

# Why are people with intellectual disabilities still being put at risk of institutionalisation?

Discussion paper on the risk of (re)institutionalisation



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**Why are people with intellectual disabilities still being put at risk of institutionalisation?**

Discussion paper on the risk of (re)institutionalisation

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Co-funded by the European Union

The European Union bears no responsibility for the contents of the report.

2021

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# Introduction

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Nearly **one million and a half persons are still living in institutions** in the European Union (EU), where they are isolated and segregated from their community, deprived of their right to independent living. This is despite the universal ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), and despite the vast body of research establishing the harmful effects of segregation and institutionalisation.

At least 1,438,696 children and adults still live in long-stay residential institutions according to a 2020 report on the transition from institutional to community-based care in the EU<sup>1</sup>.

The report also shows:

- the number of people in institutions does not seem to have substantially changed over the past 10 years;
- the number of children in residential care has slightly decreased, with them moving to live with their families, being fostered, adopted, or reaching majority and therefore leaving residential care for children;
- in all the 27 EU countries, people are living in residential care, with only a small number of it being primarily small-scale and community-based, e.g. dispersed among ordinary housing in the general community. Small-scale residential services still represent a minority of the care settings in most of the 27 EU countries;
- in many countries, and especially those who started the process of deinstitutionalisation some time ago **persons with intellectual disabilities and people with complex support needs are most likely to still live in institutional settings.**

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<sup>1</sup> Jan Šiška and Julie Beadle-Brown, Report on the transition from institutional care to community-based services in 27 EU Member States, European Expert Group on the Transition from Institutional to Community-based Care. (2020) <https://www.inclusion-europe.eu/people-intellectual-disabilities-complex-needs-institutions-report/>

## Institutionalisation

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A study for the European Commission defined a **residential institution** as an establishment in which more than 30 people live, of whom at least 80% were mentally or physically disabled.<sup>2</sup>

An institution can be defined as a **residential care facility** in which people who have been labelled as having a disability are isolated and must live together. The rules of the institution take over the resident's life. Residents rarely have any activities or social relations outside of the institution.

Common European Guidelines on the Transition from Institutional to Community-based Care:<sup>3</sup>

**“We can consider ‘an institution’ as any residential care where:**

- **residents are isolated from the broader community and/or compelled to live together;**
- **residents do not have sufficient control over their lives and over decisions which affect them; and**
- **the requirements of the organisation itself tend to take precedence over the residents’ individualised needs.”**

For the CRPD Committee, institutions can be places with more than a hundred residents, or group homes accommodating five to eight individuals, if these homes tend to isolate their residents from the community and restrict their ability to control their life<sup>4</sup>.

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<sup>2</sup> Mansell J, Knapp M, Beadle Brown J and Beecham J Deinstitutionalisation and community living – outcomes and costs: a report of a European Study. Canterbury: Tizard Centre, University of Kent. (2007)

<sup>3</sup> <https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf>

<sup>4</sup> Committee on the Rights of Persons with Disabilities General comment No. 5 on living independently and being included in the community (2017)  
[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en)

**Independent living** is a right set out in Article 19 of the CRPD. It has implications over other rights, such as the right to education, work and employment, because people with disabilities may not be able to exercise them if they are not independent.

*"Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives."*<sup>5</sup>

Independent living *"includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live"*, that it *"requires that the built environment, transport and information are accessible"* and that *"there is the availability of technical aids, access to personal assistance and/or community-based services"* according to ENIL<sup>6</sup>.

## Current situation

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There is evidence that **the number of people in institutions has not substantially changed over the past ten years**<sup>7</sup>.

Member States' access to **EU funds** (in particular, the European Structural and Investment Funds), including funds for the transition from institutional care to community-based services, **has failed to cut down the number of people in institutions**<sup>8</sup>.

Many countries still invest in residential care or move people into smaller facilities, without putting a person's will and preferences at the centre.

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<sup>5</sup> Committee on the Rights of Persons with Disabilities General comment No. 5 on living independently and being included in the community (2017)

[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en)

<sup>6</sup> The European Network on Independent Living – ENIL, <https://enil.eu/independent-living/definitions/>

<sup>7</sup> Jan Šiška and Julie Beadle-Brown, Report on the transition from institutional care to community-based services in 27 EU Member States, European Expert Group on the Transition from Institutional to Community-based Care. (2020)

<sup>8</sup> Academic Network of European Disability Experts (ANED), The right to live independently and to be included in the community in the European States: ANED synthesis report (2019) <https://www.disability-europe.net/theme/independent-living>

## Problems caused by institutionalisation

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The 2009 EU Report on the Transition from Institutional to Community-based Care<sup>9</sup> shows why institutional care is inadequate:

- **Depersonalisation**
- **Rigidity of routine**
- **Block treatment**
- **Social distance** (difference of status between staff and residents)

The **quality of care does not depend on financial investments**: *“no matter how much money is spent on institutions, the characteristics of institutional care are bound to make it extremely difficult to provide adequate quality of life for users, to ensure enjoyment of human rights and accomplish the goal of social inclusion”<sup>10</sup>.*

Women with experience living in residential institutions reported **structural violence**<sup>11</sup>. Structural violence is a consequence and part of institutionalisation.

There is often no direct perpetrator, and the violence is unintentional.

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<sup>9</sup> Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care [https://deinstitutionalisationdotcom.files.wordpress.com/2017/11/report-fo-the-ad-hoc\\_2009.pdf](https://deinstitutionalisationdotcom.files.wordpress.com/2017/11/report-fo-the-ad-hoc_2009.pdf)

<sup>10</sup> Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care [https://deinstitutionalisationdotcom.files.wordpress.com/2017/11/report-fo-the-ad-hoc\\_2009.pdf](https://deinstitutionalisationdotcom.files.wordpress.com/2017/11/report-fo-the-ad-hoc_2009.pdf)

<sup>11</sup> Inclusion Europe, Life after Violence Report (2018)

[https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication\\_web.pdf](https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication_web.pdf)



**Structural violence** would generally manifest itself in three different ways.

- **Rules and regulations linked to a feeling of powerlessness.**

Institutions need structures and rules to function because there are many people living together. But these rules can be frustrating to a person who spends their entire life there. Rules can become suffocating.

All the women had experienced having their life choices done by institutions.

- **Segregation from society.**

By separating people with disabilities from the rest of the community, the system of institutions perpetuates the idea that persons with disabilities are worth less than others. All the women involved in the study had experienced the consequences of being labelled as part of a group that faces many misconceptions and prejudices in society. The residents may also find very little support, and some even opposition, for being active in society and trying to build relationships outside the institutions.

- **Focus on disability and not on the whole person.**

There were very low expectations and ambitions for what people could achieve. Institutions were trying to care for groups of people with similar disabilities, rather than looking at individual potential.



***“The best way to prevent structural violence is to stop placing people with disabilities in institutions. Structural violence is worse in large residential institutions but is also seen in smaller group homes. European social policies should aim at ensuring that no European budget can be used for building or renovating institutions.”***

**José Smits, Inclusion Europe’s former secretary-general <sup>12</sup>**



## **Recent cases of harm in residential institutions**

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The **COVID-19 pandemic** confirmed that institutional care is not suitable for guarantying good conditions of living. People with disabilities who are placed in residential care are more vulnerable and at higher risk because the size and structure of the facilities.

People living in institutions have been one of the most heavily impacted by Covid-19, despite the fact they had to spend long time in isolation, without any contact with relatives or friends.

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<sup>12</sup> (2018) <https://www.inclusion-europe.eu/my-biggest-fear-is-that-i-will-be-put-back-into-an-institution/>

<b>Problems within institutions during Covid -19</b>	<b>Percentage of people impacted</b>
People that have been isolated in institutions	70%
People that have been prevented from receiving any visitors for months	84%
Death toll range in institutions	From 19% to 72%

Source: "Disability Rights during the Pandemic"<sup>13</sup>

People living in institutions are also exposed to dangerous of accidents and emergencies, due to the number of residents in one place, and the architectural and structural barriers.

- A fire killed 8 people with intellectual disabilities and hurt 30 more in Czechia.<sup>14</sup>
- A fire in residential care institution killed 4 people with disabilities in Slovakia. "*There were many physical barriers in this institution... the residents should have been moved out long time ago.*"<sup>15</sup>
- Floods killed 12 people with intellectual disabilities in a "care home" in Germany.<sup>16</sup>

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<sup>13</sup> Ciara Siobhan, Disability Rights during the Pandemic – a global report of the Covid-19 Disability Rights Monitor, (2020) [https://www.internationaldisabilityalliance.org/sites/default/files/disability\\_rights\\_during\\_the\\_pandemic\\_report\\_web\\_pdf\\_1.pdf](https://www.internationaldisabilityalliance.org/sites/default/files/disability_rights_during_the_pandemic_report_web_pdf_1.pdf).

<sup>14</sup> Inclusion Europe, Eight people with intellectual disabilities killed in a fire in a care home in Czechia (2020) <https://www.inclusion-europe.eu/8-people-with-intellectual-disabilities-killed-in-a-fire-in-a-care-home-in-czechia-the-authorities-must-act-to-prevent-further-harm/>

<sup>15</sup> SocioFórum, Vyhlásenie SocioFóra k tragickému požiaru v Osadnom (2021) <http://www.socioforum.sk/index.php/aktuality/35-aktuality/325-vyhlasenie-sociofora-k-tragickemu-poiaru-v-osadnom>

<sup>16</sup> Express, Germany floods: Tragedy as 12 drown as disabled care home hit by 'tidal wave' (2021) <https://www.express.co.uk/news/world/1463748/Germany-floods-latest-flooding-death-toll-drown-tidal-wave-lebenshilfe>

***“Unfortunately, many people still think that institutions are safe places. This is simply not true.”***

**Helena Dalli, EU Commissioner for Equality<sup>17</sup>**



Despite progress, good practices, laws, methodologies, people with intellectual disabilities are still at risk of institutionalisation.

To examine the risks of institutionalisation for people with intellectual disabilities, the first part will be dedicated to understanding why people with disabilities are at risk of being institutionalised, especially people with intellectual disabilities.

The second part will be dedicated to understanding if there are there still, and why, some risks for people with intellectual disabilities who are living independently to return to institutions.



<sup>17</sup> (2020) <https://www.inclusion-europe.eu/helena-dalli-unfortunately-many-people-still-think-that-institutions-are-safe-places-this-is-simply-not-true/>

# Why are people with disabilities still at risk of institutionalisation?

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To understand why in the 21<sup>st</sup> century some people are still at risk of ending up in institutions, a quick overview of the reasons that lead people to go to institutions throughout history explains a lot.

## Why institutionalisation?

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Disability was seen as an **impairment** the person suffered from and had to be **treated** for.<sup>18</sup> Institutional care was thought to be the right solution for persons with disabilities. Michel Foucault in France called this the **“great lockup”** – *“le grand renfermement”*<sup>19</sup>.

At the beginning of the nineteenth century, institutions were conceived as an instrument to **“educate”** people with intellectual<sup>20</sup>.

However, because of the large number of people in institutions and the lack of funds, they became places to **“manage”** people. Institutions were sometimes called **“asylum for the insane”**<sup>21</sup>

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<sup>18</sup> Judith Mckenzie, Models of intellectual disability: Towards a perspective of (poss)ability. Journal of intellectual disability research (2012)

<sup>19</sup> Arnaud Fossier, Le grand renfermement (2002) <https://journals.openedition.org/traces/4130>

<sup>20</sup> Carli Friedman, The Relationship between Disability Prejudice and Institutionalisation of People with Intellectual and Developmental Disabilities, *Intellectual and Developmental Disabilities*, (2019)

<sup>21</sup> Ontario Ministry of Children, Community and Social Services, The reasons for institutions, (2018) <https://www.mcscs.gov.on.ca/en/dshistory/reasons/index.aspx>

The **industrial revolution**, people moving to cities, the necessity to work lead to less time to take care of people with disabilities in the families.<sup>22</sup>

In the late 1800s and early 1900s, negative attitudes were reinforced by **eugenics movements** who believed people with disabilities were inferiors. They wanted to control them and remove them from society. Institutions were away from cities. People believed fresh air would do them good.<sup>23</sup>

In Europe, North America, former USSR, **state-run institutions** were the norm for centuries. The second half of the 20<sup>th</sup> century, the disability movement brought some changes.<sup>24</sup>

And sometimes, disability was seen as a "**shame**" for/by the family. The documentary *The Queen's Hidden Cousins* tells the story of relatives of the queen of England, Elizabeth II, were locked down in institutions, pretending they were already dead. It is to show how disability used to be seen in the British Aristocracy and British society.<sup>25</sup>

With the scientific evidence showing the negative impact institutions have, the work of the disability movement and the rights guaranteed at international level, policies are slowly changing. It is the end of the medical model.<sup>26</sup>

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<sup>22</sup> Ontario Ministry of Children, Community and Social Services, The industrial revolution, (2018) [https://www.mcsc.gov.on.ca/en/dshistory/reasons/industrial\\_revolution.aspx](https://www.mcsc.gov.on.ca/en/dshistory/reasons/industrial_revolution.aspx)

<sup>23</sup> Ontario Ministry of Children, Community and Social Services, The eugenics movement and attitudes towards people with disabilities, (2018) <https://www.mcsc.gov.on.ca/en/dshistory/reasons/eugenics.aspx>

<sup>24</sup> ENIL, The right to live independently and be included in the community, (2017) [www.enil.eu/wp-content/uploads/2017/06/The-right-to-live-independently\\_FINAL.pdf](http://www.enil.eu/wp-content/uploads/2017/06/The-right-to-live-independently_FINAL.pdf)

<sup>25</sup> Minnow Films, The Queen's Hidden Cousins (2011) <https://www.thetvdb.com/series/channel-4-uk-documentaries/episodes/4232612>

<sup>26</sup> The Common European Guidelines on the Transition from Institutional to Community-based Care (2012) <https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf>

## Risks for people with disabilities

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Risks are multiple for people with intellectual disabilities. They can be cultural and social.

### No self-determination

People with intellectual disabilities are at risk of being in the vicious **circle of exclusion**, from early education and care, through education, through employment and finally through living arrangements, from childhood to adulthood.

People with intellectual disabilities often don't have the choice or even the possibility to choose.

First, there are many EU countries with **legal capacity restrictions**. This means people with intellectual disabilities and complex support needs are not able to vote nor **make decisions**, there are never taught how to do it, and per consequence they are not empowered on how to even decide for themselves. They are not included as citizens in the community.

This is a big risk of institutionalisation, because when people are placed in institutions, there are rules to follow and people to take decisions for you. The individual gets ignored and lost very quickly.

It is an "easy" choice as all the questions of empowerment, education and participation to civic life disappear.

It starts from a very young age. When it comes to the possibility of **child participation**, it is already hard to have this right recognised and made efficient for children without disabilities, but for children with disabilities, especially intellectual disability or children with complex support needs, the possibility of participation is very little, if not completely dismissed.

## Fears of family members

Studies show parents are divided between those who think institutionalisation is a good solution for people with disabilities, those who don't have other choice, and those who will do everything in their power to prevent their child from ending up in an institution.

*"Some felt that institutionalization was a needed response to what they continue to perceive as an individual deficiency, while others felt that the absence of other support mechanisms made institutionalization their only choice"<sup>27</sup>.*

In the same way some might chose segregated education because they fear their child is going to be **bullied** in a mainstream school, institutionalisation might be perceived as a way to protect people with intellectual disabilities.<sup>28</sup>

There are **negative attitudes and stigma around people with disabilities**. It is true, but also due to stereotypes. If, from a young age, people with disabilities are not included in the community, in schools etc., then of course, people without disabilities might not know how to interact with people with intellectual disabilities and complex support needs. This is why inclusion since the beginning is important. Plus, refusing a child in a school based on his disability is a **discrimination** punishable by law.

It is also true that there are several cases of disability **hate crime**. Disability is often used also as an **insult**, which is revealing of how disability is perceived in our communities.

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<sup>27</sup> Alexis Riley, Review of Broken: Institutions, families and the construction of disability by Madeline C. Burghardt, *Disability Studies Quarterly*, (2020)

<sup>28</sup> Cooney G., Jahoda A., Gumley A., Knott F., Young people with intellectual disabilities attending mainstreaming and segregated schooling: perceived stigma, social comparison and future aspirations, *Journal of Intellectual Disability Research*, (2006)



## No knowledge around independent living and support

The concept of independent living can be confused with the idea of living far from home, alone or to carry out daily tasks without any support.<sup>29</sup>

However, **no adequate services** provided for people with intellectual disabilities in the community is another reason that causes a risk for institutionalisation, because parents won't have any other choices for their and professionals might redirect them to institutions. There is a **general lack of knowledge, information and support for the families**.

Also, if people with disabilities are **not aware**, and not able to be in control of their decisions, Institutions might seem like a solution/ the only solution.

Some people might have only known this their whole life. People with disabilities might thus be afraid to leave institutions, and not telling them that **life in the community is possible** nor having **peer support** causes a risk that these people will stay institutionalised.<sup>30</sup>

***“With the right support, women with intellectual disabilities prosper in the community, even after having suffered from violence. There is ‘Life after violence’.”<sup>31</sup>***

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<sup>29</sup> European Network on Independent Living, The right to live independently and be included in the community: addressing barriers to independent living across the globe, (2017)

[http://enil.eu/wp-content/uploads/2017/06/The-right-to-live-independently\\_FINAL.pdf](http://enil.eu/wp-content/uploads/2017/06/The-right-to-live-independently_FINAL.pdf)

<sup>30</sup> ENIL – Myth buster on independent living (2014)

<http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf>

<sup>31</sup> Inclusion Europe, Life After Violence Report (2018)

[https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication\\_web.pdf](https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication_web.pdf)

Despite the prevention measures and the good practices that exist to close down institutions with the appropriate solutions to transition in the community, some people with intellectual disabilities are still at risk of being re-institutionalised, even if they managed to get out of institutions once.

## The disability care business

While the problems of the disability care sector have been exacerbated during the Covid-19 pandemic, showing the problems happening, such as the lack of staff, the pandemic also highlighted cases of abuses.<sup>32</sup>

A parallel can be drawn when it comes to disability care institutions and old-age institutions. If sometimes, the care aspect is well done in some institutions, in some more problematic cases, there are problems and abuses, such as the ones once again revealed in the recent scandal.<sup>33</sup>

One reason is that some services are run for commercial purposes, with the aim of making a profit. Sometimes the quest for profitability takes over. The weight of the shareholders and managers weighs more than the welfare of the residents.

This can be a risk to prevent people from getting out of institutions, but also a risk of institutionalisation as these businesses might want to find new clients.

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<sup>32</sup> The impact of Covid-19 on disability services in Europe – 2<sup>nd</sup> EASPD Snapshot report (2020)

[http://easpd.eu/fileadmin/user\\_upload/Publications/second\\_report\\_impact\\_of\\_covid-19\\_on\\_disability\\_services\\_in\\_europe.pdf](http://easpd.eu/fileadmin/user_upload/Publications/second_report_impact_of_covid-19_on_disability_services_in_europe.pdf).

<sup>33</sup> RTBF, Une maltraitance institutionnalisée (2022) <https://www.rtb.be/article/c-est-une-maltraitance-institutionnalisee-apres-orpea-les-maisons-de-repos-armonea-dans-le-viseur-10934363>

# The risk of having to return into an institution

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***“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<sup>34</sup>***



There are several ways to ensure that deinstitutionalisation happens and the process to transition from institutions to community-based care and solutions happens well.

*“Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support.”<sup>35</sup>*

However, in some cases, people have left institutions, and find themselves in a situation where they have no other possibilities than to go back to institutions.

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<sup>34</sup> <https://www.inclusion-europe.eu/deinstitutionalisation-means-ensuring-people-are-in-full-control-of-their-life/>

<sup>35</sup> ENIL – Definitions <https://enil.eu/independent-living/definitions/>

***“My big fear is I will be put back into institution.  
If I feel good about something I also fear  
this good feeling will be taken away  
from me.”***



**Mirjam Braspenning <sup>36</sup>**

There are several reasons why people are at risk of going back to institutions, and mainly it is if the deinstitutionalisation process did not happen well, and discriminatory stereotypes still omnipresent in people’s minds.

## **Deinstitutionalisation done in a wrong way**

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There are guidelines based on principles drawn from good practices in the transition from institutional to community-based care<sup>37</sup>.

They need to be followed to ensure that the whole process, to ensure the autonomy of the person, to ensure the adequate support for daily activities, the necessary care, but also inclusion in the community. Inclusion in the community means the possibility to have a job, to have some hobbies, friends and a family.

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<sup>36</sup> Inclusion Europe, Life After Violence Report (2018)

[https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication\\_web.pdf](https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication_web.pdf)

<sup>37</sup> Common European Guidelines on the Transition from Institutional to Community-based Care (2012)  
<https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf>

## **Not respecting people's rights, not involving them in decision-making**

People with intellectual disabilities and their families should be part of the decision process to ensure that the solutions found are convenient for them, and that they are happy with those solutions. Otherwise, they might be willing to look for other institutions, as it is an easy solution because that is what they know.

## **Closing institutions without appropriate planning**

Finding a place in the community for each and everyone, including those with complex support need, and establishing individual plans is key.

Not preparing people with disabilities to get out is a big risk for re-institutionalisation. People need to be prepared psychologically, but there also needs to be an assessment to see if people will want to work in the community and what it entails – if there needs to be a training, some preparation?

***“I am still often scared that I will be sent back to the institution. I do not believe that I am allowed to stay in a place I actually like. I like where I am now. I like my work too. But I often think it will all be taken from me. “Now you are going to send me back there, I am not allowed to stay here anyway”. This makes me very insecure. I am always surprised***

***when I am allowed to stay. I have been here for 3  
years now.” Rebecca, aged 29*** <sup>38</sup>

## **Further investments in existing institutions**

While the transition process is ongoing, some buildings might get older and even get unsanitary and not decent anymore. If investments are still directed towards institutions to renovate them completely, there will be a need to look for more clients to make it profitable.

In the same way, renovating old houses or castles with the pretence of creating an institution to fund the renovation should not be accepted, as the person with the initiative of this will have to look for potential clients.

## **Lack or no creation of community-based services**

Closing institutions with no caring and support alternative is obviously not a solution.

However, if there are not enough services, that are both available and affordable, further admissions and return to institutional care will continue.



***“We should not just build new houses. We  
need to build an inclusive society”*** <sup>39</sup>

***László Bercse, chair of EPSA steering group  
and vice-president of Inclusion Europe***

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<sup>38</sup> Inclusion Europe, Life After Violence Report (2018)

[https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication\\_web.pdf](https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication_web.pdf)

<sup>39</sup> <https://www.inclusion-europe.eu/we-should-not-just-to-build-new-houses-we-need-to-build-an-inclusive-society/>

## **Lack of human resources**

There need to be enough trained staff.

If there is not enough staff to work in services, there won't be services, and this follows the previous idea. People might get back to institutions.

## **Inefficient use of resources**

Resources from institutions should be transferred to the community-based services.

The lack of proper funding and resources has consequences on the creation of available and affordable services, and trained professionals.

## **Poor geographical distribution of services**

In many cases, large residential institutions have been placed in remote areas outside of where most people live. During deinstitutionalisation, it is important not to reinforce this.

New support services must be set up in places where most people live (taking into account individual preferences of the people who are moving from the institution). Lack of adequate services in larger cities is a big issue as demonstrated by a report which evaluated all residential services for people with intellectual disabilities in Czechia: in cities with over 50,000 inhabitants, there are 11,000 people with intellectual disabilities, but only 756 places in adequate residential services<sup>40</sup>.

Therefore, the quality of the whole process and the results, including counting the number of people getting back in institutions must be monitored.

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<sup>40</sup> Žit jako ostatní, 2021. <http://jdicz.eu/vyzkumna-zprava-zit-jako-ostatni/>

# Misconceptions around deinstitutionalisation and fear of people with disabilities in the community

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## **“Living independently means doing everything yourself”**

Related to the misconception is the idea that deinstitutionalisation refers to closing down institutions without developing any support services in the community. As explained, once in the community, disabled people cannot be expected to be self-sufficient. In case where deinstitutionalisation was not done well, disabled people ended up homeless as few or no support services were put in place. For these reasons, deinstitutionalisation should be understood as developing adequate specialised and mainstream services that facilitate independent living in parallel with the closure of institutions.<sup>41</sup>

## **Difficulties leaving institutional life**

From the study on women who experienced violence in institutions, the women who gave testimonies explained that when leaving the institutions, they had no experience of living outside institutions. “When the women moved into the community, they took their heavy load of experiences, their worldview, and their coping strategies with them. These beliefs and behavioural strategies did not change quickly. The lack of self-worth and self-confidence got in the way of getting into a more valued position in society. Their coping strategies, which may have been efficient in the institution, now stopped them from going out and meeting new people. People who leave an institution need support to start building or rebuilding life in the

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<sup>41</sup> ENIL – Myth buster on independent living (2014)

<http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf>



community. We heard that the women who were well supported achieved very positive lives in the community, whereas women who did not have that support could get extremely lonely. We found that good support worked on a very personal level, understanding who the person was and what they had been through, preventing further harm, reducing vulnerability, and assisting them to develop valued social roles in the mainstream community. This supported women to build up a network of people who genuinely cared about them; these connections are what really keep a person safe. Unfortunately, this kind of support was not available for everyone.<sup>42</sup>



*Elisabeta Moldovan is a self-advocate, who lived long years in institutions and wrote a book about her experiences.*

*This is an extract from an interview with inclusion Europe<sup>43</sup>:*

**How did you deal with your experiences when you left the institution? How did you learn to trust other people again?**

I still think a lot about what happened. When I meet friends that used to live there too, we often talk about all these things. I trust very few people. These people know how to talk to me. How to have patience with me. I cannot say I trust people in general. Especially not men, actually only two of them. In one of them, I only gained trust after 8 years. I have friends that I am sure won't hurt me, but still, I cannot be fully open with them.

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<sup>42</sup> Inclusion Europe, Life After Violence Report (2018)

[https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication\\_web.pdf](https://www.inclusion-europe.eu/wp-content/uploads/2019/02/LAV-Publication_web.pdf)

<sup>43</sup> Interview with Elisabeta Moldovan (2018)

<https://www.inclusion-europe.eu/there-were-staff-members-who-sexually-abused-residents/>



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**20 million people with intellectual disabilities and their families from 39 countries.**



Co-funded by the European Union.