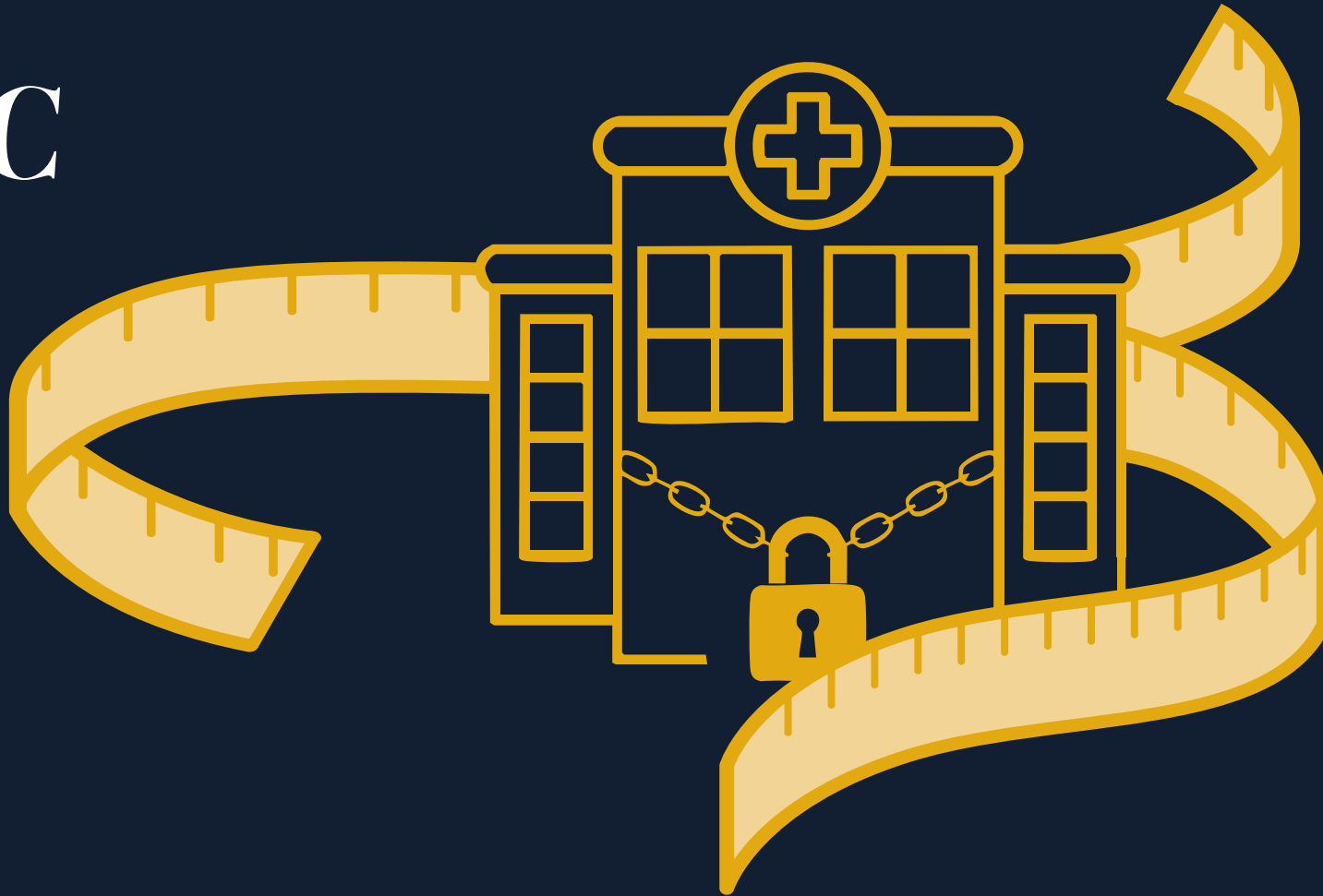


**SHRC**

Scottish  
Human Rights  
Commission



# Measuring Change on Ending Institutionalisation in Scotland

**A Toolkit for Human Rights Defenders**

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.

**[www.scottishhumanrights.com](http://www.scottishhumanrights.com)**

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# Foreword from Commission Chair

## The human right to independent living is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

An important part of the role of the Commission, as Scotland's National Human Rights Institution (NHRI) is to monitor, without fear or favour, how the lives of people in Scotland stack up against the country's international human rights obligations. As part of our Strategic Plan 2024-28, the Commission has worked with researchers and people with experience of institutions to better understand the impact of the Scottish Government's Coming Home Implementation Plan on ending the practice of institutionalisation in Scotland.

The Commission's report *Tick Tock: A human rights assessment of progress from institutionalisation to independent living in Scotland* has identified that the targets set by the Scottish Government in its Coming Home Implementation Plan to realise the right to independent living are unmet, and much of the money made available to bring people out of institutions into communities has not been spent.

We have found that despite a stated commitment to take a human rights-based approach to this work, there is little evidence of this in practice to progress the ending of institutionalisation of people with learning disabilities and/or autistic people. Clarity on what a human rights-based approach to this challenge means in practice, is necessary to deliver measurable progress towards independent living.

To help achieve this, the Commission is grateful and proud to have worked alongside Human Rights Defenders from across Scotland, with experience of institutionalisation, to create this resource. The toolkit should be read alongside our research report, which outlines an international framework to measure progress towards the human right to independent living for all.

Whilst the responsibility to deliver the change rests with duty bearers and the State, all of us have a role to play in accountability and advocacy for progress. Human rights defenders must be equipped with the knowledge and skills to challenge human rights issues and injustice. The Commission would like to thank the Measuring Change Human Rights Defenders for their work in co-creating this toolkit with us. We hope it is a helpful resource for human rights defenders with learning disabilities and/or autistic people, their families, and advocates working across Scotland to challenge institutionalisation and realise the right to independent living. We look forward to hearing from human rights defenders on their experience of using this toolkit to uphold the rights of people with learning disabilities and/or autistic people to live independently.



A handwritten signature in black ink, appearing to read 'Angela O'Hagan'.

**Professor Angela O'Hagan,  
Chair, Scottish Human Rights Commission**

# Foreword from the Measuring Change Human Rights Defenders

**We are the Measuring Change Human Rights Defenders. We are a group of four<sup>1</sup> 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 us has direct or indirect lived experience of the issues discussed in this toolkit. At the start of the Measuring Change project, we were asked what changes we wanted to see due to this work. You can see what we said on page 6 of this toolkit.

At the outset of this project, we wanted to ensure that other human rights defenders are empowered with the knowledge and skills to hold public bodies accountable for ending institutionalisation in Scotland and advocating for change in their own lives. Throughout this project, we had the opportunity to hear from each other about our own experiences and from researchers working with the Scottish Human Rights Commission on evidence of progress towards deinstitutionalisation.

From these conversations, we created a toolkit based on human rights indicators to help other defenders, including an awareness-raising video. We hope these resources will help other defenders to hold those responsible to account for ending institutionalisation and delivering on human rights standards under Article 19 of the Convention on the Rights of Persons with Disabilities.



**Chelsie Mills, Ruth Hughes, Karen Malcolm and Millicent Wenlock.**  
The Measuring Change Human Rights Defenders.

<sup>1</sup> Originally the group was made up of five human rights defenders. Due to personal circumstances one defender withdrew halfway through the project.

“ I would like people to be empowered by human rights and to keep fighting until we see change ”

“ Government to hold hospitals and social care partnerships to account as to why people with learning disabilities are still living in institutions and take ACTION – not words ”

“ Moving away from institutionalisation being the go-to option ”

“People are free and happy”

“ Clarity and oversight – holding decision makers to account ”

“ I would like to see all institutions closed. I would like people to live happily in the community with good support. I would like those in authority with power to make change to LISTEN and ACT! ”

“ Right to privacy and to make decisions about our lives ”

# Introduction

“It’s not what you say,  
it’s what you do”

This toolkit exists to help human rights defenders measure progress toward realising Article 19 of the UN Convention on the Rights of Persons with Disabilities. It explains institutionalisation through data and experiences. It also explains Article 19 of the Convention on the Rights of Persons with Disabilities and how to use human rights indicators to measure change.

This toolkit is for human rights defenders working to end the institutionalisation of people with learning disabilities and/or autistic people in Scotland.

Human rights defenders can be anyone, any person, or any group working to promote human rights. They can come from many different backgrounds. They work as individuals or as groups to promote or protect human rights in a peaceful manner.

This means anyone can be a human rights defender, including people who are fighting for their rights or the rights of their family members, working in policy in a civil society organisation, working in the NHS, working in social care to support people to live independently, or working for a regulator. Human rights defenders’ actions define them. Being a human rights defender is not about what you say but what you do.

The United Nations<sup>2</sup> says you are a human rights defender if you do any of the following:



**Protect the human rights of all – locally, nationally, or internationally.**



**Collect and share information on human rights issues.**



**Support victims of human rights violations**



**Take action to hold those responsible for human rights violations accountable.**



**Support the delivery of Human Rights standards and international human rights treaties.**



**Provide education and training on human rights.**

**If you are reading this toolkit, you are probably a human rights defender.**

<sup>2</sup> See: [About human rights defenders | OHCHR](#)

# Institutionalisation: The Facts

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

Ruth Hughes, Human Rights Defender (2024)

**66** Institutionalisation is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention<sup>3</sup>. It involves de facto denial of the legal capacity of persons with disabilities in breach of Article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to Article 14. States parties should recognise institutionalisation as a form of violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilisers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17. **99**

Guidelines on Deinstitutionalisation  
UN Committee on the Rights of Persons with Disabilities (2022)



## What is institutionalisation?

Institutionalisation is when a person is placed in a setting and does not have control over their own lives.

Examples of institutionalisation include having little choice over who you live with and who supports you, isolation and separation from your community and a high number of disabled people living in the same place, for example, a hospital. An institution can also be a home setting if you don't have control.



## Who does institutionalisation affect?

Institutionalisation affects many disabled people, especially people with learning disabilities and/or autistic people.

In Scotland, in 2019, 107 people were admitted to an NHS inpatient facility for 'learning disability'. In 2022, 65 people were admitted for the same reason.

3 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)





## How many people with learning disabilities and/or autistic people are living in institutions?

An inpatient census showed that in 2022, 150 people were in a learning disability unit, and 79 people were in a forensic learning disability unit.

In 2022, there were also 33 people with learning disabilities and/or autistic people in NHS wards outside of Scotland. There are gaps in available data; therefore, the total number of people with learning disabilities and/or autistic people in institutions is not known.



## What has been done to end institutionalisation?

The Scottish Human Rights Commission research report looked at what had been done to end institutionalisation in Scotland. We found that the Scottish Government had published an action plan called the Coming Home Implementation Plan. It promised action by March 2024, but its targets were not met, and there is no follow-up plan.



## Why is institutionalisation a human rights issue?

People in institutions may face the following situations which engage their human rights for example,

- Not being able to see their friends and family,
- Not being able to make their own decisions,
- Experiencing restraint and seclusion,
- Experiencing forced medical treatment.

Because of this, several of their human rights are impacted, including the right to private and family life, the right to live free from torture, inhumane or degrading treatment or punishment and their right to legal capacity and liberty. These are all rights protected in the Human Rights Act 1998. The United Nations Convention on the Rights of People with Disabilities also protects the right to independent living.

# Institutionalisation: Our Story

**The following story was created by individuals living in institutions across Scotland and collated by People First (Scotland) who shared this with the Commission to be included in this project.**

It is a collective story outlining many people's experiences in institutions. The Measuring Change Human Rights Defenders who worked alongside the Scottish Human Rights Commission added to the story, contributing their own experience to this composite story.

The following is a story of institutionalisation in Scotland from those whose voices are rarely heard.

"I live in a hospital, but if you asked me why, I would find it difficult to explain. Others told me that I would be looked after and be cared for and that I would be home soon. It has been almost 20 years. I have been told many times that I was being given a flat and would be moving out. I have been to see flats and then never went there again. *"Things have changed"*, I was told, or *"it isn't suitable"*. I never heard anything else. So, I wait. People come, people go, yet I stay, and I wait. My phone is taken and locked away *"for safety,"* so it can be hard for me to keep in touch. I am told that I am not allowed to use the internet unsupervised, but I am not told why. If my family asks questions, they are told they are pushy or interfering. If I question things, I am told I am being *"difficult"*. If I get upset, I am told I am being *"challenging"*. You get used to saying *"sorry"* all the time because you are frightened of saying the wrong thing. The ward is busy, hot, and noisy, and I have no

privacy or peace. All the doors and windows are locked. I can't choose when to eat, I can't choose to go out for a walk, and I can't choose who I keep company with. I must share my *"home"* with people I do not get on with. I must live somewhere that I do not want to be. So, I have learned not to speak out, I have learned not to complain, and I have learned not to question. I don't want a jag; I don't want to lose my visits (not that many come anyway), and I don't want to lose my socials. I will never have a family.

We have:

- No relationships,
- No ability to choose who we live with,
- No choice of what and when we eat,
- No freedom of movement,
- No education opportunities,
- No information about our own treatment is made available,
- No part in decisions about our own life."

 **We feel we have no rights** 

# Institutionalisation: Know your Rights

## People with learning disabilities and/or autistic people have the same human rights as all other people.

They are protected in the UK under the Human Rights Act 1998. Article 5 of the European Convention on Human Rights protects your right to liberty. Article 3 of the European Convention on Human Rights protects your right to be free from torture or inhumane treatment.

People with learning disabilities and/or autistic people also have their rights protected under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which the UK signed up to follow in 2009. Article 19 of the UNCRPD sets out the right to independent living.



### The UNCRPD

The UNCRPD is an agreement that sets out what countries must do to make sure that disabled people (including people with learning disabilities and/or autistic people) have the same rights as everybody else. Article 19 of the UNCRPD says that countries should ensure that disabled people have the same choices as everyone else about how they live and participate in their communities, that disabled people can choose where they live, who they live with and should not live in a particular place like a hospital if they don't want to.

Article 19 also says that disabled people should be able to choose from a range of different support services, including personal assistance, and should be able to choose from the same range of services that other people can choose from and get good service.

The United Nations Committee on the Rights of Persons with Disabilities produced a document called a General Comment (number 5) on Article 19 of the UNCRPD. This guidance tells a country how to ensure disabled people can live independently and in the community. A [plain English version of General Comment Number 5](#) is available to download.



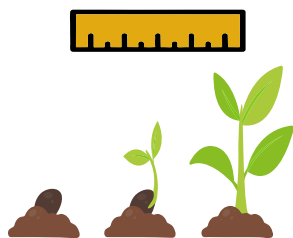
### Guidelines for Deinstitutionalisation

In 2022, the UN Committee on the Rights of Persons with Disabilities published [Guidelines for Deinstitutionalisation, Including in Emergencies](#).

The guidelines complement Article 19 of the UNCRPD and General Comment Number 5. The guidelines aim to support countries in realising the right of persons with disabilities to live independently and be included in the community. They also serve as the basis for planning deinstitutionalisation processes and preventing institutionalisation. [A plain English version of the guidelines is available.](#)

# Measuring Change: What are Indicators?

Human rights are not just nice ideas. They are tools to make sure everyone can live with dignity and respect. Human rights indicators help provide a framework for creating change. Indicators can help human rights defenders to measure progress in realising human rights, and governments and other duty-bearers to be held accountable for their progress in realising all our rights.



Indicators help you measure change.



Indicators can tell you if things are getting better or if they are getting worse.



Indicators can also tell you what's needed to make things better.

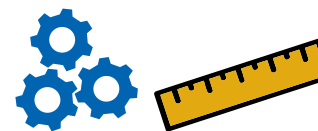
The European Union Agency for Fundamental Rights (FRA) Article 19 Indicators give human rights defenders questions to ask duty bearers to check if steps are being taken to meet the standards set out in Article 19 of the UNCRPD.

There are three types of indicators.

These are structural, process and outcome indicators.



Structural indicators measure how committed a country is to human rights.



Process indicators measure a country's effort to transform human rights commitments into actions.



Outcome indicators measure the actual results of the country's commitments and efforts.

# Measuring Change: Using Indicators to help end Institutionalisation in Scotland

## Why should human rights defenders measure the progress of ending institutionalisation in Scotland?

Without monitoring the progress in ending institutionalisation in Scotland, those responsible for progressing deinstitutionalisation cannot be held accountable.

It is easy for the State to say it is taking a human rights-based approach, but sometimes, it is hard to prove this. Indicators give human rights defenders a list of questions to ask duty bearers to help hold them to account, and duty bearers a checklist to help them demonstrate that they are.

## How can we use human rights to measure Scotland's progress in ending institutionalisation?

Human rights are universal for everyone. There are experts who spend time monitoring human rights in countries across the world. The Commission is part of the international human rights system, 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:

## 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.

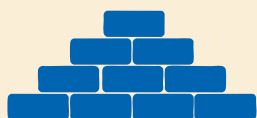
Availability of adaptations to homes for disabled people.

Availability of informal support.

Availability and adaptations of community services and facilities.

## Can indicators help to measure progress on ending institutionalisation in Scotland?

Yes. Human rights indicators help us determine Scotland's commitment to ending institutionalisation, its efforts, and the results achieved. In the context of institutionalisation of people with learning disabilities and/or autistic people in Scotland to assess what has been done, you can ask the following questions. These questions are based on the FRA approach.



### Commitment (Structural Indicators)

- Are there laws in the country that protect the right to independent living?
- Are there plans to make sure people with learning disabilities and/or autistic people don't live in institutions?
- Do the laws and plans do everything needed to protect the right to independent living?



### Effort (Process Indicators)

- How much money has been spent to make sure people with learning disabilities and/or autistic people don't live in institutions?
- Are the plans to make sure people with learning disabilities and/or autistic people don't live in institutions being implemented fast enough?
- If people themselves or their families complain about being institutionalised, what happens?



### Results (Outcome Indicators)

- How many people with learning disabilities and/or autistic people leave institutions?
- How many people with learning disabilities and/or autistic people are still in institutions?
- How many people with learning disabilities and/or autistic people are getting the support they choose in their communities?

# Indicators in Practice: Signs of Change

By combining human rights defenders' lived experiences with the FRA indicators, the Commission has created an outline of what progress could look like in Scotland, called our Signs of Change. We hope this will allow human rights defenders and duty bearers across Scotland to measure progress in ending institutionalisation and help them apply some FRA indicators in their context.

This has been done under the following headings:

**Commitment**

**Efforts**

**Results**

Based on the FRA human rights indicators, human rights defenders would expect to see more of anything beside a green arrow. Defenders said there should be less of anything next to a red arrow.

Based on the FRA indicators, these are 15 signs of change which human rights defenders can use to assess whether change is taking place in Scotland.

## Commitment

### FRA Indicators:

- Commitment to the Convention on the Rights of Persons with Disabilities.
- Action plan for transition from institutional care to community-based support.

### Signs of Change



Increase laws, policies and plans that implement the United Nations Convention on the Rights of Persons with Disabilities.



Reduction in laws which can be used to medicalise people with learning disabilities and/or autistic people.

## Effort

### FRA Indicator:

- Involvement of disabled people and their organisations in developing laws and policies that affect them.

### Sign of Change



Increased number of people with learning disabilities and/or autistic people in decision-making at government and local area levels.

### FRA Indicator:

- Training on the Convention on the Rights of Persons with Disabilities required by law.

### Sign of Change



Increase in uptake of learning disability and/or autism awareness training by public services.






Increase in uptake in training on asset-based positive support that works with families as needed.



**FRA Indicator:**

- Access to support services.


**Sign of Change**

-  Increase of community support services for people with learning disabilities and/or autistic people.
-  Increase of trauma-informed services and counselling for people with learning disabilities and/or autistic people and training in the use of de-escalation tactics for those providing support.
-  Increase in recruitment in the social care sector.

**FRA Indicator:**

- Availability of adaptations to homes for disabled people.



**Sign of Change**

-  Increase the number of available social houses.

**FRA Indicator:**

- Involvement of disabled people in deciding where to live.


**Sign of Change**

-  Increase opportunities for supported decision-making in choosing where to live for people with learning disabilities and/or autistic people.
-  Increase of family support (if appropriate) in supported decision-making in people with learning disabilities and/or autistic people choosing where to live.

**Results****FRA indicator**

- Living arrangements available for disabled people.


**Sign of Change**

-  Decrease in long-stay hospitals, private hospitals, and assessment and treatment units.

**FRA Indicator**

- Availability and adaptations of community services and facilities.



**Sign of Change**

-  Increase in the number of people with learning disabilities and/or autistic people accessing high-quality community support.

**FRA Indicators**

- Monitoring of public and private services for disabled people.
- Quality standards for public and private service providers.

**Sign of Change**

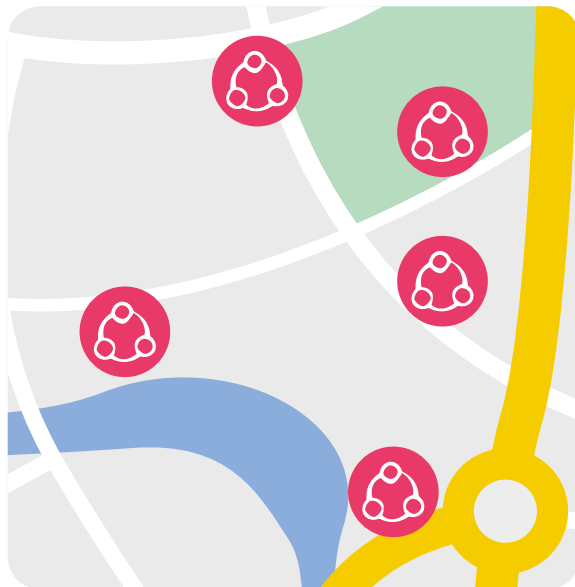
-  Decrease in the use of restraint and seclusion in institutional settings.
-  Decrease in the use of forced medication on people with learning disabilities and/or autistic people.

# Indicators in Practice: Route Map to Independent Living

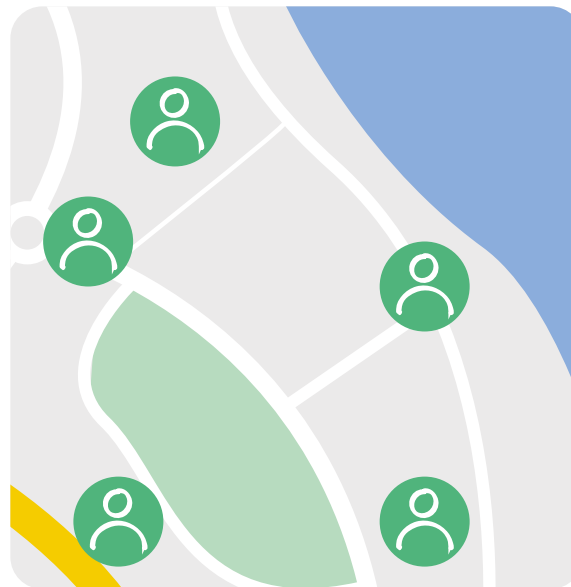
The Measuring Change Human Rights Defenders used their own experience to develop a route map for an independent life for people with learning disabilities and/or autistic people. The Commission has matched what the defenders said with relevant FRA indicators to help give examples of indicators in practice.

The following map brings the two elements together and demonstrates what outcomes for people with learning disabilities and/or autistic people would look like under key FRA Indicators:

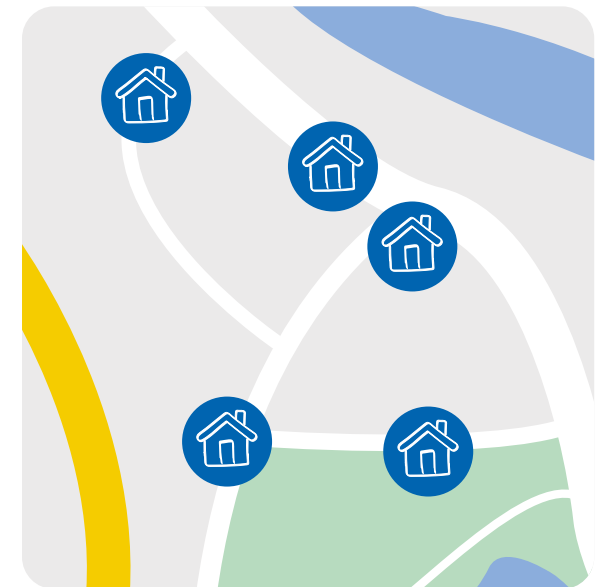
## Access to Support Services



## User Control



## Living Arrangements





## Access to Support Services in Practice



### KEY: Access to Support Services

#### Structural Indicators:

Are there laws which set out the right of people with learning disabilities and/or autistic people to receive community support services to live independently?

Are there laws setting out a right for families of people with learning disabilities and/or autistic people to receive support services?

#### Process Indicators:

How much of the budget has been allocated for community support services for people with learning disabilities and/or autistic people to live independently?

How much budget has been allocated for support for family carers of people with learning disabilities and/or autistic people?

#### Outcome Indicators:

How many people with learning disabilities and/or autistic people were using a community support service to live independently?

How many family carers of people with learning disabilities and/or autistic people received some type of family support services?



## User Control in Practice



### KEY: User Control

#### Structural Indicators

Are there laws that set out people with learning disabilities and/or autistic people's right to choose the type of support they receive and their support provider and decide any changes in their support?

Are there systems in place to ensure people with learning disabilities and/or autistic people's will and preferences are considered when choosing a support service provider and deciding changes of support?

#### Process Indicators

Do procedures for establishing community support services include a self-assessment of needs?

Is information about different types of services and quality of services provided in accessible formats?

#### Outcome Indicators:

The FRA does not provide outcome indicators for User Control.



## Living Arrangements in Practice



### KEY: Living Arrangements

#### Structural Indicator:

Are there laws recognising the rights of people with learning disabilities and/or autistic people to choose where they want to live and who they want to live with the same way other people can?

#### Process Indicator:

How much of the budget has been allocated annually to provide living arrangements in the community for people with a learning disability and/or autistic people?

#### Outcome Indicator:

What is the number of people with a learning disability and/or autistic people with complex needs living in private households or social housing compared to the general population?

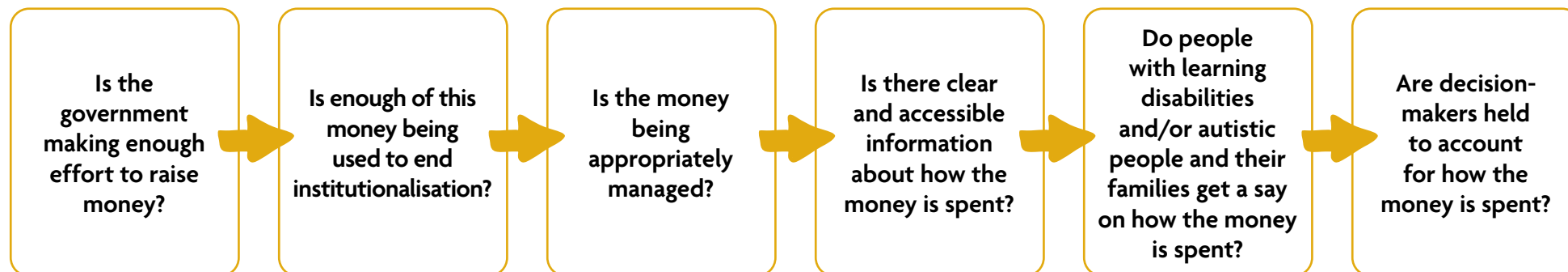
## Follow the Money

All governments must respect, protect, and fulfil human rights. How they raise, allocate and spend money plays a crucial role in how they do this. To respect, protect and fulfil human rights, governments must take positive steps to ensure that people's rights are fundamental. Steps means concrete measures using the most money they can. A helpful way to test if Scotland is making a process on ending institutionalisation is to follow the money; this will help to tell you if commitment and effort have been put into ending institutionalisation in Scotland. To help human rights defenders do this, you can carry out an exercise on human rights budget scrutiny.

### A Step-by-Step Guide to Human Rights Budget Scrutiny

Budget scrutiny is all about asking the right questions. These questions will help you determine whether money has been spent to ensure that people with learning disabilities and/or autistic people live independently in their communities.

You can read the [Commission's Human Rights Budgeting Briefing Papers](#) for more information.



### Human Rights Budget Scrutiny in Practice

Scotland spends money supporting people to live in their own homes with social care support and, at times, spend a long time in hospital. Tracking how Scotland is spending this money could help human defenders better identify patterns in spending that may indicate a problem in realising rights or gaps in spending that, if addressed, would help to uphold people's human rights. The Commission's research has identified challenges in tracking the impact of additional money allocated by the Scottish Government through the Coming Home Implementation Plan to support work to end institutionalisation.

This shows that while the Scottish Government committed to ending institutionalisation in Scotland, the effort required does not appear to be applied, meaning that we have not seen the result of people with learning disabilities and/or autistic people moving out of institutions and living independently in the community.

# What can Human Rights Defenders do?



This section tells you what you, as human rights defenders, can do to stand up for the right to independent living for people with learning disabilities and/or autistic people in Scotland.

If you, or someone you are advocating for, is living in a hospital or with people you or they do not want to live with and do not have choice and control over your living arrangements, this may be a violation of the human right to independent living.

If you are in the hospital because of a learning disability and/or autism and not because you are medically unwell then this may be a violation of your right to independent living.

The right to independent living is not protected in Scots Law currently; because of this, improvement plans, complaints, influencing, and advocacy are the best options currently available to human rights defenders. The following explains how you can use these tools to defend the right to an independent life.

## Share this toolkit

You could share this toolkit with your representative or advocate to guide duty bearers like the NHS and social workers to help them deliver a plan to uphold your human rights to independent living.

You could share this toolkit with your social care support provider or the Care Inspectorate/Mental Welfare Commission.

You could share the human rights framework in the research report with the Director of Social Work and the Chair of the Integration Joint Board and ask them to ensure that this framework is followed when changing your circumstances.

If you are a duty bearer, you can use the human rights framework in the Commission's research report to guide your plans to end institutionalisation.

## Use Complaint Mechanisms

Human rights law says you have a right to adequate access to justice.

You can complain to your MSP, the [Scottish Public Services Ombudsman](#), the [Care Inspectorate](#), and the [Mental Welfare Commission](#).

## Use the rights currently incorporated into law in Scotland:

Whilst this toolkit focuses on the measurement of Article 19 of the UNCRPD, this does not form part of the law in Scotland. However, the Commission has identified that people in institutional care because of the State failing to provide support to live in the community may be a breach of the European Convention on Human Rights, which is protected in law for people in Scotland via the Human Rights Act 1998. If you or someone you advocate for have been in hospital and are unable to leave because there is no social care support available, this may be considered a breach of your Article 5 rights to liberty. If you have experienced ill-treatment whilst being detained, this may breach your Article 3 rights to be free from torture, or inhuman or degrading treatment. It may be worth contacting a human rights legal expert to help explore whether you have grounds to take this through the court system. You would need to access legal aid to help meet the costs of this.

The Scottish Human Rights Commission is not permitted to offer individual advice. Please see our [map of human rights advice centres](#) across Scotland.

## Become a whistleblower

If you work in the NHS and know that practice contravenes any of the human rights outlined in this document, you can report this to the [Independent National Whistleblowing Officer](#).

If you work in social services and require more information on whistleblowing, you can visit the [Care Inspectorate](#) website.

For more information and support with Whistleblowing, you can contact [UK Charity Protect](#).

## Make your voice heard

Along with the Measuring Change Human Rights Defenders, you can advocate for change in Scotland in many ways, such as contacting your local MSP and engaging in opportunities for citizen participation, like responding to Government consultations.

The Measuring Change Human Rights Defenders came up with five key actions for change they think need to happen to ensure people with learning disabilities and/or autistic people are no longer denied the right to independent living. You can use these actions for change or use your own when you speak to your local MSP or take part in consultations.

For more information about the Human Rights Defenders Measuring Change Project or how to use this toolkit in your work to advocate for change, please contact [hello@scottishhumanrights.com](mailto:hello@scottishhumanrights.com).



## Actions For Change

### 1. Be Transparent

Government, health and social care partnerships and local authorities should be able to tell us how they have spent money to get people with learning disabilities and/or autistic people out of institutions.

### 2. Understand People's Differences

Mental health, learning disabilities and autism should be understood differently.

### 3. Be Accountable

There should be an independent panel of people with lived experience of institutionalisation who oversee the work of local areas to get people with learning disabilities and/or autistic people out of institutions.

### 4. Take Ownership

Government and local authorities need to take accountability and ownership for getting people with learning disabilities and/or autistic people out of institutions.

### 5. Support People with Learning Disabilities and/or Autistic People

There should be more community-based support and advocacy for people with learning disabilities and/or autistic people.



# Difficult Words and Terms

This document uses several words some people may not be familiar with. To help explain these words, we have included a section on difficult words and terms you can refer to.



## Accountable/Accountability

Accountable means being responsible for something to someone.



## Duty Bearers

A duty bearer is a person or an institution that have a responsibility to help people realise their human right. For example, councils, the NHS, prisons, transport and housing associations.



## European Convention on Human Rights (ECHR)

The European Convention on Human Rights protects the human rights of people in Council of Europe member countries. 47 Members of the Council, including the UK, have signed the Convention, which is fully titled 'Convention for the Protection of Human Rights and Fundamental Freedoms'.

The Convention consists of numbered 'articles' protecting fundamental human rights. The UK made these rights part of its domestic law through the Human Rights Act 1998.



## European Union Agency on Fundamental Rights (FRA)

The European Union Agency for Fundamental Rights (FRA) is the centre of fundamental rights expertise. It exists to provide expert advice to countries in the European Union on fundamental human rights.



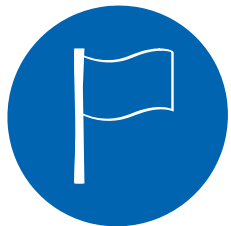
## Forensic Learning Disability Unit

A forensic learning disability unit is a service that supports people with learning disabilities who have or may have come into contact with the criminal justice system.



## General Comment

A General Comment guides how an article in a human rights convention should be understood and implemented.



## The State

The State is the Government, the rule of law and the agencies who uphold that law. For example, the police, armed forces, border control, the courts.



## Transparent

Transparent means you are open and honest and don't have any secrets. For a public body this might mean not having secrets from the people you are there to help.



## Independent Living

Independent living is a movement that advocates for equal opportunities for self-determination and respect for disabled people. The goal is for disabled people to have as much independence and autonomy as possible.



## Incorporation

Incorporation is a legal process that brings rights treaties directly into Scotland's laws; it is like putting two pieces of a puzzle together.



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