

# Why people should move out of institutions



### Contents

Page Introduction 3 Institutions 4 Your rights 6 How has COVID-19 affected people in 9 institutions? What is stopping people moving out of 15 institutions? What should happen 18 For more information 24

### Introduction





The United Nations asked the Care Policy and Evaluation Centre at the London School of Economics and Political Science to look into the situation of people with learning disabilities who live in institutions during the COVID-19 Pandemic.

The **United Nations** is an organisation made up of many countries working together. They work to make the world a safer and better place.

The **Care Policy and Evaluation Centre** is a research centre. The **London School of Economics** is a university.



An **institution** is a hospital or place where people with disabilities live together with support.



**COVID-19** is a new illness that can affect your lungs and breathing.

**Pandemic** means it is spreading around the world.

### Institutions



Rules

An institution is a place where several people live:

- which is away from any local community
- where you can't choose what you want
- where the rules are more important than what people want.





Institutions include:

- long stay hospitals
- care homes



congregate settings - these are places where people live together closely for a period of time.



Around the world, millions of people live in institutions.



Many disabled people live in institutions.

In many countries, most disabled people live in institutions.

### Your rights



The countries of the United Nations all agreed to the UN Convention on the Rights of Persons with Disabilities (CRPD).

The CRPD says that disabled people have the right to:

- live independently
- be included in a community
- choose where to live
- choose who they live with
- live in dignity
- be free to think and choose what they want
- be free to move around wherever they want to go.

But many disabled people are not allowed to do these things.



#### If you can't say what you want

Some people find it difficult to speak up about what they want.



With the right support and care, people can show what they want and where they want to be.



#### **Older people**

A lot of older people live in care homes, which are a type of institution.



Often they become more lonely and have a worse life than older people who live in their local community.



#### Children

Around the world, between 5 and 6 million children live in institutions. Most of them are disabled children.



Children have the right to grow up in a family.



Children who live in institutions often don't get the same chance to learn and mix with other people.



Often children in institutions suffer

neglect - where they are not given the care and support they need



abuse - where someone treats them badly.

# How has COVID-19 affected people in institutions?



We looked at information from around the world about how COVID-19 has affected people in institutions.

#### **Catching COVID-19**

People with disabilities and older people are:

- more likely to catch COVID-19
- more likely to be seriously ill if they catch COVID-19.

It is harder to keep away from other people if you live in an institution.

If some people have COVID-19, it is hard to keep them away from other people at the same time as caring for them.





#### **Deaths from COVID-19**

Many people in institutions have died from COVID-19.

In a group of 21 countries, 4 out of 10 people who died from COVID-19 were in care homes.

In another group of 8 countries, 1 in every 20 people in care homes has died from COVID-19.



#### **Testing people**

When COVID-19 first started, many care homes couldn't test people.

So staff didn't know who should be kept away from other people.



This meant that the illness spread in some care homes.



# People coming out of hospital

In some countries care homes would not accept new people.

They did this to keep people safe.

This meant that people who were coming out of hospital and needed a lot of care had nowhere to go.

In many places, there was not enough support for these people in their local communities.



#### Staff

Staff who work in care homes often work in more than one place.

They spread COVID-19 around from one place to another.

Managers had to stop staff from working in more than one place.

They had to bring in temporary workers.





#### Health professionals

In some places, people like doctors and nurses were stopped from going into care homes.



This meant that people weren't getting the treatment they needed.



#### Visitors

In many places, visitors were not allowed to see people in care homes.

This is bad for people's mental health and wellbeing.



#### Checking on institutions

In many places, checks on the way institutions worked stopped.

So no-one was checking that the care home was being run properly.



#### Children

In some countries, the government said that children who were living in institutions should go and live with their families.



But the families weren't given support to help them look after their child.



In some cases, the family might find it very difficult to cope and put the child in danger.

#### Thinking about what happened with COVID-19



We are worried that COVID-19 has lead to people:

being left on their own which may lead to mental health problems



not getting the right support



not getting the health care services they need.

# What is stopping people moving out of institutions?



The main reasons why people are not moving out of institutions are:

- people's attitudes towards disabled people
- people's attitudes towards older people.



We need to change the way people think about disabled people and older people.





Many disabled people who live in the community get support from friends or family.

With the right support, families can make sure the disabled person has a good life.

But carers often work hard for long hours, for no money. Many carers become very poor and very tired.







#### Money for institutions

In many countries, the government pays money for the institution, but not to help people live in the community.

A lot of people work in institutions. They would lose their jobs if the institution closes and people go and live in their communities.

Some people think that it is cheaper to keep people in institutions than to pay for support in the community.



#### Changes in the law

Some countries have laws that say disabled people don't have the right to make their own decisions.

These laws need to change.



## It takes time to close an institution

If often takes many years to move people out of an institution and settle in a community.

### What should happen



After looking into the situation of people in institutions, we think that these things should happen:

# Change people's attitudes



Countries should:

change the law so that people don't have such bad attitudes towards disabled people and older people



plan to work for many years to change the way people think about disabled people and older people.



#### Involve people

Countries should involve people with disabilities and older people when they:

- plan new services
- talk about changes to laws and how things are done.



## Set up care in local communities

#### Countries should:

set up high quality care services in local communities



support disabled people and older people to choose where they want to live



support people to choose what health services they want



check that community services are working properly



 help families to care for disabled family members



make sure that every child lives in a family



make sure older people can choose where they want to live.





Countries should:

 give enough money for support in local communities





use the money that is being spent on institutions to pay for support in the local community







help disabled people to get a paid job.

Some countries get money from abroad. They should spend this money on good support in local communities.



#### **Better laws**

Countries should:

 have laws to build community services and stop putting people in institutions



- give better healthcare for disabled people in local communities
- change laws so that people are able to make their own decisions.

# Dealing with emergencies



Countries should:

make sure services have enough money to deal with emergency situations, like the COVID-19 pandemic



remember that it is harder to keep people safe from an illness like COVID-19 in an institution



make sure the families and friends of people in institutions are involved in deciding what should happen in an emergency.



#### Long-term action

Countries should understand that it takes a long time to close institutions and move people to live in local communities with good care and support.

### For more information



If you need more information please contact us by:

Website: www.lse.ac.uk/cpec

Post:



Care Policy and Evaluation Centre London School of Economics and Political Science Houghton Street London WC2A 2AE



Email: cpec@lse.ac.uk

Easy Read by **easy-read-online.co.uk**