources

A range of publicly available data sources was utilised to inform the findings of this report.

Key sources included:

- **Public Health Scotland:** Providing health-related statistics relevant to institutionalisation.
- **Scottish Government Reports:** Detailing progress under the Coming Home Implementation Plan.
- **Scottish Commission for People with Learning Disabilities:** Offering insights into learning disability policy and practice.
- **Annual Accounts and Performance Reports:** Published by Health and Social Care Partnerships to trace the use of funds.
- **Care Inspectorate Reports:** Highlighting institutional settings and their compliance with regulations.
- **Local authorities:** Three of the top five from the rate of people on the Dynamic Support Register in Scotland, by Health and Social Care Partnership per 100,000 population as of 28 September 2023):
 - Western Isles
 - Argyle and Bute
 - East Dunbartonshire
- **Interviews and Feedback:** Data from interviews with duty bearers and other stakeholders supplemented these published sources, filling key contextual gaps.

In particular, the heads of each Integration Joint Board (IJB) were approached for information on the Community Living Change Fund, as follows:

- The amount held in reserve as of 31st March 2024
- How the fund has been used to this date
- Information regarding the process followed when deciding how to use the fund

Five responses were received.

These sources were systematically reviewed and cross-referenced to ensure a comprehensive evidence base. The reliance on publicly available data ensures transparency and accessibility, though it also introduces certain limitations, which are addressed below.

Factchecking Processes

A robust factchecking process was employed to validate the evidence used in this report. This involved cross-referencing data with publicly available records, engaging with the Scottish Government to verify findings, and addressing any potential inaccuracies. Where evidence gaps were identified, they were clearly noted in the findings to ensure transparency and integrity.

Evidence Analysis

The data analysed included both quantitative and qualitative evidence, offering a broad perspective on the issues at hand. While publicly available data from statutory bodies and government reports provided a strong foundation, gaps in some areas—such as detailed financial records and disaggregated data for certain populations—limited the scope of analysis. Interviews with stakeholders helped to fill some of these gaps, offering contextual insights and highlighting challenges in implementation. However, the reliance on publicly available data meant that some issues, particularly around transparency and accountability, could not be fully explored. These limitations are noted in the findings, ensuring that the analysis remains transparent and credible.

Challenges and Limitations

While the methodology was comprehensive, certain constraints were unavoidable. The research relied on publicly available data, which limited access to some potentially relevant information. Requests to local authorities and health partnerships for specific data were not always successful. However, these limitations were mitigated by using a strong framework of indicators and engaging extensively with stakeholders to provide a reliable assessment of Scotland’s progress.

Annex 4: Project Group

Our Project Group included people from different organisations and with different experiences, invited for their expertise in addressing situations of institutionalisation.

- Charlie McMillan: the then Chief Executive, The Scottish Commission for People with Learning Disabilities
- Sam Smith: Chief Executive, C-Change
- Fiona Clarke: autistic parent, unpaid carer and consultant
- Rosie Smith: Director, People First (Scotland), supported by Caroline Kingston
- Kate Sainsbury: Human rights defender for her son, Louis Sainsbury
- Teodor Mladenov: Senior Lecturer, University of Dundee
- Vicky Scott: Manager, Advocating Together
- Jenny Miller: Chief Executive, PAMIS
- John Dalrymple: Director, Radical Visions
- Dr Pauline Nolan: Head of Policy and Engagement, Inclusion Scotland

The group met five times. As agreed by Terms of Reference, the role of the Project Group was to

- Help inform the project by telling us what they thought we should take account of in our research and what it thought should be part of the Human Rights Defenders’ project
- Help us make sure human rights measurement works in Scotland
- Make sure the project is informed by the experiences of people with learning disabilities and/or autistic people
- Help recruit a small group of people to work with us on the human rights defenders’ project
- The Commission did not expect project group members to deliver the project

Annex 5: Measuring Change Project – Human Rights Defenders

The Measuring Change Human Rights Defenders are a group of four people who worked with the Scottish Human Rights Commission to develop a toolkit and short film to help increase awareness of the issue of institutionalisation and to share a framework to measure change in ending institutionalisation in Scotland. Each of the defenders have direct or indirect experience of institutionalisation.

Defenders met seven times throughout the project and had the opportunity to hear from each other about their experiences and from

researchers working with the Scottish Human Rights Commission on evidence of progress towards deinstitutionalisation. From these conversations, they created a toolkit based on human rights indicators to help other defenders, including an awareness-raising video. The aim of these resources is to help other defenders to hold those responsible to account for ending institutionalisation and delivering on human rights standards under Article 19 of the UN Convention on the Rights of Persons with Disabilities.

Endnotes

- 1 Professor Jo Ferrie & Dr Paul Pearson (2024), Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice p.4
- 2 European Union Agency for Fundamental Rights (2018), [From institutions to community living for persons with disabilities: perspectives from the ground](#)
- 3 Inclusion Scotland, C-Change et al, Scottish Government (2022) Coming Home Implementation: A Report from the Working Group on Complex Care and Delayed Discharge: [Stakeholder Submission on Common Concerns](#), July 2022
- 4 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#), para 16.
- 5 People in hospital who have been supported by People First, a Disabled People’s Organisation of adults with a Learning Disability in Scotland, have provided their voices to explain the reality of living in institutions. Other voices are provided by Kate Sainsbury, human rights defender for her son, Louis Sainsbury
- 6 Scottish Home and Health Department and Scottish Education Department. (1972) Services for the mentally handicapped. Memorandum from the Scottish Home and Health Department and Scottish Education Department. Edinburgh. p10
- 7 NHS Quality Improvement Scotland. (February 2006) Learning Disability Services National Overview. Edinburgh: NHS Quality Improvement Scotland. pp.74-75 & p.77
- 8 Campbell, Martin, Whoriskey, Margaret, Lyall, Ros, Davidson, Alex, and McCue, Michael. (2007) A national review of health services for people with intellectual disabilities in Scotland. British Journal of Developmental Disabilities. 53(1), January. p.29.
- 9 Scottish Government, [Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge](#), (2022) p.5.
- 10 UK Independent Mechanism, [Seven Years On: disabled people’s rights to independent living, employment and standard of living in the UK \(2023\)](#).
- 11 Scottish Government, [Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge](#) p.21
- 12 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 14-18 , United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#), para 16c.
- 13 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#), para 16c.

- 14 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies](#) (2022) para 14-18
- 15 The 2023 data was published on November 2024 and is outwith the timeframe of our research.
- 16 Care Inspectorate data downloaded on 8 April 2024 and published on 29 February 2024.
- Details of the data sources, the manner of analysis and any limitations are explained in Section 4.1 of the Research Report.
- 17 People in hospital who have been supported by People First, a Disabled People’s Organisation of adults with a Learning Disability in Scotland, have provided their voices to explain the reality of living in institutions. Other voices are provided by Kate Sainsbury, human rights defender for her son, Louis Sainsbury
- 18 People in hospital who have been supported by People First, a Disabled People’s Organisation of adults with a Learning Disability in Scotland, have provided their voices to explain the reality of living in institutions. Other voices are provided by Kate Sainsbury, human rights defender for her son, Louis Sainsbury
- 19 People in hospital who have been supported by People First, a Disabled People’s Organisation of adults with a Learning Disability in Scotland, have provided their voices to explain the reality of living in institutions. Other voices are provided by Kate Sainsbury, human rights defender for her son, Louis Sainsbury
- 20 People in hospital who have been supported by People First, a Disabled People’s Organisation of adults with a Learning Disability in Scotland, have provided their voices to explain the reality of living in institutions. Other voices are provided by Kate Sainsbury, human rights defender for her son, Louis Sainsbury
- 21 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community](#) (2017) para 49.
- 22 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community](#) (2017) para 49.
- 23 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies](#) (2022) para 14-18 para 9
- 24 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community](#) (2017)
- 25 G United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies](#) (2022)
- 26 Committee on the Rights of Persons with Disabilities, [General Comment No.1 – Article 12: Equal Recognition before the law](#) (2014)
- 27 *Winterwerp v. the Netherlands*, ECHR 24 October 1979, [Series A. no 33](#)

- 28 *P (by his litigation friend the Official Solicitor) (FC) (Appellant) v Cheshire West and Chester Council and another (Respondents)* [2014] UKSC 19 and *Stanev v Bulgaria* [2012] ECHR 46 (Application no. 36760/06)
- 29 *Stanev v Bulgaria* [2012] ECHR 46 (Application no. 36760/06)
- 30 *Rooman v Belgium* [2019] ECHR 105 (Application no. 18052/11)
- 31 [Rooman v Belgium | 39 Essex Chambers](#)
- 32 *Zehentner v. Austria*, [2009], ECHR (Application no. 20082/02); *Shtukurov v. Russia* [2008], ECHR (Application no. 44009/05); *Herczegfalvy v. Austria*, [1992] ECHR (Application no. 10533/83); *N. v. Romania (No.2)*, [2021] ECHR (Application no.38048/18)
- 33 *A.-M.V. v. Finland* [2017] ECHR 273 (Application no. 53251/13)
- 34 *Rooman v Belgium* [2019] ECHR 105 (Application no. 18052/11)
- 35 *VI v Moldova* [2024] ECHR 251 (Application no. 38963/18)
- 36 [Scottish Mental Health Law Review \(2022\), Final Report](#)
- 37 [European Union Agency for Fundamental Rights \(2018\), From institutions to community living for persons living with disabilities: perspectives from the ground.](#)
- 38 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice*
- 39 For more information on human rights measurement, see [Human Rights Indicators: A Guide for Measurement and Implementation | OHCHR](#)
- 40 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice*, p.4
- 41 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 42
- 42 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 67
- 43 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 97
- 44 Scottish Government, [Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge](#) p.4
- 45 The Scottish Government’s plans following March 2024 are outlined here [Learning Disabilities, Autism and Neurodiversity Bill \(parliament.scot\)](#). They consist of:
- Healthcare Improvement Scotland (HIS) will continue to progress the Practitioner Support Network. An expert reference group has been established and the network is due to launch in October.
 - Public Health Scotland will continue to collect and publish data from the Dynamic Support Registers.

- We have established a working group focused on improving Learning Disability, Mental Health, and Adults with Incapacity delays to discharge. Meeting weekly, it is chaired by a Chief Social Work Officer and the Scottish Government’s Associate Chief Nursing Officer.
 - The working group aims to deliver short, medium and long term improvements, reporting to the Cabinet Secretary for Health and Social Care and Councillor Kelly, COSLA’s Health and Social Care Spokesperson, on a weekly basis.”
- 46 “an established combination of health and local government formulae (a mix of relevant GAE and NRAC) to Health Boards, for onward distribution to Integration Authorities” [Community Living Change Fund Guidance](#)
- 47 For detail on the selection of the local authorities, see Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice* p.44
- 48 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice*, Table 12. Details of the data sources, the manner of analysis and any limitations are explained in Section 6.5 of the Research Report.
- 49 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice*, Table 15
- 50 Article 4(3) CRPD
- 51 United Nations, [Convention on the Rights of Persons with Disabilities](#), Article 4(3) United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies](#) (2022) para 34
- 52 Information on this project and the views of People First (Scotland) has been provided directly by People First (Scotland)
- 53 People First, [Summer 2024 Newsletter](#)
- 54 Inclusion Scotland, C-Change et al, Scottish Government (2022) *Coming Home Implementation: A Report from the Working Group on Complex Care and Delayed Discharge: Stakeholder Submission on Common Concerns*, July 2022
- 55 Letter from Kevin Stewart MSP, Minister for Mental Wellbeing and Social Care to Chairs of Inclusion Scotland and C-Change Scotland, 23 August 2022
- 56 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community](#) (2017) para 49
- 57 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community](#) (2017) para 38(g)
- 58 Details of the data sources, the manner of analysis and any limitations are explained in Section 4.1 of the Research Report. Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice*

- 59 Details of the data sources, the manner of analysis and any limitations are explained in Section 4.2 of the Research Report. Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions*, from *Coming Home to universal practice*
- 60 Scottish Government (2023), *Learning Disabilities, Autism and Neurodivergence Bill: Consultation* p83
- 61 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions*, from *Coming Home to universal practice*, Section 4.9
- 62 The Inpatient Census 2023 was published in November 2024 which is outside the timeframe of our research.
- 63 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions*, from *Coming Home to universal practice*, Table 2
- 64 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions*, from *Coming Home to universal practice*, Table 5
- 65 Data taken from Scottish Government, *Mental Health Inpatient Census 2022 Parts 1 and 2*. Details of the data sources, the manner of analysis and any limitations are explained in Section 4.4 of the Research Report. Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions*, from *Coming Home to universal practice*
- 66 Professor Jo Ferrie & Dr Paul Pearson (2024), *Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions*, from *Coming Home to universal practice*, Table 3
- 67 Scottish Government, *Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge* p13
- 68 Scottish Government, *Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge* p.23
- 69 *VI v Moldova* [2024] ECHR 251 (Application no. 38963/18)
- 70 United Nations Committee on the Rights of Persons with Disabilities, *Guidelines on deinstitutionalization, including in emergencies* (2022) paras 29 & 31
- 71 Glasgow City Joint Integration Board (2021), *Report on Enhanced Community Living for Adults with a Learning Disability*
- 72 East Renfrewshire Health and Social Care Partnership (2024), *Specialist Learning Disability Services Resettlement of People from Longer Stay Facility – Netherton*. p.81
- 73 East Renfrewshire Health and Social Care Partnership (2024), *Specialist Learning Disability Services Resettlement of People from Longer Stay Facility – Netherton*, p.85
- 74 Glasgow City Integration Joint Board (2022), *Glasgow City IJB Directions Annual Report 2021-2022*.

- 75 Glasgow City Joint Integration Board (2021), [Report on Enhanced Community Living for Adults with a Learning Disability at para 1.7](#)
- 76 Glasgow City Joint Integration Board (2021), [Report on Enhanced Community Living for Adults with a Learning Disability at para at paras 3.1 and 3.2](#)
- 77 East Renfrewshire Health and Social Care Partnership (2021), [Annual Performance Report 2020-2021](#).
- 78 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 65
- 79 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 66
- 80 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 117
- 81 Scottish Government (2023), Learning Disabilities, [Autism and Neurodivergence Bill: Consultation](#) p84
- 82 Scottish Government (2023), Learning Disabilities, [Autism and Neurodivergence Bill: Consultation](#) p86
- 83 Mental Health (Care & Treatment) (Scotland) Act 2003 [Section 64\(4\)\(a\)\(ii\)](#) Section 64(4)(a)(ii) t
- 84 Scottish Mental Health Law Review (2022), [Final Report](#) p.532 & 533
- 85 Scottish Mental Health Law Review (2022), [Final Report](#) p.540-543
- 86 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) paras 97(m)&(n)
- 87 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) Section XI
- 88 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 60
- 89 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 30
- 90 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 80
- 91 Scottish Government (2017), [Health and Social Care Standards: my support, my life](#)
- 92 Scottish Government (2017), [Health and Social Care Standards: my support, my life](#) p.3

- 93 This figure of 585 should be handled with caution. Most services identified as breaching standards had multiple breaches identified within a single report. So incidences of failure exceed the number. It would take some time to calculate this if of interest (the data buried in blocks of qualitative data). Further, some service providers are ‘repeat offenders’, indeed 55% of the 117 services that were identified in 2023/24 had also been identified as breaching standards in 2022/23.
- 94 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 97(f)
- 95 Scottish Government (2024), [Social Care – self-directed support: framework of standards](#) – May 2024.
- 96 Scottish Government (2023) [Self-Directed Support Improvement Plan 2023-27](#)
- 97 Scottish Government Freedom of Information release (2021), [Autism within the Mental Health \(Scotland\) Act 2003](#)
- 98 Scottish Independent Advocacy Alliance (2024), Learning Disabilities, Autism, and Neurodivergence Bill Consultation SIAA response
- 99 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 37
- 100 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 95
- 101 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 70
- 102 [Social Care \(Self-Directed Support\) \(Scotland\) Act 2013 statutory guidance](#) p.37
- 103 Scottish Government (2023), Learning Disabilities, [Autism and Neurodivergence Bill: Consultation](#) p.82
- 104 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 39
- 105 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 46
- 106 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 28
- 107 Scottish Government (2023), [A Human Rights Bill for Scotland: consultation](#)
- 108 Health, Social Care and Sport Committee; [Post-legislative scrutiny of the Social Care \(Self-directed Support\) \(Scotland\) Act 2013: Phase 2](#)
- 109 Mental Health (Care & Treatment) (Scotland) Act 2003 Section 328

- 110 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 80. See further Committee on the Rights of Persons with Disabilities, [General Comment No.1 – Article 12: Equal Recognition before the law \(2014\)](#)
- 111 Scottish Mental Health Law Review (2022), [Final Report](#) p.144
- 112 Scottish Government (2024), [Mental Health and Capacity Reform: Delivery Plan October 2023 to April 2025](#)
- 113 Independent Review of Adult Social Care in Scotland (2021), [Final Report](#).
- 114 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 60
- 115 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 78
- 116 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) paras 64 & 65
- 117 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 16
- 118 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) paras 61 & 71
- 119 United Nations Committee on the Rights of Persons with Disabilities, [General Comment No.5 on Article 19 – the right to live independently and be included in the Community \(2017\)](#) para 60
- 120 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 75
- 121 Inclusion Scotland, C-Change et al, Scottish Government (2022) [Coming Home Implementation: A Report from the Working Group on Complex Care and Delayed Discharge: Stakeholder Submission on Common Concerns](#), July 2022
- 122 Audit Scotland (2017) , [Self-directed support 2017 progress report](#); Care Inspectorate (2019), [Self-directed support publications](#); F Morrow and M Kettle (2021), [Self-directed support: ten years on Independent Review of Adult Social Care in Scotland \(2021\), Final Report](#).
- 123 Health, Social Care and Sport Committee; [Post-legislative scrutiny of the Social Care \(Self-directed Support\) \(Scotland\) Act 2013: Phase 2](#)
- 124 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) paras 69-74
- 125 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) para 71
- 126 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies \(2022\)](#) part IX

- 127 For more information on Human Rights Budgeting, please see the Commission’s resources on our [webpage](#)
- 128 Professor Jo Ferrie & Dr Paul Pearson (2024), Deinstitutionalisation: A human rights-based examination of Scotland’s progress in ending institutions, from Coming Home to universal practice, p.4
- 129 Article 31(2) “The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.”
- 130 Scottish Commission for Human Rights Act 2006 Section 4
- 131 Independent Forensic Mental Health Review (2021), [Final Report](#).
- 132 Scottish Government (2023), [Scottish mental health law review: our response](#)
- 133 European Union Agency for Fundamental Rights (2018), [From institutions to community living for persons living with disabilities: perspectives from the ground](#).
- 134 Scottish Government, [Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge](#), (2022) p.5.
- 135 Article 33 CRPD
- 136 United Nations Committee on the Rights of Persons with Disabilities, [Guidelines on deinstitutionalization, including in emergencies](#) (2022), para 129.
- 137 Inclusion Scotland, C-Change et al, Scottish Government (2022) Coming Home Implementation: A Report from the Working Group on Complex Care and Delayed Discharge: [Stakeholder Submission on Common Concerns](#), July 2022



Scottish Human Rights Commission
Bridgeside House
99 McDonald Road
Edinburgh
EH7 4NS

scottishhumanrights.com