

# **The Transition from Institutions to Community-based Services and Independent Living for Persons with Disabilities:**

**What role must the EU and its Member  
States play?**

A position paper by the European Disability Forum

## Contents

1.	Introduction .....	4
	Purpose .....	4
	The UN Convention on the Rights of Persons with Disabilities and General Comment 5 .....	5
	Current situation and political context .....	5
2.	Definitions .....	6
	Independent living .....	6
	Institutions .....	7
	De-institutionalisation and the transition from Institutional to Community-based living.....	8
	Community-based services .....	8
3.	Human Rights Issues faced by Persons with Disabilities .....	9
	Living in institutions .....	9
	Living in the community .....	10
	Children with disabilities .....	10
	Red flags: watching out for investments that perpetuate institutionalisation .....	11
4.	Preparing the transition from institutions to independent living and inclusion in the community .....	11
	Disaggregated data on people living in institutions .....	11
	Quantitative targets .....	12
	Quality assurance .....	13
	Independent human rights monitoring and alert systems .....	13
	Awareness of alternatives .....	14
	Supporting people leaving institutions .....	15
5.	Supporting independent living and inclusion .....	16
	Accessible and affordable housing.....	16
	Alternative housing models and housing support .....	16
	Personal assistance .....	17
	Training of support workers and personal assistants.....	18
	Independent living for people who require a high level of support .....	19
	Family support and informal care .....	20
	Peer support.....	21
	Avoiding loneliness .....	21
	Access to assistive technologies and other technical aids .....	22
	Preventative action .....	22
	Education systems that better prepare young people for independence .....	23

Affordability and availability of support services.....	24
6. Building inclusive communities.....	25
Accessible communities.....	25
Access to Employment, Education and Healthcare.....	25
Culture and Leisure .....	26
7. Crosscutting elements.....	26
Strategies and action plans .....	26
Funding .....	27
Free choice and legal capacity .....	30
Disability Assessment.....	30
Public procurement.....	30
Acknowledging de-institutionalisation and independent living as a gender issue .....	31
Involving Organisation of Persons with Disabilities .....	32
8. Recommendations to the European Union .....	33
Monitor the number of people in institutions.....	34
Monitoring the human rights of persons with disabilities in institutions.....	34
Support national disability strategies.....	34
EU Funds .....	35
Support the transition away from institutions in EU accession countries and beyond .....	36
Monitor the use of EU funds in supporting independent living .....	36
European Semester .....	37
Alert and complaint mechanism regarding EU funds .....	37
About the European Disability Forum.....	37
Recommended resources .....	38
Annex .....	38
Easy-to-read Summary .....	38
Document credits.....	38

## 1. Introduction

The European Union and its Member States have committed to transitioning away from institutions that segregate persons with disabilities. As states parties to the [United Nations Convention on the Rights of persons with Disabilities \(CRPD\)](#), they have a shared responsibility to promote and support independent living and inclusion in the community as a reality.

That is the idea at least. In reality, however, this process is stagnating. Europe has reached a dead-end. Little progress, if any, is currently being made to enable persons with disabilities to leave institutions in the majority of EU Member States. As a result, far too many people are still stuck in institutions that segregate them and cut them off from their communities.

While institutions, by their very definition, deny persons with disabilities their most basic human rights, in a number of cases these violations have been shown to be extreme. These instances, which we will highlight in this paper, shed light on how institutions can seriously compromise the safety, wellbeing and dignity of residents. These examples highlight the urgency to transition away from institutions in favour of community-based alternatives.

Despite a general awareness of the severity of the problem, and the need to do something about it, the task of monitoring institutions, either at the local, national, or EU level, is taken far less seriously. Reliable and systematic data on people living in institutions is hard to come by in Europe. This limits our understanding of who the people living in institutions are. It also calls into question our ability to measure any progress in moving away from this outdated model of “care”.

In no European country can we yet talk about a true success story. The understanding of what is meant by the term “institution” and “independent living” differ across the EU, as do ideas about how best to facilitate inclusion in the community. These are questions we would like to address and clarify, on behalf of the European Disability Forum and our [members across Europe](#), within this paper.

### Purpose

This paper serves as a basis for our advocacy towards policy makers at all levels, but particularly the EU, so it can play a significant role in ensuring equal rights and opportunities for persons with disabilities in Europe. While general recommendations for decision makers at all levels can be found at the end of each thematic section, our recommendations to the EU specifically are collected in the publication’s final section. Our analysis, and our recommendations, serve to advise the EU on how it can use all the instruments at its disposal to do this, including its funding programmes, macro-economic governance, its data gathering, human rights monitoring and the implementation of the UN CRPD, the [EU Pillar of Social Rights](#) and the [European Disability Strategy](#).

As well as delivering recommendations, this position paper clarifies exactly what we mean when we talk about institutions, the damage they cause, and what measures must be taken to move towards true independent living and inclusion.

It will also explain what is meant by other terms such as “independent living” and “de-institutionalisation”, and what positive actions the EU and its Member States should focus on to enable persons with disabilities to make the transition away from segregated institutions towards independent living.

## The UN Convention on the Rights of Persons with Disabilities and General Comment 5

European countries have a shameful history of segregation and institutionalisation of persons with disabilities. While moves to close down large-scale, segregating institutions and replace them with community living date back to the 1970s, the legal commitment to ensure the right to independent living is more recent.

The [United Nations Convention on the Rights of Persons with Disabilities \(CRPD\)](#), which is now ratified by every EU Member State and EU accession country, outlines the right to independent living and being included in the community, in its [Article 19](#) and its [General Comment 5](#). The reason this article was included was because it was recognised that forcing persons with disabilities to live together in institutional settings was a breach of their rights, their freedom of choice and their dignity. It has also proven to be harmful, with widespread cases of violence and abuse, which we explain in further detail later in this paper. In 2022 the CRPD Committee also released [guidelines on de-institutionalisation including in emergencies](#).

## Current situation and political context

The EU has recognised the importance of investing in the transition from institutions to community-based services by requiring that [structural and development funds must promote a transition away from institutions and stimulate investment in social inclusion](#)<sup>1</sup>. And yet, progress has stagnated. In a [report from 2020 funded by the European Commission](#), on the state of de-institutionalisation in the 27 EU Member States, researchers concluded, among other things, that:

- there are still at least 1’438’696 persons living in institutions in the EU, although there are still severe gaps in reliable data collection;
- of these, more than 700,000 people with intellectual disabilities remain in large institutions as people with complex support needs are left behind<sup>2</sup>;
- the number of people in institutions does not seem to have substantially changed over the past 10 years.

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<sup>1</sup> See the Common Provisions Regulation (EU) 2021/1060, recital 6, Thematic enabling condition 4.4 and 4.6.

<sup>2</sup> [www.inclusion.eu/indicators](http://www.inclusion.eu/indicators)

The persistence of EU funding going towards institutional care settings was recently criticised in the [report by the UN Special Rapporteur on the Rights of Persons with Disabilities on his visit to the European Union](#), launched in February 2023.

The European Commission, even prior to this report, had been made aware of the issue and has committed to improving how funding is used for independent living and inclusion in the community. As part of the EU [Strategy on the Rights of Persons with Disabilities 2021-2030](#), the Commission committed to creating new Guidance for the EU Member States on Independent Living and Inclusion in the Community. The aim of this document will be to provide practical instructions to Member States on how to develop the conditions for independent living and carry out de-institutionalisation processes, with a focus on how EU funds can be used to achieve this goal.

Furthermore, already in preparation for the EU's next seven-year budget starting in 2028 (also called the [Multiannual Financial Framework](#)), EU decision makers are again exploring how the future EU funding regulations can offer more clarity on how national authorities should invest in the inclusion of persons with disabilities.

EU funding is not only important for investment in the transition to community-based services in the EU. It has been, and will continue to be, equally important in countries outside of Europe, those on the path towards EU membership in the European region, and the countries around the world that receive EU development cooperation and humanitarian assistance.

## 2. Definitions

### Independent living

Independent living and inclusion in the community is a right that underpins and enables all other rights. A common misconception is that independent living refers to doing everything alone and getting by without any support. What it really means, however, is that persons with disabilities have the same choices and control in their day-to-day lives as everyone else in society.

Independent living means not having your life controlled by others. It means having systems in place that afford a person their most basic of human rights: the right to determine how they live their life and what direction that life will take. In concrete terms, this will most commonly require the following:

- Choice and control over where to live;
- Choice and control over whom to live with;
- Choice and control over how long to live there;
- Access to one's own personal possessions;
- Choice and control over how one is supported;
- Choice and control over who provides services if needed;

- Choice of one's own friends and relationships;
- Choice over how to be healthy and safe;
- Choice and control over how to take part in the community;
- Control over how to resolve issues that affect you (such as problems within the family or in a living arrangement)
- Having the same rights and responsibilities as other citizens<sup>3</sup>

Independent Living therefore means having the needed support and the opportunity to make real choices. This requires that the built environment, transport and information are accessible and that there is availability of technical aids, access to personal assistance and/or community-based services. Having the right to legal capacity and supported decision making, where necessary, is a precondition to everyone being able to make choices about their lives.

## Institutions

Institutions, by their definition given below, are not compatible with independent living. According to the United Nations Committee on the Rights of Persons with Disabilities, an institution has a number of defining elements. These include:

- isolation and segregation from the community;
- no or limited influence over whom one has to accept assistance from;
- obligatory sharing of assistants with others (having an assistant that is supporting multiple people at once) meaning that a person cannot partake in separate activities from people with whom they share assistance;
- lack of control over day-to-day decisions, such as what time to get up, what to eat, who you spend your free time with, etc.;
- lack of choice over whom to live with;
- not being able to decide freely when to visit friends or family, or having this decision taken by someone else;
- facing restrictions over if and when one can have guests over;
- rigidity of routine irrespective of personal will and preferences;
- Imposing group activities under the authority of the service provider.

The absence, reform or removal of one or more institutional elements alone cannot be used to characterise a setting as community-based.

It is important to note that an institution can be of any size<sup>4</sup>. What characterises an institution is the presence of one or more of the characteristics listed above. As we will point out in our section on human rights, this means that even people living in the

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<sup>3</sup> inspired by guidance produced by the Department of Health and Social Care in Northern Ireland in 2015, giving a definition of a "home" [HSC Service Users in supported housing accommodation | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/publications/hsc-service-users-in-supported-housing-accommodation)

<sup>4</sup> <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>

community, including with their families, can end up being institutionalised if their freedom to choose and to have control over their life is not respected.

## De-institutionalisation and the transition from Institutional to Community-based living

We often use the term “de-institutionalisation”. This refers to the process of closing down institutions, moving towards independent living with the necessary community-based services and preventing the placement of people with disabilities in institutions. However, the move from institutional care towards independent living and inclusion in the community is a transition. This reflects the fact that institutions require a detailed plan for closure, which involves supporting the people concerned, ensuring their transition to housing in the community, and building person centred support systems.

It is essential that the process of moving away from institutions does not result in residents of institutions being left homeless or in vulnerable situations because of poorly planned closures. Having said this, the transition must make steady progress in enabling all people to move out of institutions and find options for independent living in the community.

There is no reason for the transition to last a long time. This is why it is essential to create conditions for living in the community as a matter of priority, so that people can move out of institutions. Having such conditions in place will also help prevent new admissions and ensure that those living in the community are not placed back in institutions due to the lack of community-based support.

It is crucial that the transition **enables** people to leave institutions and start living in the community as opposed to **removing people from institutions** in a way that leaves them passive in the process. Supported decision-making must be guaranteed to all persons with disabilities who require it, as part of the transition. It is very important that this process is not led by providers of institutional care, but that there is full involvement of persons with disabilities (especially those living in institutions) and Organisations of Persons with Disabilities, who can provide peer support, among other things. It is also important to consult with families on their involvement in supporting the transition.

## Community-based services

We also often use the blanket term “community-based services”. This refers to a vast array of different services. The simplest definition is that community-based services are all the services outside of institutions, within the community, that facilitate independent living and inclusion on the community. They bring persons with disabilities into their local communities and enable them to be a full and present part of society, rather than being segregated.

The term can refer to mainstream services used by all people, such as healthcare, employment services or transport, for example. It also includes services specifically



in place for persons with disabilities such as personal assistance, assistive technologies, supported decision making, etc. In all cases, they are services that enable people to live, work and thrive in their community. They enable persons with disabilities to live based on their own choices, retaining control over all the decisions affecting their lives.

### 3. Human Rights Issues faced by Persons with Disabilities

#### Living in institutions

As outlined in the definition of an institution given above, the main threats to the human rights of persons with disabilities can be seen in how little control a person might have over their life. Institutions cut people off from their surrounding communities and take away the control they have over even the most basic decisions that concern them.

In some cases, institutions can even become settings of much more severe human rights violations. Along the more high-profile cases was that of [Whorlton Hall](#), a specialist hospital in the UK where adults with disabilities were subject to physical and psychological abuse. [Inclusion Europe](#), in 2022, reported on the [death of a woman with disabilities in an institution in Czechia](#) at the hands of a staff member. Even more recently still, [extreme human rights violations were observed in care centres for persons with disabilities in Romania](#) where residents faced starvation, torture and exploitation.

We have also observed, in recent times, just how dangerous institutional settings can be during times of crisis. This was notably the case during the outbreak of the COVID-19 pandemic where some [institutions became hotbeds of infection and abuse](#). With Russia's invasion of Ukraine, we also saw just how cut-off people in institutions were, and how underprepared authorities were to evacuate residents to safety, resulting in [countless fatalities](#).

Institutionalised people are also shown to face an increased risk of sexual and physical abuse, and severe disciplining<sup>5</sup>, including corporal punishment and restraint<sup>6</sup>, as well as cases of forced sterilisation<sup>7</sup>. Women are particularly at risk of such abuse<sup>8</sup>. People living in institutions might also be impeded from developing attachments and community support systems that family relationships and communities can provide. Long periods in an institution make it very difficult for a person to later assimilate back into their family and/or the community.

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<sup>5</sup> [Effects of Institutional Care | Better Care Network](#)

<sup>6</sup> [Factsheet\\_Lumos\\_Risks.pdf \(contentfiles.net\)](#)

<sup>7</sup> [Forced sterilisation of persons with disabilities in the EU \(edf-feph.org\)](#)

<sup>8</sup> <https://www.inclusion-europe.eu/violence-against-women-with-intellectual-disabilities/>

## Living in the community

Without the right conditions in place, persons with disabilities can still be institutionalised when living in the community. People living in their own homes can become trapped and cut off from their communities if the built environment (including their own home), transport and services around them are not accessible. This is why accessibility is so crucial when it comes to independent living.

The characteristics that define an institution can also be present in a person's own home. The person that is meant to provide support can institutionalise the person with disabilities by taking away their power to make decisions and to interact freely with their friends, family and community.

This is why it is crucial that persons with disabilities choose their personal assistants, and ideally control of the means of hiring and payment, such as through personal budgets. Furthermore, this underlines the importance of having training for personal assistants by persons with disabilities themselves on how to offer support in a way that respects a person's independence and their human rights, but also of having peer support for persons with disabilities, to ensure they are aware of their rights and how to use and control other services.

## Children with disabilities

Issues faced by children with disabilities differ in a number of ways from those of adults with disabilities. For example, when it comes to minors with disabilities we do not generally talk about "independent living" as an aim. We talk about the right to family care and inclusion in the community. The right to independent living, however, becomes more important in adolescence and in the transition to adulthood. The earlier a child with a disability learns how to use personal assistance the more likely it is that they will be included in the community when they reach adulthood. This also increases the likelihood of independence, allowing their family and network around them to step back from the responsibility of providing day-to-day support in a natural way.

The aim is first and foremost to support families of children with disabilities and to prevent them from turning to institutions as a solution when they think they cannot offer adequate support themselves. If this is not successful, emphasis is put on promoting other forms of family-based care, such as foster care, as an alternative to institutions.

Children with disabilities are not only more likely to end up in institutions than their peers without disabilities, they are also more likely to be in these institutions for longer periods of time, often permanently. Many will still be living in institutions as they enter adulthood and, in a lot of cases, for the rest of their lives.

It has been shown that the lack of positive, consistent and individual attention received by children in institutions can hinder their emotional, physical, mental, and social development<sup>9</sup>. Some studies indicate that being institutionalised accentuates

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<sup>9</sup> [Effects of Institutional Care | Better Care Network](#)

poor cognitive performance and language deficits in children.<sup>10</sup> Other issues noted from children living in institutions are malnutrition and symptoms resulting from “toxic stress”.<sup>11</sup> In addition to this, children and young people in institutions are less likely to attend school than their peers, missing out on the crucially formative contribution that education can provide in preparing a person for independence in adulthood<sup>12</sup>.

## Red flags: watching out for investments that perpetuate institutionalisation

- The type of service provision results in the person with a disability being isolated from the broader community
- Persons with disabilities are compelled to live together in order to receive support (housing and support all linked to each other)
- Persons with disabilities using support services do not have control over their lives and over decisions which affect them
- The requirements of the service provider takes precedence over the individual needs of the person with disabilities
- Existing institutions are refurbished under the guise of improving energy efficiency or “improving conditions” for their residents, thus extending the longevity of the institution
- Housing options or other centres for service provision are located in isolated settings, resulting in persons with disabilities being segregated and cut off from the community
- Funding goes towards mainstream services which are not accessible for persons with disabilities (such as building schools not accessible to children with disabilities, transport that is not made accessible, etc.), resulting in an increased demand for specialised services

## 4. Preparing the transition from institutions to independent living and inclusion in the community

### Disaggregated data on people living in institutions

There are significant gaps in data collection on people living in institutions in the EU. The data collected by national statistics offices and shared with [Eurostat](#), the statistical office of the European Union, typically only cover people living in households. It therefore excludes people living in any type of grouped residential settings. As a result, we lack reliable and complete data on the real number of

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<sup>10</sup> [The Effects of Institutionalization and Living Outside of Family Care on Children's Early Development - Reaching and Investing in Children at the Margins - NCBI Bookshelf \(nih.gov\)](#)

<sup>11</sup> [Factsheet Lumos Risks.pdf \(contentfiles.net\)](#)

<sup>12</sup> [Effects of Institutional Care | Better Care Network](#)

people living in institutions. This makes it very difficult to regularly monitor the progress Member States are making and whether strategies and policies for de-institutionalisation are having an impact.

Data collection is also essential to help direct us towards identifying those most at risk of institutionalisation, be it on the basis of the nature of their disability, the country or region in which they live, or indeed other aspects such as gender, ethnicity, etc. It can also highlight overlaps between household poverty and the availability of family support in preventing or worsening the risk of institutionalisation. Having this information would allow for more targeted approaches which can in turn enable more effective policy responses.

Improved and more frequent data collection on people living in institutions should also be the basis for measuring how successfully countries are moving away from reliance on institutions. Other parts of the world have already shown how this can be done in a systematic and transparent way. In the United States of America, for example, the [ADA PARC \(Americans with Disabilities Act Participation Action Research Consortium\)](#) produces a frequent report that counts the number of persons with disabilities in residential care across the country, comparing the progress of each State's de-institutionalisation process.

The lack of willingness to collect data on persons living in institutions also has a more symbolic implication. It represents a lack of interest from authorities in understanding the reality of the many people still stuck in institutions, and in acknowledging their existence and worth. Therefore, beyond the practical implementations such data collection can have on measuring the effectiveness of policies, it is also necessary to ensure that people in institutions are not forgotten.

**Recommendations for national and local authorities:** Collect regular, accurate and disaggregated data on people living in residential settings of all sizes, and what kind of settings they are residing in. This data should shed light on the number of people in institutions, what groups are disproportionately represented within them (type of disability, age, ethnicity, gender, date of admission, place from which admitted) and where institutions are located. It should also be used as a means to keep track of each country's progress in moving away from dependence on institutions.

## Quantitative targets

The collection of data should be combined with targets for the reduction in the number of people in such settings. The targets should be ambitious and result in a tangible decrease in the number of people living in institutional settings. The targets should be linked to a timeframe. Both short-term and long-term targets should be established. It should also include people who split their time between living in institutions and living with their families.

**Recommendations for national and local authorities:** Cease the building or commissioning of institutions. Set up quantitative, time-bound targets for the number of people entering and leaving institutions. This information should be made public and easily available and should be monitored against disaggregated data to assess the progress of the country's transition from institutional to community-based living.

## Quality assurance

It is important that authorities develop quality assurance systems by setting rules on what services for persons with disabilities should look like in order to enable persons with disabilities to live independently and with dignity. This quality assurance should always be developed together with national and local organisations of persons with disabilities. The quality assurance should be tailored to the national context and the needs of the local community, all linked to the implementation of the CRPD.

**Recommendations for national and local authorities:** Work alongside Organisations of Persons with Disabilities to design quality assurance standards for services for persons with disabilities so they support independent living. This should be done in line with the national context and the needs of the local population of persons with disabilities.

## Independent human rights monitoring and alert systems

It is important for people to be able to raise the alarm when they see cases of human rights abuses in institutions, as well as in other settings. This will limit cases such as those mentioned earlier in this paper, where violations of people's human rights go unreported and continue for long periods of time.

For this to be feasible, the alert system must be simple. It must be very clear and made well known how and to whom a person can raise concerns. We need well-known and easy-to-reach contact points that take into account the accessibility needs of persons with disabilities. The contact points should be completely independent from any service provider. It should also be compulsory for the availability of this service to be advertised clearly in all residential settings or centres where services are provided. This could be done, for example, through a requirement to display posters that indicate whom to contact in case of concern, with all contact details made available, and a QR code that can be used to put the person through directly to someone who can handle their complaint.

Anonymity and protection must also be guaranteed to people who raise the alarm on human rights abuses, particularly for those who are still residents in institutions or who are working within them.

In addition to the above, there also needs to be a clear requirement for oversight and outreach from Human Rights institutions to ensure standards and identify

shortcomings. There are many individuals who for a range of reasons may feel too scared or unable to use the communication methods offered to highlight abuses.

**Recommendations for national and local authorities:** Establish a focal point for receiving warnings and complaints about human rights issues faced by persons with disabilities. The contact details for this should be made well-known to all, accessibility must be foreseen for people to communicate their concerns freely, and protection and anonymity must be guaranteed to those who raise the alarm on human rights abuses.

Human Rights monitoring should take place regularly in all existing institutions. Human Rights organisations and Organisations of Persons with Disabilities must be involved in ensuring standards according to which this monitoring should be conducted and in identifying shortcomings during this monitoring.

Further facilitate access to justice through legal capacity and supported decision making.

## Awareness of alternatives

In order for community-based services to be useable, they must also be known to the people who are eligible to use them and their families. The information on the alternatives to institutions must therefore be clearly shared with the people living in these settings and their support network. It is particularly important that information on these services be provided in an easy-to-understand way and in accessible formats. It is crucial that this information also reaches people currently residing in institutions and that their options and the implications of each choice be clearly presented to them.

A very good way to facilitate this sharing of information is through peer support. Persons with disabilities who have made or currently make use of community-based services can explain clearly to their peers how the services work and what differences they have made for them. Particularly important is peer support from people who themselves have made the transition from institutions towards independent living. This type of peer support can shed light on the many changes and new experiences a person will encounter outside of institutional settings.

**Recommendations for national and local authorities:** Widely disseminate information on the types of services available to persons with disabilities, in various accessible and easy-to-understand formats. It is especially important that this information be made available to people currently living in institutions and their support network.

## Supporting people leaving institutions

The move away from institutions is a transition. In the same way, getting used to life outside of institutions for persons with disabilities is a transition. During this transition, former residents of institutions will most likely need ongoing person-centred support to succeed and thrive.

Leaving an institution and embarking upon independent living means getting used to a life where you can make decisions, and where these decisions have a real impact on your daily reality. For many people that have lived in institutions, this freedom of choice will be something completely new.

It is therefore important that the assistance a person gets outside of an institution and within the community is not only limited to support linked to their impairment. There should also be additional support in helping the person adapt to a new life outside of the constraints of an institution and navigating community living, including assistance to find and purchase any appliances and furniture that will be necessary to ensure the person can live independently in their home. There also needs to be a focus on avoiding loneliness and isolation through forging links with the local community, reconnecting with friends and family (if the person wishes) and getting involved in social and cultural activities. Again, it can be particularly effective to provide this through peer support.

**Recommendations for national and local authorities:** Ensure adequate support for all people leaving institutions. This should take into account the following:

1. Providing accessible information and support to persons with disabilities who had been living in institutions to clarify what their options are for accommodation and support services outside of institutions.
2. Accompanying former residents of institutions in their transition towards living in the community and assisting in readjusting to a life based around their own choices and control. This should be done through peer support, by other persons with disabilities and their organisations or specialised social services. It should not be done by the staff working in institutions.
3. Rebuilding links with families or friends, if this is what the person wishes.
4. Dealing with the psychological and physical trauma people have experienced in institutions, through access to rehabilitation, therapy, support groups, legal support etc.
5. Providing opportunities for employment, education, etc. of former residents and making sure they have access to all necessary mainstream services with the necessary support.



## 5. Supporting independent living and inclusion

### Accessible and affordable housing

Inaccessible housing is one of the reasons why certain persons with disabilities are forced to move to residential institutions. The insufficient stock of accessible and affordable housing in European countries<sup>13</sup> should be urgently addressed by public authorities.

A disability perspective must be embedded in housing policy. This means, for example, that social housing projects need to respect accessibility, and that there is a fixed percentage of adapted houses with higher accessibility features. Persons living in institutions or at risk of being institutionalised must be given priority in accessing social housing that is accessible to them.

Additionally, the public administration should also allow for financial support to retrofit inaccessible housing or undertake the necessary adaptations so that a person with a disability can live independently in their home.

Housing in the community for persons with disabilities should follow the principle of “regular streets, regular houses”. Persons with disabilities should be able to live alongside persons without disabilities, as full members of the community, and without a distinction made about where and in what kind of settings they are able to reside.

Accessible and affordable housing will also benefit every person in society as we age, enabling us to “age in place”, living healthier active lives in our own communities.

**Recommendations for national and local authorities:** Adopt housing policies that increase the availability and affordability of accessible housing, including through social housing projects. Put in place housing support that enable persons with disabilities and their families to remain in their homes.

### Alternative housing models and housing support

Independent living does not rule out the possibility that some people may choose to live together alongside others, be they other persons with disabilities or non-disabled people.

In some cases, for example, persons with disabilities may prefer to share their accommodation to reduce rental costs. One example of how this can be done is through self-managed co-housing. Unlike a residential facility, the decision about the living arrangements and co-tenants is in the hands of the person with disabilities. Just as is the case for shared housing of persons without disabilities, self-managed co-housing can refer to shared accommodation between:

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<sup>13</sup> 2021 OECD report: <https://www.oecd.org/publications/a-crisis-on-the-horizon-306e6993-en.htm>



- People who know each other prior to living together and have made a joint decision to share accommodation;
- Someone who is the principal tenant of the accommodation and is involved in the selection of a co-tenant (through advertising etc.), just as is the case for persons without disabilities who share accommodation;
- Someone for whom sharing housing is the only choice financially at a given time, but who can opt to change living arrangements later on if co-housing no longer suits them;
- People whose support or personal assistance is not linked to their housing and does not have to be shared with someone else. For example, two people living together with their own personal assistants;

In their co-housing arrangement, residents should have a contract for residence, with the same protection against sudden eviction and the same right to terminate a contract as is the legal norm in their country. The contract for residence should be completely separate from any contracts for support services. It is also important that the tenants under guardianship have independent facilitation to enter into or break a rental agreement when they wish.

For self-managed co-housing to become an option, it is crucial that sufficient accessible and affordable housing (including social housing) be made available to persons with disabilities, including those who have limited income.

**Recommendations for national and local authorities:** Promote self-managed co-housing as an option for those who want it. Support should also be given to help people find accommodation in the community, complete rental agreements and arrange in-home support as required.

## Personal assistance

While personal assistance is not the only support service that should exist, many people could not live independently without it. When done correctly, personal assistance gives persons with disabilities control over their life and enables children with disabilities to grow up in their families. Personal assistance is one of the pillars of independent living and can be combined with other personalised services.

For personal assistance to facilitate independent living, persons with disabilities must choose who supports them (if needed, with help through supported decision making). This can be facilitated by having a personal budget that gets delivered directly to the person with disabilities rather than going through the service provider.

As mentioned above, it is important for personal assistants to receive training by the person who will employ them, in order to be able to provide the kind of assistance that this person wants and requires. In turn, persons with disabilities should be trained in how to manage their assistants, and additional training should be provided to all to ensure good working conditions and compliance with employment laws.

Organisations of persons with disabilities, such as Centres for Independent Living, play a key role in this respect.

**Recommendations for national and local authorities:** Greatly increase the budget given to personal assistance schemes, in order to make it a viable option for people who want it.

In order to make personal assistance programmes work for persons with disabilities, it is essential to:

- Increase the amount of personal assistance that is covered by the State, in line with each individual's support needs;
- Ensure that personal assistance is provided for in work settings and in the home setting, in education, or wherever the person requires it;
- Reduce waiting times for people who have applied for State-funded personal assistance;
- Make sure personal budgets go to the person requiring personal assistance rather than going directly to the service provider;
- Make sure personal assistance is not taken away from people because assistance had only been provided as part of a short-term project that has stopped or because the funding has run out.

## Training of support workers and personal assistants

Service providers need to be taken into consideration in the de-institutionalisation process. They are key to making independent living a reality and play an essential role in providing personalised services for persons with disabilities in the community.

Service providers need to be given tools to support persons with the disabilities using a personalised approach. Preparation and training for their roles should be founded on the articles of the United Nations Convention on the Rights of Persons with Disabilities and its General Comment 5. This means that they need to be made aware of what the rights are of the person using their services. They also need to be trained in how to take their lead from the person with disabilities they are assisting and how to adapt the type of assistance they provide to the needs and wants of the person.

Training should be developed in collaboration with the person with disabilities. It can be delivered by persons with disabilities themselves, who can train personal assistants in a way that helps them understand the individual needs of people using the services. This is something that currently happens in a number of countries, including [Norway](#). It can also be provided by Centres for Independent Living or Organisations of Persons with Disabilities.

Attracting workers to the sector and ensuring good working conditions and potential for career progression is also key to the functioning of service provision, and to ensuring that the availability of personal assistants and other support workers can keep up with demand.

It is also crucial that staff working in mainstream services be trained in how to make their services accessible to persons with disabilities. This should be the case in all services, but particularly in those that are frequently used such as transportation, medical services, education and public administration.

**Recommendations for national and local authorities:** Promote careers in the field of personal assistance and invest in the quality training of personal assistants and service providers based on the principles of the UN CRPD. Training given by persons with disabilities themselves should also be promoted.

It must also become a priority to train staff working in mainstream services to be able to understand and meet the needs of persons with disabilities in the work they do.

### Independent living for people who require a high level of support

The right to independent living does not cease to apply simply because a person has higher support needs. [Article 19 of the CRPD](#) does not differentiate between people with different support needs and applies equally to all persons with disabilities. This means that everyone should have the right to live independently, regardless of which barriers they face.

As we mention above, independent living does not mean doing everything alone. It means receiving the support needed based on one's wishes and preferences in order to make independent and autonomous choices, just as anyone else does.

However, people with high support needs are more likely to be placed in institutions than persons with lower support needs. Even when living in the community, or with family, there is a heightened risk of being controlled in all aspects of one's life.

For people who face barriers to having their preferences understood, such as people who are non-verbal, particular care must be taken to ensure the right to make choices. While there is no one-size-fits-all solution to facilitating decision-making in such cases, what is essential is that all possible effort is made to clearly present to the person what their options are. Clear and accessible information is key, for only on the basis of this information can a decision be made. These types of choice can range from things as simple as choosing what to eat for lunch, to deciding where one spends their free time or where and with whom they would like to live.

Presenting options clearly can be facilitated by any number of tools, including through the use of pictograms and photographs. Again, what works for one person might not work for another, and the best way of presenting clear information will very much depend on the individual.

Understanding a person's expression of preference, when they are presented with a choice, is often easier if those offering support know the person well and can interpret any non-verbal signs. Particular attention should be paid to reading non-verbal cues that indicate positive or negative reactions to things. If more than one person offers support, or if a new assistant starts supporting the person, these cues

to look out for should be clearly communicated to them, to assist in understanding the person's choices<sup>14</sup>.

**Recommendations for national and local authorities:** Set up personalised mechanisms to maximise the person's control over their own life. This should include fulfilling the preferences of persons requiring a high level of support, in order to guarantee their independent living in the community.

## Family support and informal care

Many persons with disabilities rely on informal care and/or support, including from family members. Women are particularly likely to act as informal carers. In some cases, those offering assistance are themselves persons with disabilities.

In many cases, informal care happens because of the absence of public support services and personal assistance. Lack of knowledge and information about their rights or what exists results in some families providing support for their family member with a disability until they are physically or emotionally unable to continue. Sometimes it can be linked to cultural norms and an expectation in some countries or regions that the family, and not the State, takes responsibility for offering support. In other cases, it can be the preference of the person with a disability.

With informal and family support, it is first and foremost crucial that this be the choice of the person with disabilities and is not imposed on them, nor on the informal carer. In countries with a culture or tradition of families taking on assistance roles themselves, it is all the more important that the option for external personal assistance be made available and that the person is not forced to receive assistance from a family member if they do not wish to.

If it is indeed the person's preference to receive assistance from a family member, then it is important for the informal carer or person offering support to be compensated for the work they do. In this case, as is the case with a personal assistance budget, the funding should go through the person with disabilities. This means that, if the person decides at any point to change whom they receive support from, they are able to do so.

It is also important that informal carers and family members are provided with other support services that enable them to rest and to retain their relationships as friends, neighbours or family, not just care providers. They should be able to take a break from their supporting role and have this facilitated by the State. This can also be facilitated by making it possible to combine informal care with external assistance when needed, and to offer respite services within the person's own home.

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<sup>14</sup> [www.inclusion-europe.eu/empowerment-of-people-with-complex-support-needs-report/](http://www.inclusion-europe.eu/empowerment-of-people-with-complex-support-needs-report/)

**Recommendations for national and local authorities:** Offer greater financial support and guidance to families and informal carers, and make sure all people offering informal care are made aware of the support that is available to them.

## Peer support

Peer support, which in this context refers to a person with a disability who lives independently offering guidance or assistance to another person with a disability, is essential for supporting independent living.

Peer support can be particularly helpful when it comes to offering advice to people who have left institutions and are acclimatising to a new life in the community. It can be especially useful in offering guidance on how to take up direct payments for assistance costs, how to manage one's personal budget, how to select and employ personal assistants, and how to navigate access to other services and forms of support.

**Recommendations for national and local authorities:** Facilitate and fund peer-exchange among persons with disabilities living in the community, and with those living in residential institutions.

## Avoiding loneliness

Recent research from the UK has highlighted the extent to which persons with disabilities suffer from loneliness. It suggests that 61% of persons with disabilities are chronically lonely. This number rises to 70% for young persons with disabilities<sup>15</sup>. Two thirds of those surveyed as part of the study claimed that social isolation was affecting their mental health. Other studies too have also shown that persons with disabilities are disproportionately impacted by loneliness<sup>16</sup>.

It is not only the fact of living in isolated settings that has an impact on loneliness. Equally damaging is the inability of a person to have control over who they are allowed to meet and when, as well as if and when a person can receive guests in the place where they are living. Loneliness can also be exacerbated by a loss of connection with one's family, or control over a person's right to form meaningful and loving relationships.

**Recommendations for national and local authorities:** Services that facilitate independent living should have a primary focus on maintaining and strengthening a person's link to their community. Particular efforts should be made to maintain links with the persons family, if this is what they wish. The person with disabilities should have freedom to meet who they want, when they want, in the same way that any other person would. A persons access to mainstream community facilities should

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<sup>15</sup> [https://www.campaigntoendloneliness.org/disability-and-loneliness/#:~:text=People%20with%20disabilities%20have%20been,with%20no%20disability%20\(6%25\).](https://www.campaigntoendloneliness.org/disability-and-loneliness/#:~:text=People%20with%20disabilities%20have%20been,with%20no%20disability%20(6%25).)

<sup>16</sup> [https://www.campaigntoendloneliness.org/disability-and-loneliness/#:~:text=People%20with%20disabilities%20have%20been,with%20no%20disability%20\(6%25\).](https://www.campaigntoendloneliness.org/disability-and-loneliness/#:~:text=People%20with%20disabilities%20have%20been,with%20no%20disability%20(6%25).)

also be enabled in order to be able to socialise easily and not have to rely on disability services to build friendships.

### Access to assistive technologies and other technical aids

One of the biggest innovations in the area of independent living and inclusion in the community, is the role that new technologies can play. It is also an area where things are constantly evolving.

The first thing to clarify is that technology will never be a substitute for human support and personal assistance. However, technology can reduce the amount of assistance that a person requires and can underpin their independent living in the community.

Current mainstream technologies are increasingly accessible and convenient for persons with disabilities, such as virtual assistants, voice control and other modes of operation. Beyond this, technological advances are also reaching devices specifically designed for persons with disabilities. We refer to these as “assistive technologies” which can facilitate self-care, mobility, communication, or access to other mainstream technologies.

It is therefore important that persons with disabilities and disability-services in the community can easily access these technologies, and receive the necessary technical and financial support to choose, use and maintain them.

**Recommendations for national and local authorities:** Ensure the availability and affordability of assistive technologies and other technical aids which can support the independent living of persons with disabilities in the community. Support persons with disabilities with costs incurred by obtaining such technology or for receiving training in how to operate them.

### Preventative action

A big reason for persons with disabilities being institutionalised is that support is not provided to enable them to remain living at home. Other factors to add here are:

- family poverty
- exclusion of children from education
- General Practitioners and other health professionals not being adequately trained in disability related issues, resulting in reliance on “special treatment centres” or hospitals
- Professionals advising families to place their children in institutional care

Parents, in particular, may feel they do not know how to address their child’s needs, and thus resort to institutional care. As mentioned above, support and advice must be easily and readily available to families and informal carers. Critical times to provide this support to prevent institutionalisation are:

- Early years when a disability is recognised

- Starting school
- Leaving school
- Moving on from family home
- Cases of illness or bereavement
- Cases of Relationship or mental health crises

People might also be institutionalised later in life as their family get older or eventually pass away. In many cases, families worry about who will support the person with disabilities after their passing, if insufficient support is provided to enable them to remain in their own home. As persons with disabilities get older and reaches the age of retirement, the way their allowance is provided may also change. This can sometimes cause problems regarding the amount of allowance a person is entitled to and increase their chances of being institutionalised.

The complexity of systems for accessing disability allowance, housing, personal assistance and other support makes it difficult for the family and person with a disability to get all the elements they need in place at the right time. In some cases, the risk of being institutionalised can be accentuated by a breakdown in a person's relation with their family and the lack of a support network within the community.

In other cases, the person might have been living away from their family but, without support to find and retain employment, or to manage household expenses, etc, might find themselves unable to make ends meet. For some, ending up in an institution comes from a fear of living on the streets in the absence of other support mechanisms. It does not need to be this way.

**Recommendations for national and local authorities:** Invest in the prevention of institutionalisation happening in the first place through actions such as:

- Financial support for informal carers
- Guidance for families on managing certain medical conditions
- Guidance on understanding support systems and planning for the future
- In-home support for the person with disabilities and their family
- Mechanisms to retain personal links to one's family and local community
- Support in finding employment and managing finances
- Support in finding or retaining accommodation in the community

## Education systems that better prepare young people for independence

Education for all young people should have a focus not only on preparing for the world of work, but also for how to manage the challenges that arise when living independently. EU funding can play a role in making this a reality for persons with and without disabilities alike.

This should include education in (but not exclusively):

- Managing household finances
- Understanding your rights as a tenant
- Completing and breaking a rental contract



- Administrative processes to complete when moving house
- Paying bills
- Setting up a bank account
- Use of online services (such as banking and other services)
- Cooking and nutrition
- Using public transport
- Personal hygiene
- Family planning
- Maintaining cleanliness of the home
- Understanding of services to go to in case of issues with neighbours, of domestic violence, etc.

For some, there may be interest in preparing for how to manage and interact with a personal assistant or other service providers in order to get the support one requires and to have the tools needed to exercise control over it. This might include advice on:

- Managing one's personal support plan and budget for assistance
- Developing communication skills and techniques that can help give clear directions to service providers, to manage and control any service received
- Training on the legal obligations and rights of someone employing a personal assistant

**Recommendations for national and local authorities:** Assist all young people in learning skills that will help them live independently as adults. Preparation for independent living should be offered to learners with disabilities and without disabilities alike and be integrated into mainstream education curricula.

### Affordability and availability of support services

The alternatives to institutions will not be real alternatives if there is not a range of options for different support and if they are too expensive for the people who require them. For this reason, it is essential that support for independent living and inclusion in the community be made affordable and available to persons with disabilities and their families.

**Recommendations for national and local authorities:** Focus not only on the types of services available but how realistic it is that the people requiring them will be able to pay for them, including using allocated budgets from the government. Every effort must be made to ensure a balance between quality, availability and affordability. Support must be on hand to assist persons with disabilities to cover the cost of the service of their choice. Nobody should be obliged to forgo their human rights because of the cost of support services and personal assistance.



## 6. Building inclusive communities

### Accessible communities

Inaccessible public spaces, transport and housing make the prospect of independent living and inclusion in the community impossible. It is therefore crucial that efforts to enable persons with disabilities to make the transition from institutions to independent living are done in parallel with a larger commitment to making our societies more accessible.

Improved integral accessibility benefits everyone and will also ensure the useability of our public infrastructure, and the habitability of our housing stock, for an ageing population. Persons with disabilities can only have a choice in where they live, and agency over where they go and how they spend their time, when they can access these spaces.

It cannot be stressed enough just how important it is that we improve accessibility in Europe, not only in newly-developed built environments and transport, but also in retrofitting existing structures. Europe has a very long way to go in this area. Urgent and ambitious investment is needed. If the investment is not made now, however, we risk having an ever-increasing proportion of public spaces, public transport and housing stock that is simply not useable for a large part of the population.

**Recommendations for national and local authorities:** Invest urgently and ambitiously in improving the accessibility of communities for all people, particularly persons with disabilities. This requires making sure that public spaces and buildings are accessible, as well as all forms of public transport and public services. A big investment in making housing accessible must also be undertaken, ensuring that all new-builds are either readily accessible for persons with disabilities or can be easily and inexpensively rendered accessible, and retrofitting existing housing to be made accessible wherever possible.

### Access to Employment, Education and Healthcare

Inclusion in the community can be greatly facilitated by having access to quality healthcare, inclusive education and the open labour market.

Let us begin with the open labour market. Employment is a means to forge connections with the community. Wages from employment are also, crucially, a way to access other essential amenities, such as housing, transportation, etc.

Inclusion in the open labour market is inseparable from the need to receive a quality education. It is therefore crucial for persons with disabilities to have the opportunity to be educated in mainstream learning environments and provided with the support they require to succeed within them. Mainstream education settings are a means to access high quality and recognisable qualifications that are sought by employers.

Access to healthcare that can meet the particular needs of persons with disabilities is also crucial to promote independent living and inclusion in the community. Persons

with disabilities should be able to access healthcare in medical centres and hospitals that operate for persons with and without disabilities alike. Receiving necessary medical care should not require persons with disabilities to attend segregated medical facilities intended solely for persons with disabilities, in separate settings to where persons without disabilities receive healthcare.

**Recommendations for national and local authorities:** Ensure the possibility to access inclusive, mainstream education, and provide all learners with disabilities with the necessary assistance to learn and thrive in their education.

Increase support for access to the open labour market by making it easier to retain disability allowance when in work, having reasonable accommodations provided more easily and systematically in all workplaces, and investing in job-matching services for persons with disabilities, as well as [other initiatives for inclusion in employment](#).

Make sure that persons with disabilities can receive the medical care they might require, tailored to their needs, within mainstream medical facilities not created exclusively for persons with disabilities.

## Culture and Leisure

Being included in the community is not just about accessing services and amenities that are crucial for getting by and making ends meet. Inclusive communities should also be ones in which cultural and leisure activities are able to welcome persons with disabilities. They should enable persons with disabilities to enjoy what the community has to offer in the same way as they do for the rest of the community.

**Recommendations for national and local authorities:** Promote the integral accessibility of all cultural and leisure facilities in the community.

## 7. Crosscutting elements

### Strategies and action plans

Strategies and action plans for de-institutionalisation are not an end goal in themselves. It is not the existence of the strategy that is important, but what it actually achieves. However, having a strategy in place is important to address the complex task of moving away from dependence on institutions in favour of independent living and inclusion in the community. It can assist in ensuring coherence between all the different actions it takes to set the de-institutionalisation process in motion. It also helps keep track of the many moving parts in enabling people to leave institutions.

De-institutionalisation strategies and action plans should be built around all of the elements mentioned above in this paper. To ensure they can make a difference, it is very important to have a serious and realistic approach to funding all the actions

proposed. This is particularly important when it comes to covering the “cost of transition” that we will explain below. It is also very important to collect data, monitor progress on a regular basis, and design all actions in collaboration with Organisations or Persons with Disabilities from the beginning.

The strategy will also set the direction for policy, programmes funding, and human technical resource development.

**Recommendations for national and local authorities:** A strategy for de-institutionalisation is essential. The strategy should, among other things, clarify what kind of community-based settings for persons with disabilities are needed and prioritise making these available, set time-bound targets for how many people will make the move from institution towards the community-based service of their choice in a given period, lay out a clear budget for supporting the transition and assign responsibilities. This should be done in close cooperation with Organisations of Persons with Disabilities and be led by the experiences and priorities of persons with disabilities themselves.

## Funding

### Supporting the cost of transition

As the transition from institutions to independent living and community-based services takes place, there will be a period during which costs to the State will increase. This is because, being a transition, there will be a time of overlap where the institutions being replaced will exist alongside the community-based services being introduced to replace them. There will therefore be a moment in which two parallel systems are operating at the same time- one scaling up and the other closing down.

As people move away from institutions, there will nevertheless remain certain fixed costs that do not disappear until the institution has been entirely closed down. As people gradually move away from institutions, the running costs per resident therefore gradually increase. Eventually, once an adequate arrangement has been found for all former residents of the institution, it can be entirely defunded and the costs to the State will again drop. Policy makers must therefore foresee and plan ahead for a period of increased costs for the provision of services during the transition process.

While ensuring the process is indeed a transition, the cost associated with funding institutions and community-based services simultaneously should underline, as mentioned above, that the transition does not need to last a long time and must be addressed in a proactive manner and with a sense of urgency.

**Recommendations for national and local authorities:** Budget for increased costs that will likely be incurred during the transition period, when institutions are still operating alongside community-based services, and before all residents of institutions have been able to find a suitable alternative.

Institutions should not be renovated or built as part of the transition process. Any new investment in institutions takes away resources from community-based services and delays the process further.

### Personal budgets

Personal budgets for persons with disabilities should be strongly encouraged. Personal budgets that are delivered directly to the person requiring the service allow for greater autonomy. They increase the person's options to choose their preferred service, and make it clear for the personal assistant or service provider that the person with a disability is their employer.

In some cases, personal budgets may be used to fund places in institutional care; for example, because there are not enough community-based services or the amount provided is too low to pay for the needed support in the community. This should be addressed by providing adequate funding, creating financial incentives for people to use services in the community, and developing a range of community-based services to meet various support needs.

**Recommendations for national and local authorities:** Use personal budgets as a way of ensuring persons with disabilities have control over who provides assistance to them, and what kind of services they use. Ensure that personal budgets are not used to fund placements in institutions.

The allocated amount for personal budgets must be high enough to cover the costs of a person's own needs and the extra cost of living that comes with having a disability. It must also cover the salary costs of personal assistants, as well as any other costs linked to the hiring of assistants such as insurance, accounting services and administration fees, etc.

### Data gathering and monitoring

Gathering data on persons with disabilities living in institution is not something that can be done for free. It will require budgeting for. This is something national governments and/or local authorities must plan for in a realistic way. Support also needs to be given to the National Statistics Offices to ensure they are collecting the type of data required, and in a regular way that allows for detailed monitoring of whether the country in question is upholding the rights of persons with disabilities.

Monitoring requires investment. If civil society organisations are being expected to observe and report on how State and EU funding is being invested, then they must be supported financially for the essential role they are playing.

**Recommendations for national and local authorities:** Set aside a sufficient budget that will allow for data collection on people living in institutions and do the same for supporting organisations that monitor the de-institutionalisation process.

### To support Organisations of Persons with Disabilities

Monitoring the transition from institutions to independent living and inclusion in the community is far from the only role played by Organisations of Persons with Disabilities.

Such organisations are often at the forefront of making independent living a reality. They help advise policy makers on how to design services that meet the needs of persons with disabilities. They are also often the ones delivering support services themselves. They can help train personal assistants, accompany former residents of institutions in their move towards life in the community, support families, etc.

In other words, without Organisations of Persons with Disabilities, the transition from institutions to independent living would not take place. To be able to fill these countless roles, these organisations must receive financial support. This funding must be long-term. Organisations filling such an essential purpose should not be required to use up unnecessary amounts of time and energy on fundraising activities, when they could be focusing on their core objectives.

**Recommendations for national and local authorities:** Provide long-term and sufficient financial support to Organisations of Persons with Disabilities, to allow them to continue playing their central roles in supporting independent living and inclusion in the community.

Set up Centres for Independent Living led by Organisations of Persons with Disabilities, which operate with the role of facilitating the transition from institutions to community-based services.

### Make use of the possibilities offered by EU Funding

Funding for the actions above does not need to rely entirely on national budgets. EU funding can also help in making them a reality. In order to improve the selection of activities that will respond to the needs of persons with disabilities, it is essential that the Managing Authorities in the Member States include Organisation of Persons with Disabilities in the partnership process, and that they have their say in where the money is allocated.

If needed, it can be useful to make use of the [EU's Technical Support Instrument](#) in developing reforms to service provision. This is a tool at the disposal of EU Member States and can make a difference in making sure reforms fulfil their purpose.

**Recommendations for national and local authorities:** Channel available EU funding into actions that promote Independent Living and the inclusion of persons with disabilities in the community. Ensure that Managing Authorities overseeing the use of EU funds fully and meaningfully involve Organisations of Persons with Disabilities as partners (in line with the [Partnership Principle in Article 8 of the Common Provisions Regulation](#)) at all stages of EU funds use (programming, implementation, monitoring and evaluation).

Make use of the EU's Technical Support Instrument when advice or external

expertise is needed for reforms, while ensuring full involvement of persons with disabilities and their organisations.

## Free choice and legal capacity

Persons with disabilities should be enabled to retain their legal capacity. They should be able to exercise their legal capacity in choosing, managing and terminating the provision of community-based support. For some people, it might be necessary to offer support in exercising legal capacity, through supported decision making. This should be provided as a service to the persons concerned.

Legal capacity is not only important when it comes to having the final say on the type of services or support one uses. It is also a legal requirement for many other socio-economic rights that facilitate independent living, such as employment and rental contacts and issues affecting a person's civil status.

**Recommendations for national and local authorities:** Make independent living and the right to choose a reality by ending restrictions of legal capacity and replacing them with supported decision-making.

## Disability Assessment

Eligibility for support services can be linked to a person's disability assessment. It is therefore essential that disability assessment looks beyond a person's condition and considers the real barriers they face in their life as a person with a disability. In this sense, disability assessment should also include an accurate **needs assessment** for each individual. It should focus on how much support and what kind of assistance a person is likely to need in order to be able to enjoy independent living in the community.

Personal circumstances that might create extra barriers should also be taken into account, and the person with a disability should be fully involved making this assessment. For example, the amount of disability allowance that a person is granted should take into account the cost of living where they reside. Extra support should also be on offer for people living in areas with limited services on offer.

**Recommendations for national and local authorities:** Integrate a detailed needs assessment into disability assessment procedures. The needs assessment should evaluate the individual barriers a person faces and what support is needed for them to live independently. It should take into account their individual circumstances and not be linked solely to the nature of their disability. The person with disabilities themselves should be involved in the process of analysing their individual needs.

## Public procurement

Public procurement as a model for the selection of service provision can be problematic. This is particularly the case because price nearly always outweighs quality as a criterion for winning the service contract. The regularity of contract



renegotiations also results in a short-term approach and means that persons with disabilities using the service have to adjust to frequent changes in who provides it, and how it is done. This removes stability from people's lives and takes out of their control the choice over who is best placed to offer them support.

Attempts to link public procurement to quality criteria can be difficult and ineffective. The choice of the best service provider for a person with a disability is something based on personal needs and preferences and cannot be measured with a one-size-fits-all list of criteria. Individual needs and aspirations are often not taken into account in public procurement. Instead, the procedure is designed for large groups of people. It is a system that is not well-matched with the principles of independent living and inclusion in the community.

**Recommendations for national and local authorities:** Identify alternative funding models to public procurement that fully consider the needs and preferences of people with disabilities.

## Acknowledging de-institutionalisation and independent living as a gender issue

The gender perspective needs to be at the heart of actions and strategies promoting independent living and de-institutionalisation. The issue of care and support affects women differently than it does men in a number of ways.

To begin with, women are more likely to take on roles as informal carers, be it towards a child with a disability, a parent, a partner or another loved one. Offering informal care is often a full-time job, done with little or no financial compensation from the State, and offering little in the way of possibilities for the person providing care to make a living through paid work. This can have huge impacts on the material wellbeing of families, and particularly on women who are more often the ones who find themselves directly in such situations. Not only does it have an impact on their material wellbeing and ability to avoid the risk of poverty in the immediate term, it also has significant implications on pension entitlements later on in life. Acting as an informal carer can therefore pave the way for a lifetime of material precarity.

Informal care can have many other impacts on a person, beyond hampering their financial situation. Offering support can be physically and mentally demanding. Unlike paid assistants, an informal carer will most likely be on call around the clock, with no clear respite period. It is also a role that a person is likely to take on throughout their lifetime, for as long as the loved one with a disability requires their assistance. This can mean that the informal carer continues to offer support even when they enter older age and lack the strength or stamina to perform certain more physical tasks. Not being supported in their caring role can therefore affect their own well-being and their right to age healthily.

Women are also more likely to be persons with support needs themselves. First of all, it is worth noting that, according to the United Nations, there are more women with disabilities worldwide than there are men with disabilities. The UN puts the

global prevalence of women with disabilities at 19% of the population, compared with 12% for men with disabilities. This points to a likelihood of women with disabilities being, by and large, the majority when it comes to people requiring support services to live independently.

While we lack detailed and disaggregated EU data on persons with disabilities requiring long-term support, we do possess very revealing data on older people with support needs. This data indicates that around 37% of women over 65 report needs for long-term care, versus 23% of men over 65. On average, women live 3.5 years longer than men and spend 12.7 years with a chronic health condition or disability, compared to 9.2 years for men<sup>17</sup>. This again underlines that women are not only more prevalent in roles as caregivers, but also as recipients of care.

**Recommendations for national and local authorities:** Ensure that informal care from family members only occurs when it is the choice of the person with a disability or their family member, and never as a necessity due to the lack of community based services or assistance.

Ensure that those who do provide informal care, particularly women who are overrepresented in such roles, are financially compensated for the work they do. This compensation should also pave the way for robust pension schemes that will reduce the risk of poverty later in life. Furthermore, respite services must be made affordable and easily available to all, as well as frequent in-home support to relieve informal carers of a share of the responsibility they hold.

Given the prevalence of women with disabilities as users of support services, ensure that services are designed with their needs in mind. Particular care must be taken to ensure that women with disabilities receiving support to live independently are kept safe from the risk of harassment or gender-based violence, of which they are disproportionately the target.

## Involving Organisation of Persons with Disabilities

All of the actions mentioned above should be designed and implemented in partnership with Organisations of Persons with Disabilities. Involving such organisations early on and in a meaningful and collaborative way will result in better designed responses. It will help ensure that the actions respond to the real needs of persons with disabilities and that they focus on the most pressing issues.

Involving Organisations of Persons with Disabilities will make for a more efficient response. They can give guidance to the responsible authorities on what to focus on first and how to do so. It will ultimately reduce the chance of mechanisms being put in place that are ineffective and need to be revised later on.

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<sup>17</sup> <https://ec.europa.eu/social/BlobServlet?docId=24081&langId=en#:~:text=The%202021%20Long-term%20care%20report%2C%20jointly%20prepared%20by,care%20provision%20and%20key%20challenges%20across%20the%20EU.>



As well as working in collaboration with Organisations of Persons with Disabilities, there should also be State support going towards facilitating the work they do. This financial support should enable them to:

- Provide peer support
- Assist people in managing their personal budgets
- Provide training to people with disability on how to employ personal assistants
- Provide legal advice and support
- Provide advice and support regarding disability allowance
- Offer support in finding accommodation in the community
- Monitor access to the right to independent living locally

**Recommendations for national and local authorities:** Meaningfully involve persons with disabilities and their representative organisations at all stages when designing new policies or actions that affect them.

Provide funding support to Organisations of Persons with Disabilities to enable them to provide the link between persons with disabilities, the State and local authorities in the provision of support services.

## 8. Recommendations to the European Union

The European Union has a significant role to play in facilitating the transition from institutions to independent living and inclusion in the community for persons with disabilities. It also plays a role in bridging the gaps we observe between different Member States and localities when it comes to the opportunities and level of support persons with disabilities are afforded to live independently.

The European Union, through its [Cohesion Policy](#), aims to bridge the gap between the most prosperous and developed parts of the European Union, and those with the biggest challenges, including when preparing accession countries for their entry into the Union.

When it comes to the transition away from institutions to community-based support, each country, region and locality has had a different starting point and is at a different stage in the process. For some, transforming outdated models of care and service provision will still be a substantial undertaking. It is, however, important to stress that the problem of institutions is not limited to any one country or region of Europe. Institutions remain a problem in western Europe and in the older EU Member States just as they do in the newer Member States of central and eastern Europe.

The European Disability Forum therefore calls on the European Union to take the following actions, with a particular focus on localities where the most people are still living in institutions:

### Monitor the number of people in institutions

It is essential that the Commission, together with the National Managing Authorities and Organisations of Persons with Disabilities, develop indicators for measuring the progress of investments into social inclusion and independent living. If EU-funded actions prolong the life of institutions or result in no significant progress being made in the transition from institutional care to community-based services, the funding going to these projects must stop. In the cases of pilot projects that work well, these initiatives should become long-term funded programmes put in place in the Member State.

Monitoring is also dependent on improved data collection on people living in institutions, an area where data collection at EU level is currently severely lacking. It is therefore crucial that [Eurostat](#), together with National Statistics Offices, start collecting disaggregated data on people living in institutions (as defined in the General Comment 5) that gives an indication of their numbers, as well as aspects such as age, gender, ethnicity, etc. We would strongly recommend that this monitoring of the number of people in institutions be integrated into the [Social Scoreboard](#) and closely monitored on a regular basis.

### Monitoring the human rights of persons with disabilities in institutions

The European Union should look deeper into the human rights violations against persons with disabilities in institutions, as is proposed by European Commission in [action 36 of the EU Strategy on the Rights of Persons with Disabilities](#). There are existing agencies which could be considered to undertake this work, such as the [European Union Agency for Fundamental Rights](#).

The focus should be not only to uncover the most serious human rights violations, but also to give an indication of what the reality is like in the majority of institutional settings and what common issues institutionalised people across Europe are facing, in order to raise awareness of the need to transition away from institutions.

### Support national disability strategies

The EU should assist the Member States in developing national de-institutionalisation strategies. Use should be made of the EU's [Technical Support Instrument](#) to support the Member States in designing strategies that are fully in line with the UN Convention on the Rights of Persons with Disabilities

Eligibility for EU funds in the upcoming regulations governing the rules for funding, including for EU accession countries, should be linked to the existence of or ongoing development of such a strategy at national level. Strategies, as already mentioned should include targets, and continuous monitoring of progress.

## EU Funds

### Earmarking part of the European Social Fund Plus for disability support services

More funding for community-based services and personalised support should come from the [European Social Fund Plus](#) (ESF+) than the [Regional Development Fund](#) (ERDF) – as spending should go towards support schemes rather than building residential settings.

ESF+ money can be earmarked for:

- Personal assistance support programmes
- Education programmes to help prepare young people for greater autonomy
- Practical and financial support to families of children with disabilities
- Inclusive child care and afterschool provision
- Programmes to assist persons with disabilities in accessing housing
- Campaigns to promote personal assistance as a job
- Programmes to make it easier for persons with disabilities to recruit personal assistants (such as online platforms/pools run by Centres for Independent Living, for example)

In the next Multiannual Financial Framework, the budget for the Social Fund should be increased to reflect important role it can play in supporting independent living and inclusion in the community for persons with disabilities.

### Using the European Regional Development Fund to improve accessibility of public spaces and increase accessible housing

Money from the Regional Development Fund and the Cohesion Fund should go, as an absolute priority, towards making public spaces and public transport fully accessible to persons with disabilities. This investment in accessibility should be viewed equally as an investment in social inclusion and a key facilitator of independent living.

The Regional Development Fund and Cohesion Fund should also be used for the purpose of increasing the availability of accessible housing in the community.

The European Commission should ensure that any internal or external guidance on the use of ERDF and other funds includes an absolute prohibition of investing in institutions, in line with the UNCPRD.

### Supporting Member States to meet the cost of the transition from institutions to community-based services

The European Union should help support the extra costs incurred by Member States during the transition from institutions to independent living and inclusion in the community. This refers to the temporary increase in State expenditure while institutions still exist in parallel with the community-based services put in place to replace them. During this time it is important not to invest in preserving or renovating

institutions for future use, and to move proactively away from dependency on institutional settings.

This kind of support to Member States should be foreseen within the EU's next [Multiannual Financial Framework](#) and in its [Technical Support Instrument](#).

## Support the transition away from institutions in EU accession countries and beyond

### Pre-accession assistance

Other funding mechanisms should also be used to promote the transition from institutions to independent living and inclusion in the community. This is particularly crucial for the funding that goes towards [pre-accession assistance](#), for countries in the process of joining the European Union. It should be clear that taking a serious approach to the transition from institutions to independent living and inclusion in the community is a pre-requisite for EU membership. This includes, in particular, monitoring the number of persons in institutions, human rights monitoring and development of a strategy for the transition from institutional to community based living).

### Neighbourhood, Development and International Cooperation Instrument

Rules that prevent spending of EU funding on institutional settings should not cease to apply once the money is used beyond the EU's borders. There can be no differentiating between the rights of persons with disabilities in and beyond Europe. The promotion of independent living in inclusion must be maintained no matter where EU money is used. Support for full inclusion in the community should be one of the key objectives in the use of EU funding for international cooperation, notably the [Neighbourhood, Development and International Cooperation Instrument \(NDICI\)](#).

## Monitor the use of EU funds in supporting independent living

A report should be conducted on how much EU funding has gone towards projects for independent living in the EU Member States, and to what extent these are aligned with the UN CRPD and General Comment 5. The report should outline the extent of the funding to date, where this has taken place, and examples of what the funded actions have done to further the transition towards inclusion in the community.

A rigorous review should also be done of the implementation of the current [Common Provisions Regulation](#), which governs the use of a number of key EU funds for the inclusion of persons with disabilities. Particular attention should be placed on how organisations of persons with disabilities are included in the selection and monitoring of operations (Article 8) and rules on ensuring accessibility for persons with disabilities (Article 73).

## European Semester

The [European Semester](#) should be increasingly used as a tool to guide Member States away from their reliance on institutions and towards support for independent living and inclusion in the community. This will be facilitated by better data collection, which will allow for more accurate monitoring of progress.

It is important for the European Commission to stress that investment in community-based services and the de-institutionalisation process is a priority. This should be underlined through concrete recommendations and clear targets that the Member States are expected to achieve. The Semester is also a useful tool for guiding Member states in how they should make use of EU funds, which again is why it is crucial for de-institutionalisation to be much more present in the recommendations it delivers.

## Alert and complaint mechanism regarding EU funds

It should be made simpler for all citizens to be able to make contact with the European Commission to alert them to cases of EU funds being used in a way that further segregates persons with disabilities.

The Commission should better publicise its online [complaint form for the breach of EU law](#) and ensure that responses are sent in a timely fashion to those who have raised concerns, in an easily understandable way that enables the person making the complaint to understand what action will be taken and what the immediate steps will be.

Citizens should not be expected to navigate the internal structure of the European Commission in order to raise concerns of EU-funded institutions. The whole process must be simplified and made well known to ordinary people. The office of the EU Ombudsman should also be involved in the process and given access to all complaints.

The Commission's responses to complaints must take into account the EU's obligations as a state party to the UN CRPD, and result in immediate action against any EU-funded activities that run counter to the rights of persons with disabilities.

## About the European Disability Forum

The European Disability Forum (EDF) is an umbrella organisation of persons with disabilities that advocates for the rights of over 100 million persons with disabilities in Europe.

We are an independent non-governmental organisation (NGO) that brings together representative organisations of persons with disabilities from across Europe.

We are run by persons with disabilities and their families. We are a strong united voice of persons with disabilities in Europe.

## Recommended resources

- [United Nations Convention on the Rights of Persons with Disabilities, Article 19](#)
- [United Nations Convention on the Rights of Persons with Disabilities, General comment No.5 on Article 19 - the right to live independently and be included in the community](#)
- [UN Guidelines on deinstitutionalization, including in emergencies \(2022\)](#)
- [Transformation of services for persons with disabilities \(January 2023\) – report by the UN Special Rapporteur on the Rights of Persons with Disabilities](#)
- [EU Guidance on Independent Living and Inclusion in the Community - European Expert Group on the Transition from Institutional to Community-based Care \(2022\)](#)
- [EU Funds Checklist to Promote Independent Living and Deinstitutionalisation – European Expert Group on the Transition from Institutional to Community-based Care & Hope and Homes for Children \(2021\)](#)
- [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 \(2020\)](#)

## Annex

### Easy-to-read Summary

(Coming soon)

### Document credits

This document was prepared by [Haydn Hammersley](#)



The European Disability Forum  
Mundo Madou  
Avenue des Arts 7-8  
1210 Brussels, Belgium.

[www.edf-fehp.org](http://www.edf-fehp.org)

[info@edf-fehp.org](mailto:info@edf-fehp.org)