

# SHRC

Scottish  
Human Rights  
Commission



## “Tick Tock...”

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

January 2025

EXECUTIVE SUMMARY

# 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. **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.

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 possible 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
<b>Action plan and strategies</b>		
<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>	
<b>Disabled persons organisations involvement</b>		
<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
<b>Institutions</b>		
<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>	
<b>Training</b>		
<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
<b>Complaints</b>		
<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>	
<b>Monitoring</b>		
<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>	
<b>Quality standards</b>		
<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
<b>Awareness of support services</b>		
<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>	
<b>Empowerment</b>		
<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>	
<b>Living arrangements</b>		
<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>		
<b>Involvement in deciding where to live</b>		
<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
<b>Access to support services</b>		
<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>	
<b>Transferability of support services</b>		
<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>	
<b>Eligibility for community support services</b>		
<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>	
<b>User control</b>		
<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.”</p>	

Summary of indicators	Key gaps in implementation	Assessment
<b>Informal support</b>		
<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>	
<b>Access to justice</b>		
<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>	









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