



This is what you do

Guide to deinstitutionalisation for people with intellectual disabilities

inclusion europe

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Guide to deinstitutionalisation for people with intellectual disabilities.

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Why deinstitutionalisation matters

Living in your own place.

Having friends.

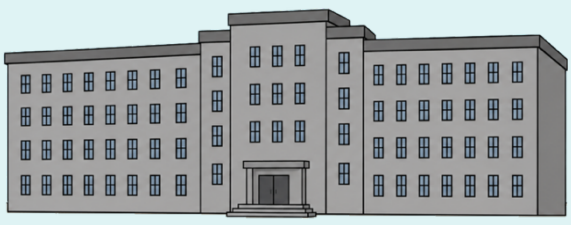
Making your own choices.

Being good at something.

Belonging.

That is what it means to live independently and be included.
For many people, this is just part of everyday life.
They do not think much about it.

But for a lot of people with intellectual disabilities, this is not the case.
A lot of people with intellectual disabilities live isolated in “care” institutions.



What's wrong with "care" institutions?

Close to 1 million people with intellectual disabilities in Europe are segregated in "care" institutions.[1] Most at risk of this segregation are people with complex support needs.[2]

"Care" institutions are residential buildings and services which:

- Separate people in groups, based on their disability.
- Place them far away from their families, friends, and others in society.
- Rule over the person's life with the institution's procedures and rules.
- Remove all the daily stuff people would usually do and replace it with group activities called "therapies", "activisation" or "outings".
- Deny people the opportunity to experience life, gain social skills, build relationships, and grow with age. All in the name of "protection".

Placing people in institutions and subjecting them to these harms is called **institutionalisation**. Institutionalisation is very harmful to people.

It denies them their place in this world, and it denies them their rights.[3]

Despite what institutions like to say, they are not safe places that protect people. Institutionalisation causes psychological harm and puts people at risk of neglect and abuse.[4]

Institutions do not affect only the people living there.

[1] Inclusion Europe, n.d., Statistics
[2] EEG, 2020, Report on the Transition from Institutional Care to Community-Based Services in 27 EU Member States
[3] UN, 2006, Convention on the Rights of Persons with Disabilities (CRPD)
[4] EDF, 2025, It's time to end institutionalisation once and for all!

They also impact their families and friends. When someone lives in an institution, their relationships with people outside are often restricted or lost over time.[5]

Institutions are also a threat to those people with intellectual disabilities who are not institutionalised. Yet.

Many people with intellectual disabilities depend heavily on their families, because there is no support to live independently. The public money has already been spent on institutions.

As a result, parents, siblings, and other relatives may spend years providing support and advocating for their family member.[6]

And for a lot of people with intellectual disabilities, institutionalisation is what awaits them when their families can no longer provide the support they need.[7]

As long as institutions exist:

- They continue to harm people and prevent them from living independently and being included in the community.
- They consume a lot of money that should instead be used to provide support in the community.

For these reasons, institutionalisation is a key issue for the disability rights movement, including people with intellectual disabilities and their families.

The segregation of people with intellectual disabilities and isolation of their families must end.

"Care" institutions must be closed and replaced with support in the community.

[5] Inclusion Europe, 2026, For decades, Prague has sent people with intellectual disabilities away. We're asking the Council of Europe to make it stop.
[6] Inclusion Europe, 2026, Families Should Not Have to Carry Everything Alone
[7] Inclusion Europe, 2025, Inclusion Indicators 2025

What is deinstitutionalisation?

Closing “care” institutions, preventing new ones from being built, and supporting people to live independently and be included in the community is called **deinstitutionalisation**.

To live independently and be included in the community means:

- Making your own choices about where and with whom to live.
- Living your daily life as you want.
- Having the support you need.
- Being able to use public services like everyone else.
- Having people you can rely on, like family, friends, or others.
- Taking part in and contributing to community life.

Everyone can live independently. Some people need more support than others in that.[8]

Independent living does not mean living without support.

There are many people with intellectual disabilities who live independently and are included in their communities.[9]

They have been supported to prepare for adult life, just like other young people.

They can rely on family members, friends, neighbours and organisations, while contributing to the life of others. Just like everyone else.

[8] Navas et al., 2025, Empowering lives: How deinstitutionalization and community living improve the quality of life of individuals with intellectual and developmental disabilities
[9] Plena Inclusión, 2024, Video de viviendas del proyecto 'Mi Casa: una vida en comunidad'

They use public services alongside everyone else because those services are accessible and inclusive.

They can rely on a good disability support.

This is possible for all people with intellectual disabilities.

This is the right for everyone.

Important laws and recommendations

United Nations Convention on the Rights of Persons with Disabilities (CRPD), especially Article 19 on independent living and inclusion in the community.

CRPD Committee General Comment No. 5 (2017), which explains governments' obligations under Article 19.

CRPD Committee Guidelines on Deinstitutionalization, Including in Emergencies (2022).

European Strategy for the Rights of Persons with Disabilities 2021-2030, which calls on EU Member States to advance deinstitutionalisation.

European Commission's Guidance on Independent Living and Inclusion in the Community for Persons with Disabilities in the Context of EU Funding (2024).

Why did we write this guide?

Inclusion Europe wrote this guide because a lot of people with intellectual disabilities are still segregated in “care” institutions.

At the same time, there is a lot of work being done in the name of deinstitutionalisation. And a lot of confusion about what it means.

Sometimes, governments and service providers say they are doing deinstitutionalisation, but in reality, they are not.

- Moving people into smaller institutions, or into "modern” buildings that still separate them from the community, is not deinstitutionalisation.
- Leaving people without support is not deinstitutionalisation.

Policymakers, public authorities and service providers often say that it is not clear how to do deinstitutionalisation, or that it is too complicated. This is incorrect.

- Deinstitutionalisation is not a rocket science. It has been done in many places before. We know it is possible.
- Countries have already closed many institutions and replaced them with support in the community. Some countries are working on it right now.[10]

This guide is mainly for policymakers, public authorities, and service providers responsible for planning, funding, or delivering deinstitutionalisation.

It can also be useful for people with intellectual disabilities and their families who want to understand what deinstitutionalisation is.

[10] Inclusion Europe, 2026, Deinstitutionalisation in Europe - Research brief No. 2

This guide is based on the knowledge we have gained over many years, participating in deinstitutionalisation work and talking with many people involved in it (from people with intellectual disabilities, through service providers, to policy-makers).

It gives recommendations about how to do deinstitutionalisation, and it provides a framework to evaluate whether the process has led to independent living and inclusion for individual people.

Read this guide, and start doing the work to make independent living in the community a reality for all people with intellectual disabilities.



“Living in the community is important
because we can meet other people
and be part of regular life.
We can find work and play an active role in society.”

László Bercse
Chair, European Platform of Self-Advocates

1. Choose your approach

It is the responsibility of governments and service providers to end segregation of people with intellectual disabilities.

Policymakers, public authorities, and service providers must recognise this responsibility and set a clear strategy for deinstitutionalisation.

Strategy is your approach to solving the problem.

Strategy is not a document.

Strategy is nothing without actions that carry it out.

1.1 Set up a structure to guide the change

- Set up a body at the relevant level (for example national or regional), with organisations representing people with intellectual disabilities and their families, and others involved in the transition.
- Make sure this body works in plain language[11] and provides reasonable accommodation so people with intellectual disabilities can take part in discussions and decisions.[12]
- This body should guide the strategy, support implementation, and evaluate the changes.

Always listen to and learn from people who have lived in institutions and now live a new life in the community.



"It is crucial to better involve self-advocates in the deinstitutionalisation process.

To hear their ideas and make sure that their needs are really met.

The whole process should strengthen self-advocacy, so that people moving out from institutions can learn how to speak up for themselves.

People moving out from institutions need to decide freely about where, with whom and how they want to live."

László Bercse
Chair, European Platform of Self-Advocates

[11] Inclusion Europe, n.d. Easy to read
[12] Inclusion Europe, 2026, Events for people

1.2 Different ways to deinstitutionalisation

There are several ways to move deinstitutionalisation forward. They have their advantages and weak points. They can be used together and strengthen each other. The only thing that truly matters is if they lead to people living independently and being included the community.

Changing the law

- Change laws to create a human rights-based framework for disability services.
- This provides clarity and removes excuses not to act.
- The downside: this can take a long time, and implementation is still needed.

Do not wait for the law to change before starting deinstitutionalisation.

One person at a time

- Support people to move out of institutions one by one.
- This can lead to very good outcomes for those who move.
- The downside: it takes time and often people are replaced by new residents.

This approach must be scaled up and combined with closing institutions.[13]

[13] Inclusion Europe, 2026, One example for many: Ceva de spus in Romania.



Now I fight for the 16.607 people who are still in institutions in Romania.

We took out 11 people with disabilities, and I help support them.

All of them are working.

But I also help them in situations when it is hard for them to get used to the life in the community.

Elisabeta Moldovan, Romania

Service provider takes responsibility

- In some cases, the head of the institution takes responsibility and decides to close it.
- This can be very effective and show others that change is possible.
- The downside: it has limited impact on the wider system and is very demanding on the people involved, as it typically means challenging the authorities.
- This approach needs to be linked to wider system change so the results go beyond one institution.

Change driven by money

- Funding, including EU funds, can push public authorities and service providers to act and can help kick-start the transition at a larger scale.
- The downside: it often focuses on building houses rather than improving people's lives and their inclusion in community. It can also take a long time due to complex rules. Meanwhile, national funding continues to be used to maintain and build institutions.

Funding must support independent living in the community, not just buildings, and never segregation. Building smaller institutions is not deinstitutionalisation.

1.3 Do not take forever

Whichever strategy you choose, do not take forever. There is no reason for this process to take decades.

When well prepared and managed, institutions can be closed within a few years.[14]

Do not wait for society to “change” or “be ready” for inclusion.

Society changes because people with intellectual disabilities are present in everyday life, using services, working, and being part of the community.

1.4 Money talks. What does it say about you?

Whatever their “strategic documents” say, budget is where governments, service providers, and funders show what they value.

Many organisations say they support deinstitutionalisation. The real test is where they invest their money. Funding can either maintain segregation, or support people to live independently and be included in the community.

[14] Inclusion Europe, 2026, One recent example for many: Svojšice in Czechia.

All funders have this responsibility: governments, the European Union, private foundations, and philanthropists. They must listen to people with intellectual disabilities and make sure their funding supports inclusion.

Stop funding institutions

No public or private funding should be used to build new institutions.

Do not fund renovations of institutions. Poor conditions in institutions should not be addressed through renovations. Resources must be used to help people move to homes of their choice with the support they need.

When people leave institutions, the funding attached to institutions must be redirected to housing, disability support, personal assistance, accessible public services, self-advocacy, and other measures that enable independent living.



"People in institutions do not need renovations.

They need encouragement,
and they need to live in the community."

Elisabeta Moldovan, Romania

Fund the change

Funders should give their money to actions and changes for inclusion:

- Support to live independently and be included in the community
- Training for people with disabilities, and for professionals responsible for the change.
- Self-advocacy organisations and groups.

- Activities that help people build relationships and participate in community life.
- The practical costs of transitioning from institutional to community-based support.

Pilot projects and examples of good practice are valuable, but they are not enough without clear measures to make them a lasting, structural change.

- Funders should not distract providers with tasks that have little relevance to ending segregation.
- Funders should resist moving on to the next topic before institutionalisation has been resolved.

Money talks.

If funding continues to go to institutions, institutionalisation continue.

If funding supports independent living and inclusion, good things start to happen.

More about funding deinstitutionalisation

European Commission: Guidance on independent living.

EEG: Checklist on EU funds.

Inclusion Europe: Position paper on EU money,

2. Close the institutions

Governments and service providers must support people to leave institutions and to build a new life in the community.

And they must close the institutions for good.

The larger the number of residents, the more urgent the need to close the institution. But a building does not stop being an institution simply because it has fewer residents. Smaller institutions must also be closed.

Just moving people out without providing the support they need is rights, and it's not deinstitutionalisation. Closing institutions without providing housing and support puts people at risk. Support for independent living must be in place every step of the way.



2.1 Move people out of the institution

Find new homes

Each person moving out of an institution must have a real home in the community. It is necessary to find and secure a place to live for every person.

- Find out about each person's preferences and choices.
- Make sure people are on public (social) housing waiting lists.
- Use housing that already exists in the community, such as apartments and family houses in residential areas.
- Make adaptations needed for people with reduced mobility.

There is not enough housing in many places in Europe.[15] Because of this, new housing needs to be built, including for a lot of people with intellectual disabilities:

- When building housing, reserve a part of it for people moving out of institutions.
- Build housing in regular residential areas, with good access to public services; not in isolated locations.
- Do not build in remote areas with poor access to transport, health care, or other public services. This increases dependence.
- Don't build housing in industrial areas or on the ground of institutions (such as hospitals or care homes).

[15] Inclusion Europe, 2025, "What the EU's new Affordable Housing Plan means for people with intellectual disabilities and their families"

Housing must be a real home:[16]

- Do not combine the home with a service space (for example, no staff office inside the home).
- Do not place other disability services (such as day centres or workshops) in the same building.
- People should need to leave their home to go to work or activities, like everyone else. As a rule of thumb: is the person able to walk from their room into a “day centre” or “workshop” without having to put their shoes on? “Yes” is the wrong answer.

Housing and disability support must be separate. A person with intellectual disabilities should have a home that is not linked to using a specific service.

- Changes in support must not affect where the person lives.
- People should not risk losing their home if they change or stop a service.
- As a minimum, there should be separate contracts for housing and for disability support.



“It took me about 3 years to move out and look for a place.

I got support from two organisations.

One was a group that helped people to get out of institutions and taught people how to manage their own budget.

They also allowed you to choose a support person and you choose who you pick.”

Paul Alford, Ireland

[16] Inclusion Europe 2024: Housing for people with intellectual disabilities: Issues, ideas, practices

Support each person to establish a new life

Every person leaving an institution needs support to build a new life in the community.

This includes support to recover from the harm and trauma caused by institutionalisation.

- Provide individual support to each person during and after the move.
- Include people with complex support needs from the start, and make sure there is enough support. They are frequently and wrongly viewed as incapable of living independently.[17]
- Do not "cherry-pick" only those seen as easier to support. With the right support, everyone can live in the community.

"Julia was always seen as too disabled to be involved in the community, or even to be involved within the houses she lived in: Other residents were 'more able' than her. She was destined to a life of drowsing and children's songs.

When she became too bored with life she would slump in her chair and sleep most of the time. Her parents saw this as a sign that Julia was unhappy, and decided to move her into her own home.

When Julia moved into her own home, we first looked at which support workers she wanted to take with her. The aim was to create a good life together with Julia.

Julia is always involved with the interviews of potential new staff. There is always someone whom she trusts from her circle and another team member.

[17] Vehmas, S. & Mietola, R., 2021, Narrowed Lives - Meaning, Moral Value, and Profound Intellectual Disability

All of us have to think about what a good life for Julia means. And what responsibilities choices bring with them.

She has come to know many people in her neighbourhood and now has an important role in connecting neighbours to each other."[18]

Understand the person and their wishes

- Find out about each person's experiences, expectations, and ambitions.[19]
- Use a person-centred and collaborative approach.
- Help the person capture their life story and wishes for the future.
- Involve the people who are important to the person's life, with their permission.

People living in institutions may have had few chances to make choices or try different things. This can limit what they expect from life.

Help people explore options and gain new experiences, so they can make informed choices about their future. This must include people with complex support needs.



"I know my life and all what I do stand on very fragile legs.

I am always afraid I might have to return to an institution and lose my freedom."

Senada Halilčević, Croatia

[18] Inclusion Europe, 2018, "When people meet Julia now, they see someone who is awake and intensely enjoying life"

[19] Inclusion Europe 2026: Supported decision-making

Prepare the transition

- Give people the chance to visit their new home several times before moving.
- Help them get to know the home, neighbourhood, and neighbours.
- Make sure that funding, support, healthcare, and other practical arrangements are agreed and in place.
- Have clear plans for who will provide support and what will happen if problems arise.

Support relationships and community inclusion

- Support the person to build and keep relationships, and to take part in everyday social life.
- Help the person develop social roles, such as being a neighbour, friend, or colleague.
- Make sure the person has a trusted contact outside the institution to support them during the transition and provide a connection to the new life. This can be a professional, a friend, or a volunteer.

Address harm and trauma

Many behaviours described as “challenging” are a response to institutionalisation and trauma.[20]

- Stop viewing behaviour as “challenging” and recognise it as a form of communication.[21]

[20] FRA, 2025, Places of Care = Places of Safety? Violence against persons with disabilities in institutions
[21] Challenging Behaviour Foundation, 2024, Communication and Challenging Behaviour

- Acknowledge the harm, abuse, or neglect the person may have experienced.
- Provide appropriate support, including psychological support where needed.

Violence in institutions

Life after violence report: regular version in English.

Easy-to-read version in:

- English
- Dutch
- Croatian
- Italian
- Lithuanian
- Romanian

How to talk about violence with women with intellectual disabilities.

(All links open PDF files.)

Compensate people for the work many have done and are still doing in institutions without any pay.



"I got money from the government
because when I was in the institution,
I had to work in the workshop, and it was slave labour:
50 pence a week working for 10 hours in a news agent
and doing everything they wanted."

Paul Alford, Ireland

2.2 Close the institution for good

Institutions must be closed when people move out. Leaving institutions open creates serious risks:

- New people may be placed in the institution to “fill empty beds”.
- Institutions continue to use money and staff that should support people to live in the community.
- As fewer people remain, institutions become more expensive to run. This can create the false idea that deinstitutionalisation is costly.

There should be a clear plan for what will happen to the building after the institutions closes, to make sure it isn’t re-used as another institution. But not being sure how the building can be used isn’t an excuse to keep segregating people in it.

Stop all new admissions

Stop all institutions from taking in new people.

- Clearly announce that institutions will no longer accept new residents, using easy-to-understand language.
- Explain why institutionalisation is harmful.

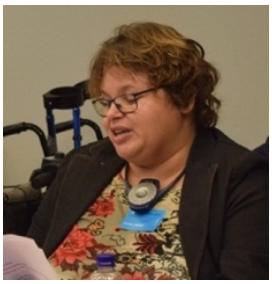
While they are still open, institutions must carry a clear warning: placing people with disabilities in institution is harmful, segregates them, and prevents full inclusion in the community.

For every person who would otherwise be placed in an institution:

- Offer person-centred support to understand their situation and wishes.
- Help them find ways to live independently in the community instead.

Never take in a new person to replace someone who moved out of the institution.

- Each time a person leaves, reduce the institution's official capacity.
- As people move out, redirect the money from the institution's budget to support them to live independently and be included.



"My biggest fear is that I will be put back into an institution.

If I feel good about something I also fear that this good feeling will be taken away from me."

Mirjam Braspenning, the Netherlands

Set a clear timeline

- Large institutions can be closed within 3 to 5 years. It has been done before.[22]
- The longer the process takes, the more expensive it becomes and the longer people are exposed to harm.
- Clearly communicate the closing date to everyone involved.

[22] Doing DI, 2024, Institution for 116 people in Czechia - CLOSED

Plan and manage the transition

Create a transition management structure and set a clear plan of action.

- Set up a team that includes people living in the institution, staff and management, and external organisations involved in support.
- Develop a clear plan of action, so everyone understands what will happen, in what order, and what their role is.

Communicate clearly about the change

- Explain in plain language why institutions must close and how they harm people.
- Describe what the change will look like and what the result will be.
- Talk about people and how their lives change for the better, not about complex processes, projects, or buildings.
- Avoid expert language and unnecessary complexity.
- Give people who have lived in institutions the support and platform to speak about their experiences.
- Inspire. Build a positive vision of the future.

Support and retrain the staff

Educate staff in relevant skills and understanding of deinstitutionalisation:

- Provide training and support to the staff to prepare them for new roles.
- Develop training together with people with disabilities, especially those who experienced (de)institutionalisation.

- Make sure the staff understand why the change is happening, what the goals are, and how each person can contribute to achieving them.
- Support the staff to see their role in the change and the benefits for their professional development.

Stay focused

Many issues may emerge along the way of closing institutions, and there will often be pressure to slow down, postpone decisions, or shift attention elsewhere.

Stay focused on finding each person a new place to live and helping them to have the support they need to live independently and being included.



End of segregation means I can be part of the community in which I live.

I can work, study, meet new people and make friends.
I am no longer invisible.

For the first time people notice me in society.
I am much more than my disability.

I am Senada Halilčević: sister, daughter, friend, colleague, athlete, employee.

Senada Halilčević, Croatia

3. Support inclusion in the community

People with intellectual disabilities have the right to live independently and to be included in the community.

This means having the right to decide, and support in decision-making. It means housing, accessible public services, education, employment...

It means governments preventing institutionalisation and supporting families who provide support.

All of this is important.

But sometimes, governments and service providers use it as an excuse to avoid deinstitutionalisation. They say that to close institutions all these things have to in place. That's untrue.

Institutions can and should be closed without waiting for a complete transformation of the system.

Still, there are things that need to be done.

3.1 Provide housing

Everyone needs a place to call home.

Home is a room over your head and a place where you feel safe, are comfortable, and have privacy. It's where you have your own keys and where you decide who can come in.

Some people with intellectual disabilities are homeless. Some live with family because there are no other choices. Some still live in institutions. All these people need real housing options in the community.[23]

People need ongoing access to housing.

- Build housing in the community and designate a portion of public and private housing for people with intellectual disabilities.
- Support to help people find and keep their home, or move when needed.
- Make sure people have enough income to pay for rent, bills, and daily living costs.
- Pay for accessibility changes to homes (including private ones) so people do not have to leave when their needs change.

"The sheltered housing staff helped me overall along with the carer: What to expect in the flat, what to look out for. They also helped me find independent living services.

Then, sheltered housing made a referral for me when I applied for a council flat.

It is a little harder now. I have been living in the city's youth starter home for 3 years. But my lease is up, and I am looking for another place.

[23] Inclusion Europe, 2024, Housing for people with intellectual disabilities: Issues, ideas, practices

Every now and then my former guardian lets me know that a city apartment is available. I'm waiting for the city to get back to me about an apartment becoming available. It is not easy."

Lukáš Kudlička, Czechia

3.2 Make public services accessible and available

Public services must be available and accessible to everyone. This includes schools, health care, employment support, libraries, community centres, or transport.

When public services are not accessible, people with disabilities cannot use them.

Barriers can include buildings that are hard to enter, information that is hard to understand, strict rules, or not enough trained staff.

These barriers push people with disabilities out of everyday services and into separate, disability-specific places.

- Make public spaces and buildings accessible. Remove physical barriers, and use universal design. Make signs easy to understand.
- Provide information in easy-to-read formats, so everyone can use services independently.
- Support staff to work well with everyone. This includes fair pay, good working conditions, and training for the right attitudes and skills.

3.3 Make disability support available to everyone who needs it

"Recognising" the right to live independently is not enough. People need disability support to make this real in everyday life.

Disability support can take many different forms. There is no one solution that works for everyone. Support must be flexible and based on clear principles.

Personal assistance is an example of support that is person-led and flexible. It means the person chooses who supports them, when, and how. It should be available to everyone who needs it, wherever they live.



"From this year, I have the support of a personal assistant, and this has changed my life.
In these four months, I have had many beautiful moments which I had never dreamed of.
I never thought how wonderful our lives can be.
I want others to have a life without any problems too."

Gayle Mugliette, Malta[24]

Politicians, public authorities, and disability service providers must scale up what works and make it available to everyone. They should:

- Invest in disability support that helps people live ordinary lives.
- Remove administrative and organisational barriers.
- Make support available where people live, without forcing them to move house, region (or country!) for disability support.

A person's life cannot be left to a "post-code lottery", where their rights and quality of life depend on where they live.

Good disability support exists in every European country, but it is not available to everyone.

[24] Photo from Roberta Metsola's Facebook page

There's disability support and there's "disability support"

Good disability support should:	Disability support should NOT:
Focus on the person's life, wishes, strengths, and goals.	Focus only on a person's "limitations" or try to "fix" them.
Help people live an ordinary life and be a part of the world around them: to be part of a family, to have friends, to have a job, to be good at something.	Replace relationships and public services with artificial activities and artificial relationships.
Support people to use mainstream public services, such as healthcare, education, transport, and leisure activities.	Take control of a person's life because other services are not inclusive.
Be available where and when the person needs it: at home, at work, or when going out.	Force people to go to a specific place at a specific time or move into institutions to receive support.
Be led by the person. The person decides what the support is for and how it works.	Treat people as passive "service users" of fixed services.
Communicate in ways that work for the person, using easy-to-understand language or other means of communication suitable for the person. Be clear about how the support works and how the person can influence it.	Use complicated systems or expert language to keep power away from the person and make it difficult to understand how to influence the service.
Be reliable and stable, so people do not live in constant uncertainty.	Leave the person in uncertainty about their future because of short-term funding or sudden changes in support.

Provide tools for people to control their disability support

People with intellectual disabilities need to have control over how their disability support is organised and funded.

- At individual level, people should have access to tools such as personal budgets. Personal budgets must be easy to understand, easy to use, and flexible so people can choose the support that fits their life.
- At national, regional, and local levels, disability organisations must be present and active in making decisions about disability support funding.

Provide funding and organisational support for self-advocacy organisations to organise, speak up, and influence laws and policies.

- Make sure people with intellectual disabilities are actively involved in how services are run, including being part of decision-making bodies of support providers.

Apply thorough monitoring of disability services. Monitoring must be:

- Led by people with intellectual disabilities.
- Focused on rights and quality of life.
- Done independently from service providers and funders.
- Performed with reasonable frequency.
- Have results that are easy to understand and easy to access for the public.
- Lead to real consequences and improvements in case of wrongdoing.

3.4 Restore people's right to decide about their life

People with intellectual disabilities have the right to make decisions about their own lives and the support they receive.

This right must be respected in practice. All restrictions that take decision-making away from the person must be removed. This includes full or partial guardianship and other forms of substitute decision-making.

People must be supported to make their own decisions. Governments should:

- End guardianship systems that replace a person's decisions with decisions made by others.
- Invest in supported decision-making, where people get the help they need to understand options, express their will, and make choices.
- Develop and share clear resources, good practices, and tools that support people's right to decide.[25]



"Volunteers came to the institution. People who cared about me and supported me. They took me on trips, and I visited other places. Thanks to them I got to know the outside world!

It didn't take long to know I wanted to leave the institution.

I started working, doing the laundry and ironing. But I still lived in the institution, and they were trying to forbid me everything. That's when I started to get help from a supported decision-making group. I did not have full legal capacity, but I could take more decisions on my own."

Barbora Mikulová, Czechia

[25] Inclusion Europe, 2026, Supported decision-making

3.5 Provide support for families of children with intellectual disabilities

Families need support to be a family, not only "an informal care provider".[26]

- Provide early diagnosis and early intervention that is easy to access and easy to use for all families.
- Support families to help their child grow, gain experience, and learn skills for an independent life.
- Help families during "transition periods", such as between different stages of schooling, between school and work, and between the family home and a place of one's own.

3.6 Don't wait for "society to change"

People with intellectual disabilities have the right to live independently and to be included.

They have the right now; not when someone decides society's ready.

Many things still need to improve.

People with intellectual disabilities need good education, jobs, money to cover costs of living with a disability, the right to make their own decisions...

Governments and society must work to improve all of this and more.

But it isn't an excuse to delay action on independent living and inclusion.

[26] Inclusion Europe, 2026, Families Should Not Have to Carry Everything Alone

Do not wait for society to “become inclusive” before deinstitutionalisation.

Do not wait for all systems to be perfect before “allowing” people with intellectual disabilities to move out of segregation and into the community.

Change does not happen before people are included.

Change happens because people are included.



Uphold everyone’s human right
to live in a home of their choice,
in a community they choose,
close to the people they love!

Heather Gilchrist, Scotland, UK

4. Study it. Share it. Repeat it.

Deinstitutionalisation means closing institutions, preventing people from being institutionalised, and supporting independent living and inclusion in the community.

How do you know if your work contributes to this?

This chapter presents a draft of a framework for governments, service providers, organisations and others can use to monitor deinstitutionalisation.

To understand whether deinstitutionalisation is happening, two things matter:

1. How many people are segregated in “care” institutions, and how many were supported to leave them?
2. What kind of life do people have?

The data available to you will depend on your situation.

- You may have numbers, for example about deinstitutionalisation processes in your country.
- You may have stories and experiences from people who left institutions.

Both are important.

If you have no data available, the first step is to start producing it.

4.1 How many people?

The first thing is to have numbers to know how many people are affected and how many benefit from deinstitutionalisation.

- How many people are in “care” institutions?
- How large are these institutions?[27]
- How many people have left institutions?
- How many institutions have closed?
- How many new institutions have opened?

Find these numbers, publish them, and update them regularly.[28]

4.2 What kind of life do people have?

To understand how people’s lives change after leaving institutions, look at what happens in the main areas of people’s lives:

- Decision-making: Does the person have the right and support to make their own decisions?
- Housing: Where does the person live? Is it their own home in the community?
- Relationships: Does the person have meaningful relationships and social connections in their community?
- Work: Does the person have a job and income?
- Leisure: Does the person take part in everyday activities in the community and get support to do things for fun?

[27] Inclusion Indicators offer some ideas about how to monitor size of institutions.

[28] Example of long-term monitoring of institutionalisation: Institute on Community Integration at the University of Minnesota.

What to look for in each area

In each of these areas, it is important to look beyond appearances. Some situations may look good at first, but do not mean that the person lives an independent and included life.

- A person might live in their own apartment, but never choose themselves what to eat for dinner.
- A person might have contact with friends and family, but no opportunities to make new connections.
- A person might do sports regularly, but only in settings organised by disability services.

When looking at the different areas of a person's life, we base this draft framework on **"Five Valued Experiences" by John and Connie Lyle O'Brien.**[29]

Five Valued Experiences are:

- Belonging: having relationships and being part of the community.
- Being respected: being seen for your abilities and treated with dignity.
- Sharing ordinary places: taking part in everyday community life.
- Contributing: doing things that matter and are valued by others.
- Choosing: making your own decisions about your life.

Use these five ideas to ask questions about each area of someone's life.

Ask people themselves about their lives and experiences. People with intellectual disabilities must be supported to take part in assessments.

This includes making sure that people with complex support needs can have their say in ways that work for them.

[29] Neighbours International, 2019, 5 Valued Experiences and the 5 Accomplishments

What questions to ask

Area	What to look at	Questions to ask
Decision-making	• Legal capacity situation • Support to make decisions • Control over everyday life	Do you have the right to make their your decisions? Are you under guardianship or other forms of substituted decision-making? Do you have support to make choices when you need it? How do you make choices in you daily life?
Housing	• Type of housing (institution, group home, family home, own home) • Connection to the community • Choice and control over housing	In what type of housing do you live? How many people live together in each room and in each place? Is your home located in ordinary neighbourhood? Who decided that you'll live here? Can you change your house and support without losing one or the other?
Relationships	• Personal relationships • Community connections • Opportunities to build relationships	Do you have regular contact with family and friends? (if you want to) Do you have relationships with people outside of disability services? How do you take part in community life? What kind of role do you have in other people's lives?
Work	• Type of work (open labour market, sheltered, daycare, none) • Choice of work • Work support	What type of work are you doing? Are you paid fairly for you work? Can you choose if and where you work? Do you have support to find and keep meaningful work? Do you have opportunities for education and training?
Leisure	• Type of activities • Choice of activities • Support for interests and hobbies	Do you take part in everyday activities in the community? Who decides how you spend your time? Do you have support for your personal interests and hobbies (transport, funding, staff), including in different places and at all kinds of hours?

Check change over time

It is important to look at change over time. This helps to see whether improvements are real and lasting.

- What was the situation before leaving the institution?
- What changed after the move?
- Is the change still there after 1 or 2 years?

4.3 Talk about the change

What you find out through your work and monitoring is worth sharing. Talking about deinstitutionalisation does two things:

1. **It shows progress.** Tell people what has changed. This makes progress visible, and it holds governments and service providers to their promises.
2. **It inspires more work.** A lot of what we hear about deinstitutionalisation is negative. People need to hear that deinstitutionalisation works. When people see that someone moved out of an institution and now has a home, a job and friends, they understand that change is possible.

It’s urgent and necessary, and it’s not a rocket science

Deinstitutionalisation is clouded by many misunderstandings and distractions. This doesn’t help people with intellectual disabilities live a full life, included in society.

I have been involved in deinstitutionalisation in different countries. I often travel to help governments and organisations understand what they need to do. I meet people who are a little surprised how clear the task is – and very willing to help make it happen.

This guide is for them, and I hope for you. It shows in plain words how important and urgent the issue is, and what needs to be done.

“Care” institutions segregate people with intellectual disabilities from everyone else, because of their disability. They separate people by place: away from where others live, behind walls or fences. And by activity: sleeping, “working” and free time, always in the same place, with the same people you did not choose. Institutions take away person’s control over their life, deny them relationships and social roles, and put them in harm’s way.

In short: Involuntary congregated housing + Segregation in space and activity + Someone else’s rules = Institutionalisation

Deinstitutionalisation means removing these elements.

It means providing support that puts the person at the centre, so they can be part of the world around them: to be part of a family, to have friends, to have a job, to be good at something. It means supporting families so they can simply be families, for all their members.



None of this is rocket science.

It has been done before, and it is being done right now.

So, let’s close institutions everywhere, and support everyone to have a home and to be included – to have places to be, things to do, and people to see.

Milan Šveřepa