inclusion
europe

Submission for the European Commission's "Guidance recommending to Member States improvements on independent living and inclusion in the community"

#End Segregation

Making decisions

Belonging.

Europe... of peop... intellec... and the...

Living independently

Going to school and having a job

For me, the end of segregation means that 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.

Now people can understand that I am much more than my disability.

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

And every day, I try to show I can achieve everything I want.

Senada Halilčević, Croatia[1]

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[1] I am no longer invisible, for the first time people notice me in society - Senada Halilčević

Living in your own place.

Having friends.

Making your own choices.

Being good at something.

Belonging.

That is what the right to live independently and to be included means to us.

Most people take these things for granted, and barely think about them.

But for a lot of people with intellectual disabilities, it's not even a dream.

It is something that was never introduced into their life.

They live constantly overshadowed by someone else's decisions, dependent on the will and rules of others. They must prove themselves again and again: That they can do this or that, that they can work, that they can be good parents, that they are able to make decisions…

A lot of people with intellectual disabilities are segregated in "care" institutions.

These institutions

- separate people in groups, based on their disability;
- place them away from their families and friends, from 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 from the person, and replace it with group activities called therapy or activisation;
- deny the person their opportunity to experience life, to gain social skills and build relationships, to grow with age – to have a place in this world.

A lot of people with intellectual disabilities live in a situation where they are completely dependent on their relatives for support and care.

They cannot set up their own home when adult.
They cannot decide about their own things.

This also often means that instead of being a mother, father, sister, or brother, family member becomes full-time carer, therapists, services coordinator and administrator.

Of course, there are also many people with intellectual disabilities who do live independently and who are included in their community.

Mostly people whose families have set out to prepare them for independent life in adulthood. Just as most families would do for their children.

People who have relatives, friends and organisations in their life, where they can rely on and benefit one another in all kinds of ways. Just as all other humans do.

People who use public services just as anyone else would, as the services are accessible, and the person has the means to pay for them.

People who have good disability support.

To live this way, to live independently and to be included is the right of every person with a disability.[2]

That is the law.

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[2] [Convention on the Rights of Persons with Disabilities | OHCHR](#)

This law that has been explained many times, often in a very good and clear way.[3]

Politicians, public authorities, and disability service providers cannot pretend they don't know this law, or that they don't understand it.

Nor can they pretend they don't know what good disability support looks like.

Still, many politicians, public authorities, and disability service providers act as if they don't know the law, or have never heard of good disability support.

They keep forcing people into "care" institutions, giving money to these institutions, even building new ones.

They often delay the necessary change towards de-segregation with talk about "need for evidence", or about "need to find good practice".
Harmful nature of institutions was described in the 1960s, and countless times since.
There is plenty evidence already.

> "Sometimes asking for more evidence is just another way of justifying human suffering".[4]

Some politicians, public authorities, and disability service providers delay this change saying they must "protect people with disabilities" and inclusion will only be possible when "society is ready".

Others still paint this change in such an overcomplicated and unnecessarily complex way that nobody would even know where to start.

Sometimes, countries or service provides call "independent living" and "deinstitutionalisation" actions that have nothing to do with either of them.

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[3] General comment No.5 on Article 19 - the right to live independently and be included in the community | OHCHR

[4] http://revisionisthistory.com/episodes/22-burden-of-proof

For all these reasons, it is a good idea for the European Commission to write a "Guidance recommending to Member States improvements on independent living and inclusion in the community":

- The document should set out actions in support of the right to live independently and be included.
- It should focus on structural reforms, to overcome the limitations of current approach based on "projects", "pilots", and "good practice examples".

The document does not need to be explaining what the right to live independently and to be included means; This is clearly stated in the CRPD[5], and has been repeatedly explained and demanded by disability activists.
"Lack of understanding" is not the issue, lack of action is.

I think community-based living is important because we can meet other people and be part of the regular life of our communities.
We can find work more easily, live independently with the right support,
and play an active role in society.
We need inclusive communities who support us to take part.
László Bercse, Hungary[6]

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[5] And well clarified in General Comment on article 19 of the CRPD.

[6] Living freely and being members of communities like everyone else

What does it mean?

Inclusion Europe's view of what some things are (and are not):

Living independently and being included	
Living in your own place. Having friends. Making your own choices, having control of the way you live. Being good at something. Belonging. To live independently, we all depend on others. We have mutually beneficial relationships. Some people may need more support in some areas of their lives than others.	It doesn't mean everyone is living on their own, left to their own means and devices, without any support at all. It is not subject to person's skills or abilities: Nobody can say "this person cannot live independently". This is especially relevant for people with complex support needs, who are very frequently considered as "incapable of living independently" or as "unable to see any difference in how things are". These claims are manifestly not true.[7]
Independent living service	
It can and should be many things. It should be what every disability support service aims to achieve and has its guiding principle. (See dedicated section below for details.)	Many countries and service providers use this term to describe some kind of service for people with disabilities.

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[7] 'Narrowed Lives. Meaning, Moral Value, and Profound Intellectual Disability', discussion with the authors Reetta Mietola and Simo Vehmas - Inclusion Europe (inclusion-europe.eu)

| | Often, and despite its name, the service does not support people to live independently and to be included.

For example, a residential service for a large group of people with disabilities is called "independent living" in some places. |

"Care" institutions	
Places where people with disabilities are segregated from society because of their disability, where all relationships and social interactions are restricted to the staff and other residents, where the institution's rules control the person's life, and where every usual human activity has been removed and replaced with "therapies" and "activisations".	Despite to what they like to claim, "care" institutions are not a safe space for the people living there. Institutionalisation causes psychological and developmental harm. A lot of abuse and violence happens in institutions.

Institutionalisation is a form of violence. |

Deinstitutionalisation	
Supporting a person to move from "care" institution, and to set up own home and life being included in the community.

Changing disability services (including their laws, funding etc) so they no longer segregate and subjugate people, but instead provide them with support they | Taking people from one institution and placing them in a "nicer", modern institution is not deinstitutionalisation.

Placing people with disabilities in a group of smaller houses in the same location is not deinstitutionalisation. |

need to have their own place to live, to be part of a family, to have friends, to have a job, to be good at something; To belong.	Leaving people without any support at all, or just sending them back to their family is not deinstitutionalisation. Deinstitutionalisation is not an "Eastern European" issue. There are "care" institutions all over Europe. Deinstitutionalisation is not an "innovation", nor is it a "pilot project" for EU funding; It is an obligation. It has been in practice for decades.

"From this year, I am benefitting from the support of a personal assistant, and this has changed my life. There are still hiccups in the system, but I am now living a 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 feel lucky that I come from the age bracket when positive changes started to happen in Malta.
I want others to have a life without any problems too.
Gayle Mugliette, Malta[8]

Actions in support of the right to live independently and to be included

Every country needs to:

1. Make public services accessible and available.

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

Limiting their accessibility (with physical and cognitive barriers, wrong rules, lack of staff etc.) prevents people with disabilities from using these services, and contributes to the creation of segregated disability-specific places and services.

- Make public spaces and buildings accessible, remove barriers in physical environments, use universal design, and make signage accessible;
- Make information about these services easy to understand so they can be used by everyone;[9]
- Support employees to be ready and happy to work with anyone. Provide good pay and working conditions. Educate all employees for appropriate attitudes and skills.

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[9] Easy-to-read - Inclusion Europe; CEACOG. Centro Español de Accesibilidad Cognitiva

2. Provide housing for people.

Everyone needs a place to live.

Many people with intellectual disabilities are homeless, either literally or virtually. There are many homeless people who have intellectual disabilities. And there are many people with intellectual disabilities who have been living with their parents for ever or placed in "care" institution as there is no housing available to them.[10]

- Build housing.
- Designate a relevant portion of housing (public and private) to people with intellectual disabilities.[11; 12;13]
- Enter people with intellectual disabilities onto the waiting list for public (social) housing.

> Individualized housing arrangements consistently demonstrated favourable human rights outcomes, specifically for self-determination, choice and autonomy. Individualized housing options also demonstrated favourable outcomes in regards to social relationships and participation in domestic tasks.
> The review also demonstrated the importance of formal and informal supports for the success of individualized living arrangements.[14]

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[10] „I've been on the waiting list for social housing for so long. All my brothers and my cousins have one but being disabled with two children doesn't seem to be enough to be prioritised. [...] My son is 12 years old and no longer concentrates in school. This situation has been going on for 11 years and has affected my whole family." Mr. S., on the waiting list for social housing for 11 years. 7th overview of housing exclusion in Europe (2022), p 33.

[11] To be very clear: We mean for a portion of general housing to be made available for people with intellectual disabilities. We do not mean disability-specific housing (such as a house where only people with intellectual disabilities would live).

[12] Malta: „Renovation of 200 properties confiscated from the Mafia to underpin … social inclusion of homeless people, victims of violence, elderly people, people with disabilities, the Roma, and young people." 7th overview of housing exclusion in Europe (2022), p 13.

[13] Unaffordable and inadequate housing in Europe provides many examples of how housing for people with disabilities is supported in EU countries.

[14] The outcomes of individualized housing for people with disability and complex needs: a scoping review (tandfonline.com): „There were many significant gaps in the research, including an absence of systematic and comprehensive evidence of the outcomes associated with individualized housing, particularly for people with acquired disability and complex needs."

- Provide support for people with intellectual disabilities to access and retain housing.
- This includes providing them with sufficient income to cover the costs of housing and the costs of living. (More on support in next section).

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 support 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.
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[15]

- Provide money for accessibility renovations of houses and apartments, including private ones. Prevent people from having to leave their home just because they may have reduced mobility and cannot move around the house, or cannot leave it to go shopping, see a doctor, or visit friends.

- Build public infrastructures serving multiple communities. Avoid building "centres" just for older people, or just for people with disabilities. Build for everyone to encourage social inclusion and save public money.[16]

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[15] "No institution can replace a proper family"

[1616] Space for Community: Strengthening our Social Infrastructure

3. Restore people's right to decide about their life.

Remove all restrictions to person's right to decide (full or partial guardianship or other forms of substitute decision making).

Give money and provide structural support to supported decision-making initiatives.

[Right to decide](#) resources, practices and more.

4. Make disability support available to everyone who needs it.

"It is hard to talk about the formal right to live independently and be connected to the community without talking about the kinds of services needed to make it a reality."[17]

Disability support can have many different forms. There is not one size that fits all. Different people have different expectations, and different organisations can have different approach to how they provide support.

Identify disability support based on the right principles; Scale it.

In disability support, invest in people, not in bricks.

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[17] Transformation of services for persons with disabilities [Report of the Special Rapporteur on the rights of persons with disabilities](#), p 5.

What we think disability support should (and should not) be about:

Disability support	What disability services shouldn't do
Seeks to find out about the person's experience, expectations, and strengths, and helps them to live their life to the fullest. providing support and care that puts the person and their wishes and needs at the centre of supporting them to be part of the world around her or him – to be part of a family, to have friends, to have a job, to be good at something.	Identify the person's "limitations" and "disabilities" and set out to "compensate for their lack of skills and abilities".
Is highly focused on helping the person to have the usual social roles and interactions, and to make use of typically available public services.	Replace personal relations and public services with artificial "therapies" and "activisations". Take over many aspects of the person's life, with the excuse of "but this or that public service does not accept people with disabilities".
Is available wherever and whenever the person needs it. In their home, at work, when going out or during a trip with friends.	Force the person to come to a specific place at a specific time. At its worst, make the person to move from their home to a "care" institution.

Is lead by persons with disabilities, who decide about the purpose, shape and form of the support.	Reduce the person to a "user" of pre-defined services.
Is reliable, stable within the terms set by the person; Stable and secure in its foundations.	Leave the person to live in uncertainty about their future because of short-term funding, sudden or unconsulted provider changes etc.
Uses easy to understand language to describe itself to the person and to everyone else. Is clear about its purpose, about how it works and about how the person can benefit from and influence the support.	Talks in expert language lacking any meaning outside of the service itself. Uses difficult language to keep power over the "service user". Operates in a complicated way and puts barriers in the way of a person trying to understand what the service is about and how to influence it.

Every disability service needs to support the person's independence and inclusion.

- This applies also to day centres, workshops or any kind of disability service.

Politicians, public authorities, and service providers need to ensure that these kinds of services do not segregate people with disabilities either, and that they do not waste their lives by meaningless activities designed to keep them occupied and under supervision for a part of the day.

- Reform all services and centres to support the person to live independently and be included.

> „Inclusion Europe noted that persons with disabilities should not be reduced to their physical needs, as if impairment was the only thing that defined them. With respect to language, it asserted that terms such as "service users", "clients" or "care receivers" served to reinforce that stereotype. It asserted that services and support should not focus on security and protection in a narrow sense. It emphasized that services tended to be delivered in groups, in a one-size-fits-all-fashion."[18]

The life of a person with intellectual disabilities cannot be left to a "post-code lottery", where their rights are impacted and the quality of their life suffers if they have the misfortune of being born in place where good support is not provided.

In every European country, there are places that provide good disability support.

It is the responsibility of politicians, public authorities, and disability service providers to scale this support and make it available to everyone.

- Invest in disability support that helps the person to live an ordinary life.[19]
- Remove administrative and organisational barriers that prevent people with intellectual disabilities from benefiting from disability support.

> "ENABLE Group provides self-directed health and social care through the PA model. ENABLE supports individuals in planning and designing the services they want, so that they can build their own bespoke team of personal assistants.
> The main barrier to implementing a personal assistance scheme is the lack of confidence that individuals and families have when it comes to being a recruiter and an employer. The organisation runs an internal recruitment agency that facilitates the recruitment and onboarding processes for PAs.
> The agency works to people's demands and criteria to ensure that the personal assistants hired are tailored to each individual's needs.
> In parallel, the agency ensures that it attracts the right people into the profession. Individuals are recruited for their values and experiences, but not necessarily their social care experience. ENABLE pays PAs more than the Scottish living wage."[20]

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[18] Transformation of services for persons with disabilities Report of the Special Rapporteur on the rights of persons with disabilities, p 8.

[19] With reservations to some terms and words used, normalisation principles could be helpful in developing aspects of support to live independently and be included: "Normal rhythm of the day. Normal rhythm of the week. Normal rhythm of the year." Normalisation and social role valorisation: Method for human service development

[20] "A gloriously ordinary life'

- Make support available where people live and need it.

  Do not force people to move house, region (or country![21]) for disability service. In some countries, there is a mismatch between where people with intellectual disabilities live, and where a lot of "disability services' capacity" is.[22]

Provide support for families of children with intellectual disabilities. Support families in being a family, not a care-providing unit.[23;24]

- Make forms of early diagnostic and early intervention easy to use and available to all families of children with intellectual disabilities.
- Support families in helping the family member with intellectual disabilities to grow as a person, get experiences and skills, set up for a life of their own.
- Help families during "transition periods": Between different stages of schooling; Between school and a job; Between parents' home and a place of one's own.

For us as parents, it was clear that our son Markus would have a life of his own, just like his older brother and younger sister. We always had the idea of him moving to a home of his own.

Jyrki Pinomaa, Finland[25]

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[21] 7,500 adults and 1,500 children from France are place in Belgian institutions. guidesocial.be

[22] This is a result of "care" institutions being placed in remote, rural, scarcely populated areas. The development of new disability support must overcome this, increasing access to disability support where it is under-represented and needed (in heavily populated areas). "For almost 11,000 people with intellectual disabilities who live in cities with 50,000+ inhabitants [in Czechia], there are only 755 places in residential services compatible with social inclusion." Výzkumná zpráva Žít jako ostatní

[23] "The use of solely informal care varies from around 30% to around 85% across Member States. However, while informal care is sometimes a matter of preference, it may often be the only option due to a lack of accessible and affordable formal care." Long term care report 2021, p 14.

[24] "Many States highlighted the pivotal role that families played in providing informal support. Inclusion Europe emphasized that formal services ought not to be the ultimate objective and stressed that as much as 80 per cent of all long-term support was provided by informal carers. It underscored that support policies and provision must take that fact into account and ensure that families did not bear the brunt of caregiving, including becoming "care managers, care administrators and service coordinators"." Transformation of services for persons with disabilities Report of the Special Rapporteur on the rights of persons with disabilities, p 10.

[25] Long Journey to a 'New New' Home

Who cares?[26]

Figure 1: Estimates of the value of care for adults
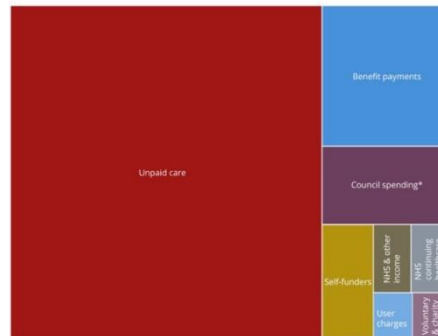
5. Provide tools for people to control disability support themself.

Person with disabilities needs to have control over how disability support is organised and paid for.

- At individual level, this can be done in a form of personal budget that is easy to understand and administer, and allows the person to pay for whatever disability support they need to live their life to the fullest.
- At the level where disability support is shaped with national, regional, local budgets, disabled persons' organisations must be present and active in making decisions about this money.
- Provide funding and institutional support for self-advocacy organisations and groups to organise, strategise, and influence relevant laws and policies. This is crucial to overcome structural discrimination faced by people with intellectual disabilities.

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[26] "In most cases, the family at home and friends in the community: the 'unpaid carers'. Recent analysis of data from 2001 to 2018 revealed that 65% of adults have provided unpaid care in their adult life, which increases to 70% for women. The average person now has a 50% chance of becoming an unpaid carer by the time they reach 50." "A gloriously ordinary life'', paragraph 9.

People with disabilities need to have control over how disability support is run and delivered.

- Being present and active in decision-making bodies of disability support providers.

Apply thorough controls of disability services. Controls that are:

- Lead by people with disabilities.
- Focused on respect to people's rights, and on the person's quality of life.[27]
- Done by a body independent from those who pay for or provide the services.
- Performed with reasonable frequency to have impact on the services practice.
- With easy to understand results and findings, easily available to the public.[28]
- With immediate consequences for the provider, and actions to restore any wrongdoings.

6. Close bad disability services.

As long as "care" institutions and other bad disability services remain in place, they will continue to suck up and waste resources, leaving those outside stranded for funding.

All progress towards inclusion goes through closure of "care" institutions and redirecting of their resources to support people to live independently and be included. (See following section for more information.)

Institutionalisation is a form of structural violence.[29]
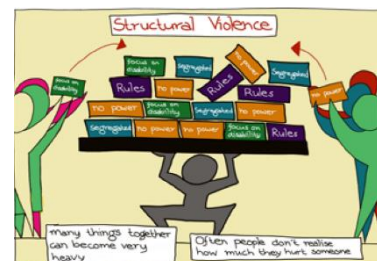
[27] Quality control for social services;
Quality of life standards

[28] Care Quality Commission

[29] Life after violence study.

7. Don't wait for "society to change" or for all things to fall in place.

Yes, for people with disabilities to be able to fully enjoy their right to live independently and to be included, many other rights need to be respected and many policies and actions need to change.

People need to get good education.[30] To have a job.[31] To have money to cover the costs of living with a disability. To have the right to decide (indeed, see above). And many more.

- Politicians and public authorities as well as everyone else need to work for improvements in all those areas.

But this cannot be and excuse for inaction on the right to live independently and to be included!

- No more waiting "for society to become inclusive", or for "reforms in the area of… to facilitate inclusion".

"What you leave behind is not what is engraved in stone monuments,
but what is woven into the lives of others."
Pericles, Ancient Greece

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[30] Why we care about education.

[31] Employment and social inclusion

Move people from harmful places and help them to set up a new life.

Main actions countries should do to end segregation of people with intellectual disabilities in "care" institutions:

1. Make disability support available to everyone who needs it.

See above section for more.

2. Stop putting people in "care" institutions immediately.

Identify "care" institutions in the country.

- Every "care" institution should carry a warning that placing people with disabilities there is a form of segregation, it is harmful to the person's wellbeing, and that it prevents the person from living their full life included in the community.

There are many ways of defining which kind of place amounts to a "care" institution:

- Some definitions of institutions are based on the culture of institutionalisation, and do not consider number of residents as the ultimate criteria.[32]

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[32] „Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization." CRPD General Comment number 5; or EEG Guidelines

- Some countries use a maximum number of residents in a household as key characteristic, usually combined with other requirements.[33]
- For the purpose of research on institutional care in the EU, a far too big number of 30 residents has been used.[34]

To stop people with intellectual disabilities being segregated and placed in harmful environment, it may be useful to adopt some criteria related to a number of people in one place:

- In every country, there is a statistically typical number of people in one household. This number can serve as a baseline to establish which residential care services need to be prioritised for closure and prevented from taking in new people (services where the number of residents in the household is higher than the national household average[35]).
- The bigger the number of people in one "care institution", the more urgent the need for closure of such place. Every place with 30+ people[36] must be recognised as an institution and closed as a matter of urgency; All other places segregating people with intellectual disabilities must be closed too.
- The number of residents in one household must be considered in relation to other characteristics, especially where the household is, proximity to other disability services etc. (See below for more.)

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[33] In Czechia, the ministry of labour standards define residential social care as community care when the number of resident is 4 or 6 people in one household. The standards allow for placing as much as 3 such households into close proximity. Doporučený postup č. 2/2016
A report by Czech organisations used slightly different approach, labelling residential services as adequate for community living (maximum 3 persons), acceptable (4-6 persons), not very good (7-12), and unacceptable (12+). Žít jako ostatní

[34] Report on the transition from institutional care to community-based services in 27 EU member states

[35] This concept is offered for the purpose of the initial analysis, avoiding clear risk of segregation. In terms of a disability service being able to support people in inclusion, other principles and characteristics need to be in place; see through-out this document.

[36] Report on the transition from institutional care to community-based services in 27 EU member states

"After 27 years in institutions I moved to sheltered housing.

I finally started to live a normal life.

It's been 8 years, and I've been tempted to go further. I'm currently looking

for an apartment and it looks like I'm going to make it and move."

Petr Laník, Czechia[37]

Stop all "care" institutions from taking new people in:

- Announce the decision clearly, with easy to understand explanation about the harms of institutionalisation.
- To every person who "applies" for a place in "care" institution, offer and organise person-centred case management intervention to find out about their expectations and situation, and to help them organise their life independently and included in the community.

3. Find a new home for the person moving out of an institution.

Find and secure a place to live for the person out of the institution.

- Use existing housing (apartments, family houses) in residential areas.
- Find out about the person's preferences.[38]
- Make any adaptations needed for people with reduced mobility.

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[37] Finally my life is what I want it to be

[38] Often, service providers argue that the person placed in an institution in a rural area "likes to live in a rural area and wishes to stay there". It is important to consider that in most cases this person has not experience any other living arrangement (at least as an adult), especially not when they would have the support to live independently and be included, therefore being able to benefit from the things other types of areas offer. Similarly, when answering "I like it here" the person may be speaking about the things they value in the current situation (some people they like, some aspect of the disability service they came to appreciate), not about the actual location or not knowing they could have the same things available in other arrangements. Support to get new experience is crucial.

There are nearly 1.5 million people in institutions in the EU[39] (and countless others living with their families as adults even when it would be otherwise typical to live on one's own). To find a new home, it will be necessary to build new housing. When building new housing for people moving out of institutions, it is important to follow key rules:

- Build "general" housing, and make a portion of it available for people moving out of institutions. (see 1. in previous chapter)

- Build the housing in residential areas. Never place the new housing in an industrial area, on the property of another institution (such as hospital, senior care home etc.).

- Avoid building new homes in remote areas with scarce public infrastructure (even if they are marked for residential purposes "in the future"). Lack of public services (transport, medical services etc.) increases the person's dependence on the service provider. This contravenes the principle of inclusion, and makes the service more expensive.

- Do not combine housing function with other functions:
  Do not place a "care workers' room or office" in the same household.
  Do not place another disability service in the same building as the household.
  (As a rule of thumb: Would the residents be able to walk from their bedroom into a "day centre" or "workshop" without having to put their coat or shoes on? "Yes" is the wrong answer.)

"It took me about 3 years to move out and look for a place.
I got support from two NGOs. 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[40]

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[39] Report on the transition from institutional care to community-based services in 27 EU member states

[40] "Live a life of your own, get education and experience, get a job with proper money"

Separate housing and disability support.

A person with intellectual disabilities should have a place to live that is not tied to using a disability service. Change to the service cannot be linked in any direct way to a change in housing arrangements.

- As a minimum requirement, the person should have separate contracts for housing, and for disability support.

4. Support the person to establish a new life.

Every person leaving an institution needs support in establishing a new life, and in overcoming the harm and trauma caused by institutionalisation.

Start with people with complex support needs.[41]

- Do not "cherry-pick" people who "are most suitable to live independently".
- Do not reduce people with complex support needs into indifferent care-receivers.[42]
- Provide support for inclusion of people with complex support needs.[43]

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.

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[41] „In many countries… persons with intellectual disabilities and complex needs are most likely to still live in institutional settings" https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf

[42] Narrowed lives. Stockholm University Press, 20221. The book provides excellent, readable, research-based account of the social lives of person with severe disabilities.

[43] Empowerment of people with complex support needs

"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.

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."[44]

Find out about the person's experiences, expectations, and ambitions in life.

- Use person-centred, collaborative approach to find out about the person.
- Broaden the person's scope of possibilities, experiences and expectations. If the person didn't have the opportunity to experience and form views about many aspects of life (social relations, different types and possibilities of living arrangements etc.), their expectations of what can come after institution will be limited by this. The person needs to have a real experience and options, to make an informed choice about their future life.
- Help the person capture their life story so far, and wishes for the next stage.
- Involve many different people (with the person's permission) who are relevant to the person's life.

Focus on restoring and strengthening the person's capacity for social interactions, for forming and maintaining social roles and relationships.

- It seems very valuable to try and establish a supportive relationship with someone outside of the institution, who provides a connection to the new life, offers some stability during the transition.

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[44] "When people meet Julia now, they see someone who is awake and intensely enjoying life"

This purpose seems to be fulfilled by professionals (social worker, youth worker, guardians…) as well as by a friend or a volunteer.[45]

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[46]

Consider the harm done to the person during their time in an institution (including potential abuse and violence), and provide appropriate support and restitution. [47]

- A lot of behaviour that people find "weird" or "challenging" is a response to institutionalisation and the resulting trauma.

Arrange for expert psychological support when appropriate.

"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, Netherlands[48]

Compensate people for the harm done to them, and for the work many have done and are still doing 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 newsagent and doing everything they wanted.
Paul Alford, Ireland[49]

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[45] Testimonies by survivors of institutionalisation.

[46] Deinstitutionalisation: ensuring people are in full control of their life
[47] Life after violence.

[48] "My biggest fear is that I will be put back into an institution"

[49] "Live a life of your own, get education and experience, get a job with proper money"; More about unpaid work by people with intellectual disabilities

5. Close the institution.
Redirect its money to disability support.

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

- As soon as any person moves out of an institution, reduce the institutions' „capacity" in the official registration.

As the person moves out of the institution, re-allocate relevant amount from the institution's budget towards the person's support to live independently and be included.

Set a timeframe within which the institution closes.

- From experience, it is perfectly reasonable to expect even large-scale institution to close within 3-5 years.
- The longer the change takes, the more expensive and demanding on all involved[50]. (Besides exposing people to the harm of institutionalisation for longer.)
- Let everyone know when the institution closes.

Create a structure to manage the transition, and set a clear plan of action.

- Establish a transition management team, which will represent key people involved: People who live in the institution; Staff and management; External organisations cooperating on the change such as different disability support providers.

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[50] The institution is there and costs money untill it's closed. The costs of change (trainings, project management etc. need to be covered the whole time.

- Plan the key steps during the transition, so that everyone is clear about the direction of the change and their role in it.

Educate staff for relevant understanding and skills.

- Training and other education methods need to be developed and delivered in collaboration with people with disabilities, especially those who went (or are going) through deinstitutionalisation.
- Focus on clarity of purpose and direction (why the change is happening, what its purpose and desired outcome is). Strengthen the staff's belief in their role in the change, their capacity to contribute and the benefits to their professional development.

6. Have a clear strategy.

Politicians, public authorities, and service providers who run "care" institutions must recognise their responsibility, and set a clear strategy to end institutionalisation of people with intellectual disabilities.

Set up a body at the relevant level (eg. national, regional), with representatives of people with intellectual disabilities, and others involved in the transition (service providers, public authorities etc.)

- The body needs to work using plain language, and providing reasonable accommodation for people with intellectual disabilities to be able to take part in relevant discussions and decisions.
- This body should discuss and formulate strategy for change, evaluate the changes etc.

There are several strategies that have been put in place to close institutions. They can be effective in so far as they lead to de-segregation of people with disabilities, establishing independent life in community. They can combine, strengthen each other.

1. Law-driven change. Rewriting of relevant laws to set a human rights-based framework for disability services.[51] It is a necessary part of the change, it provides clarity, and it removes room for individual choice (excuses) of those who run institutions about whether they should do it or not.
The downside: This can take long time to achieve. Even when the law change is done, it still requires implementation.[52]
Don't wait for the law to change to start deinstitutionalisation.

2. Individual departures. Support for people to move out of the institution is arranged on individual bases, for example based on finding them a new place to live or a new job. Given its selective and highly individualised nature, this approach is very successful in achieving inclusion for those lucky enough to benefit from it. It should be scaled.
The downside: This takes a lot of time. And often, the person who moved out is replaced with a new one taken into the institution.[53]

Now, I fight for the 16.607 people who are still in institution 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[54]

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[51] Useful overview of this approach is provided in: *Narrowed lives,* Stockholm University Press, 2021; *Development, Conceptualisation and Implementation of Quality in Disability Support Services,* Karolinum Press, 2020.

[52] "No amount of positive law reform will be sustainable unless the underlying ecosystem of support and services changes." Transformation of services for persons with disabilities.

[53] Těžká cesta z ústavu domů. Česko se dosud nedokázalo zbavit v péči o mentálně postižené dědictví komunismu

[54] "Now I support others to get out of institutions"

3. Institution closure driven by the director. In some cases, the head of the institution decides (rightly!) it's their responsibility to close the place down, despite whatever the relevant authorities may think. It is quite effective in achieving the change for the people living in that institution, and in demonstrating to others it can be done.
The downside: It is limited in impact on the overall system of care, and it is very demanding on all involved as it typically means fighting with the authorities every step of the way.

4. (EU-)funds driven change. Money is a strong incentive. It makes public authorities and service providers take actions they would normally not, sometimes even that they don't agree with. It is an effective way of kickstarting the transition at a larger scale.
The downside: Money means bricks. The process will become largely about building new homes and moving people there. A lot of these homes are a big improvement compared to where and how people lived before, but they are far from what needs and can be achieved. Also, it takes a veeery long time: Building new houses usually does, especially so when done in the highly regulated environment of EU funds and public administration.

Whichever strategy you chose, build it around people.

- The people moving out of the institution are the focus and the purpose of this, not the service provider. Make it so in every relevant document.
- Use appropriate language: This is not about "transformation of service", or "modernisation service"; Such language puts the service provider in focus.

Do not take forever.

There is no reason why the changes should take decades to materialise.

When well prepared and managed, the transition can be done effectively and relatively quickly. Save people's lives and public money by doing exactly that.

What should politicians, public authorities, and service providers avoid when setting their strategy for deinstitutionalisation:

- Forget about "changing peoples' minds". That's the toughest job, and it rarely works. People with intellectual disabilities won't wait for the society to "become ready". Inclusion in the community is not a rhetorical exercise: Just do it.[55]
- Do not build the transition on the original institution.
  People with disabilities need to be in the driving seat, not the service provider. In many cases, the "service capacity" needs to move from the location where the institution is to another location (see above). If the change is based solely on the original institution, this becomes very hard to achieve.

Communicate clearly about the changes.

- Explain in plain language why institutions need to close (how they harm people).
- Describe what the change will look like and what the result of it will be.
- Talk about people and how they lives change for the better (not about processes, projects, or buildings).

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[55] „Abruptly, our project came to a stop. When the neighbourhood found out about a house for people with disabilities being planned in their area, they made a complaint against building it. There was no real reason, other than the fact that when people do not know enough about disability, it tends to create fear. This was more a rule than an exception when trying to build houses for people with disabilities. Complaints take time away from progress, but cannot stop strong advocates like us. We continued with our plans. Ultimately, the formal complaint was not successful, as they seldom are. Finally, the building plot and the house itself started to take shape. We started perceiving the different apartments there and could "go into" Markus' and Robin's new homes." Long Journey to a 'New New' Home

- Provide platform (training, support, media exposure) for people directly affected by institutionalisation to talk about their experience.
- Inspire.

  Build a positive picture of the future, in every communication about the change.

  Do not confuse people with expert talk and unnecessary complexity.[56; 57]

  Transition from institutions to community-based support is perfectly doable.

7. Learn from what you (and others) are doing.

Listen to people who live(d) in institutions, and who established a new life included in the community.

Describe the starting position (how many people in institutions, how many institutions, how expensive the institutions are etc.).

Monitor and evaluate progress.

- How many people have moved out into their new home, what are their new settings in terms of disability support?
- Set and monitor indicators relevant to the purpose of the changes: How has the person's life changed in terms of living independently and being included?

  Does the person have their own place to live in?

  Does the person have more social roles (family member, friend, colleague etc.)?

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[56] Discussion on disability rights, social care and change;

[57] How to build public support to transform social care

Does the person have a job, are they attending a training etc?[58]

- How much does the new situation cost compared to when people were in institution? (Caution.[59])

Set up a mechanism for learning from experience.

- It can be a platform for those involved in the changes to meet regularly and discuss what works and what doesn't.
- It can be an analytical body collecting, processing and communication on the various experience, progress (or lack of), on what strategies are effective.
- The formats can be multiple and various. But it is crucial to establish some mechanism for this, so that the transition can learn from how it works, become more effective.

"What you leave behind is not what is engraved in stone monuments,
but what is woven into the lives of others."
Pericles, Ancient Greece

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[58] "212. Wellbeing is defined as relating to the following: personal dignity; physical and mental health and emotional wellbeing; protection from abuse and neglect; control by the individual over their day-to-day life, including over the care and support that is provided to them; participation in work, education, training or recreation; social and economic wellbeing; domestic, family and personal relationships; suitability of living accommodation; and the individual's contribution to society." "A gloriously ordinary life'

[59] It is important to compare this on a relevant basis. What usually happens is that people who moved out of institutions and no longer use disability services (or use disability service provided by an organisation without a direct link to those doing the maths), they are not counted. Only people who remained in the directly connected services are counted: For many reasons, these services are often more expensive on a person-costs scale. This flawed calculation is then used to argue against deinstitutionalisation.

Money, money, money

What funders need to change and to consider in how they distribute their money.

By funders we mean:

- Countries (including national, regional, local public budgets);
- European Union and its funds;
- Private foundations and philanthropists.

Funders have responsibility for what their money does.

All funders need to respect the rights of people with disabilities. They need to listen to what people with disabilities are saying about how the money should be used.

"People in institutions do not need renovations.
They need encouragement, and they need to live in the community."
Elisabeta Moldovan[60]

It is not acceptable for funders to continue supporting segregation of people with intellectual disabilities.

1. No money should be given to (re)build or establish new "care" institutions.
2. No money should be given to the renovation of "care" institutions.
   But do not leave the people who live there in bad conditions: Help them move away from the institution, instead of refurbishing it.

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[60] During Hear our Voices! self-advocacy conference in 2017.

For more on which actions are desirable to fund, and which aren't:
[EEG guidance on independent living](#)
[EEG Checklist to promote independent living and deinstitutionalisation](#)
UN Special Rapporteur: [Transformation of services for persons with disabilities](#)[61]

Funders should provide money specifically for the changes necessary for people with intellectual disabilities to live independently and to be included, especially:

1. Funding for self-advocacy organisations and groups to be able to effectively advocate and influence relevant laws and policies.
2. Funding of costs associated with transition from institutional to community-based support.

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[62]

Private initiatives should end their support sustaining segregated "care" institutions, providing them with volunteers and other support:

*   This often serves to hide the institution's responsibility and inability to support people in social interactions and inclusion.

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[61] [Summary of the report,](#) by Inclusion Europe

[62] [It is crucial to better involve self-advocates in deinstitutionalisation](#)

Do not leave the people in institutions alone and abandoned.

- Use the resources to help them reconnect with the world outside, to explore ways they could set up to live independently.

Volunteers came to the institution where I lived. 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 before I knew that I wanted to leave the institution.
I started working in a laundry, 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 yet have my full legal capacity, but I could take more decisions on my own.
Barbora Mikulová, Czechia[63]

Funders should not distract disability service providers with topics and actions not relevant to their core function until they change to support people to live independently and be included.

- Service providers need to focus on the necessary changes they need to make to properly support people to live independently and be included.
- They should not waste their time and limited resources on side-projects, which may be otherwise important but are irrelevant in terms of ending segregation of people with intellectual disabilities.

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[63] "It didn't take long before I knew that I wanted to leave the institution"

Stick with it until the problem is solved.

- Do not move to new hot topic with every budget cycle. If the problem persists, stick with it until it's resolved.

Support activities that may seem mundane and unsophisticated, but that are the fabric of communities and actually help to solve segregation.

- Activities for social inclusion may sometimes look banal: A group of people meeting regularly to have a tea and a chat together. Not hot topics, no innovations involved. Just people getting on with their lives. We need more of it.

European Union funds need to facilitate structural change in EU countries towards inclusion and independent living.

- Pilot projects and good practice examples are not enough if not followed by measures and resources to scale them.

EU funds should be conditioned on real progress in ending segregation of people with intellectual disabilities in "care" institutions:

- What number of people will be supported to set up a new life.
- How many "care" institutions will close, when.
- How will be the resources of the closed institutions redirected towards support for living independently and be included.

These indicators could be set out in stages, allowing to check on progress.

- If a country is on its fourth "deinstitutionalisation project" funded with EU money yet no institution has closed as a result, something is clearly not ok.

EU funds should facilitates structural change:

- For example, for every 1 million EUR from EU funds used for disability services, the country should be required to move 1 million EUR within its national disability services budget from institutional care to disability support. Currently, countries can use EU funds to do "some deinstitutionalisation" and establish new services, but at the same time can have their entire national budget for social services untouched by these requirements and continue funding the segregated institutionalised system.

Monitor the situation and changes. National data needs to be collected and accessed at regular intervals, comparable across the EU countries.

- Examples how this can be done exist.[64]

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[65]

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[64] State of the States in Intellectual and Developmental Disabilities

[65] It's everyone's right to live in a home of their choice, in a community they choose, close to the people they love

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