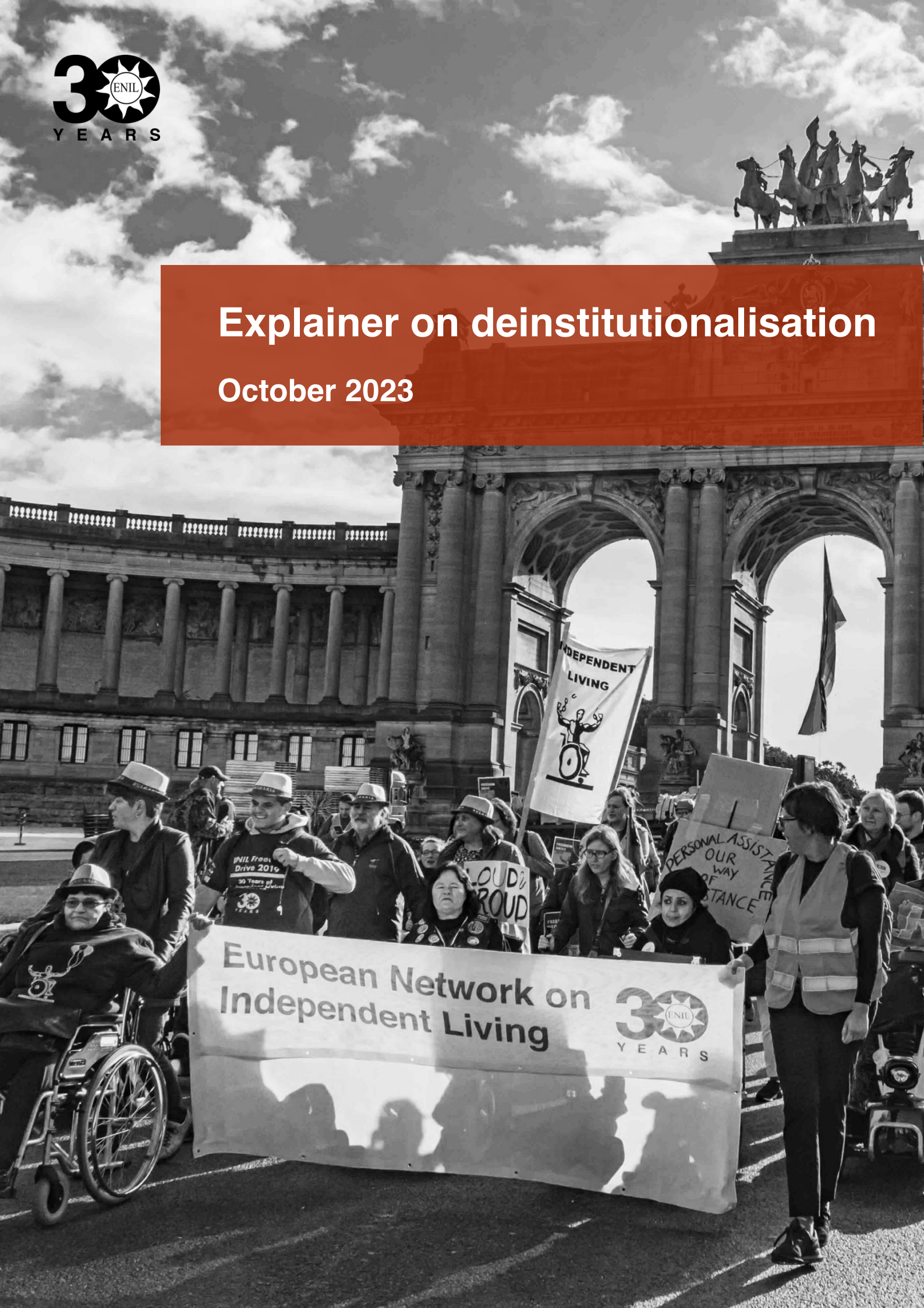




Explainer on deinstitutionalisation

October 2023



Explainer on deinstitutionalisation, based on the *Guidelines on deinstitutionalisation, including in Emergencies*

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1. What are the Guidelines on deinstitutionalisation, including in Emergencies?

The purpose of the Guidelines on deinstitutionalisation, including in Emergencies (further referred to as “the *Guidelines*”) is to make sure that when countries are implementing deinstitutionalisation reforms, they do it in line with the [UN Convention on the Rights of Persons with Disabilities](#) (further referred to as “the Convention” or the “CRPD”). The *Guidelines* also aim to encourage countries to commit to and start the process of deinstitutionalisation and to prevent the placement of disabled people in institutions.

The *Guidelines* were put together and published by the Committee on the Rights of Persons with Disabilities in September 2022. This Committee was established by the Convention, in its Article 34, as a body of independent experts in charge of monitoring the implementation of the Convention.

The role of the Committee is to:

- Examine reports from State Parties (i.e., countries which ratified the Convention) and decide if they are implementing the Convention
- Give recommendations to State Parties on how to improve their implementation of the Convention;
- Help State Parties interpret and understand their obligations under the Convention;
- Examine complaints from individuals who are victims of violations of the Convention (relevant to those State Parties that ratified the Optional Protocol to the Convention).

The drafting of *Guidelines* and the General Comments corresponds to the interpreting function of the Committee, which is sometimes referred to as ‘providing authoritative guidance’. This helps State Parties understand how they should apply the Convention, what certain concepts or articles mean, and what are the minimum obligations. In the case of the *Guidelines*, they clarify the application of specific aspects of the Convention and guide further action. They can be used by State Parties when reporting to the Committee, and by the Committee when examining reports.

Until now, the Committee published two *Guidelines* – on the right to liberty and security of persons with disabilities (2015), and on deinstitutionalisation, including in emergencies (2022).

The *Guidelines*, as well as General Comments, are non-binding, meaning that they do not have the same status as the Convention and do not create legal obligations to State Parties under international law. But, as authoritative guidance, they should be

used to support the interpretation of the Convention, they can guide action, and they may support advocacy at the national and regional level.

2. How are the Guidelines different from already existing documents?

The *Guidelines* do not create new rights or modify the Convention. However, they are complementary to other documents on the right to independent living adopted by the Committee and should be used together. In particular, they complement:

- **General Comment 5 on Article 19 of the Convention**

The General Comment 5 on the right to living independently and being included in the community explains how States Parties should implement this right. It highlights the main barriers to independent living, includes the key definitions (such as independent living, institution, personal assistance), lists the core elements of Article 19 and explains which parts of the article should be implemented immediately and which are subject to progressive realisation. It also states what State Parties should not do, such as investing in institutions. The General Comment 5 is on the right to independent living, not just on deinstitutionalisation. Independent living is much broader – the Independent Living movement refers to the 12 Pillars of Independent Living (<https://enil.eu/independent-living/>).

Even though the General Comment 5 also includes a definition of an institution and explains what the components of a deinstitutionalisation strategy should be, the Guidelines take us a step further and go into more detail, clarifying what is needed for deinstitutionalisation to be successful.

- **Guidelines on Article 14, on the right to liberty and security of persons with disabilities**

The Guidelines on Article 14 discuss the right to liberty and security of disabled people. Similarly to the *Guidelines on deinstitutionalisation*, they provide further clarification for the implementation of this article. The topic of detention in institutions and forced treatment, particularly in psychiatric hospitals, is discussed in both documents. However, the *Guidelines on deinstitutionalisation*, while reiterating that this is a breach of the Convention, go much further, especially in describing the specific actions to be taken by countries to prevent such rights violations.

➔ See Section II of the Guidelines

3. Why are the Guidelines important?

The *Guidelines on deinstitutionalisation* were adopted in September 2022, after the COVID-19 lockdowns in many countries around the globe. The impact of the COVID-

19 on people living in institutions was a wakeup call for many. The neglect and isolation over many months, and the high COVID-19 infection and death rates of those living in institutions, were a result of existing inequalities and discrimination. The Guidelines come at a timely moment, taking advantage of the momentum of COVID-19 to push for action, but also because these experiences showed that the closure of institutions could no longer be delayed.

Another reason for the *Guidelines* was that governments are not doing enough to close institutions. Also, in many countries, deinstitutionalisation reforms are not carried out the way they should be, in line with the Convention. For example, instead of providing disabled people with opportunities to live independently in the community, many governments are simply replacing large institutions with smaller ones. Some are keeping the system of institutionalisation in parallel with providing community-based services.

While the *Guidelines* do not create legal obligations for State Parties, they have a key role to create a better understanding of the steps that should be taken to complete the process of deinstitutionalisation. The *Guidelines* clarify obligations under the Convention, but also tackle the myths around the right to independent living.

The *Guidelines* also provide practical advice, for example explaining how a deinstitutionalisation plan must be put in place, and what it should contain. Different types of community-based services that should be put in place are also listed, as are the pieces of legislation that countries should adopt. Such practical advice can be used by State Parties and other actors to put together deinstitutionalisation strategies and action plans, or further down, in the process of developing new services.

→ See Sections I and II of the *Guidelines*

4. What is an institution?

Institutionalisation is any detention based on disability, which typically occurs in institutions. ‘Detention based on disability’ means that someone is put into a facility (a social care home, a psychiatric hospital etc.) just because they are disabled or perceived to be disabled (and not, for example, because they committed a crime).

Institutions share at least one of these defining elements:

- Obligatory sharing of assistants with others and no or limited influence as to who provides the assistance;
- Isolation and segregation from independent life in the community;
- Lack of control over day-to-day decisions, such as what to wear or eat;
- Lack of choice for the individuals concerned over with whom they live;

- Rigidity of routine irrespective of personal will and preferences, including having to go to bed and wake up at a certain time;
- Identical activities in the same place for a group of individuals under a certain authority;
- A paternalistic approach in service provision, making decisions for the persons thinking they know what is best for them;
- Supervision of living arrangements;
- A disproportionate number of persons with disabilities in the same environment.

When it comes to children, an institution is anything other than a family.

The *Guidelines* list different types of institutions, but there might be more places that are not on this list. The names will also vary in different languages. The examples listed are social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels and leprosy colonies.

→ See Section [III, A](#) and Section [IV, C](#) of the *Guidelines*

5. What is deinstitutionalisation?

Deinstitutionalisation requires taking different actions at the same time. This can include developing support services in the community, such as personal assistance, finding housing, restoring people's legal capacity, addressing the trauma of living in an institution. According to the *Guidelines*, the focus of deinstitutionalisation should be on restoring (giving back) autonomy, choice and control to disabled people, so they can decide how, where and with whom they wish to live. It is important that those involved in managing institutions are not asked to lead the process of deinstitutionalisation.

→ See Section [III, B](#) of the *Guidelines*

6. What should States do to end institutionalization?

The CRPD creates an obligation to end institutionalization. Institutionalization goes against several rights of the CRPD, including independent living, the right to legal capacity, security and liberty of the person. Institutionalisation is a form of discrimination. This is because disabled people are not given an equal opportunity to live in society and must live in an institution in order to receive support, because of poverty or stigma.

Because institutionalization is discriminatory, States have a duty to close institutions immediately and to allow people to leave institutions. They should also immediately stop new placements in institutions and stop building or renovating institutions.

Community-based services, and everything that is needed for independent living, can be put in place gradually. But it is important that this is done without delay,¹ so that people can leave institutions.

→ See Section II of the *Guidelines*

Therefore, States must take action and dedicate all resources that are available to them to supporting the right of disabled people to independent living. There are several things that States must do in this respect:

- **Stop investing in institutions**

The first step towards deinstitutionalisation is to stop financing institutions and stop building and renovating institutions. This funding should instead be used towards supporting disabled people to live independently. States should also provide extra funding to disabled people leaving institutions, including children, to help them start a new life in the community or in a family (in case of children).

- **Provide safe and accessible housing**

Having a place to live after leaving an institution is necessary for the success of a deinstitutionalisation strategy. States parties should ensure safe, accessible and affordable housing in the community, through social housing, rental subsidies or other solutions, for persons leaving institutions. Such housing should not be under control of the mental health systems or other service providers. Persons leaving institutions should have their own rental or ownership agreements.

- **Ensure access to community-based support**

Access to community-based support is a core element of the right to independent living. A key part of this support is that it responds to the choices of disabled people, so they can choose, manage or end the support they are receiving. The *Guidelines* list different types of support services: personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help, and other community-based services. What is crucial is that these services fit the individual needs of the person. Support from family members is a controversial topic, but the *Guidelines* accept it as long as it is with the express concern of the disabled adult.

¹ There are rights of immediate effect and rights of progressive implementation. In the case of rights of progressive implementation, States may take some time to fulfill the right, but they are obliged to take some actions immediately. This includes taking steps such as developing plans and strategies, to the maximum of their available resources. It also means they cannot take steps back, such as building new institutions.

- **Create an enabling environment**

See question 12.

- **Adopt a deinstitutionalisation plan**

Even if countries can create all the conditions for independent living progressively, to fulfil it they must start the planning without delay, and the planning process should not take a long time. This means they have to adopt a deinstitutionalisation strategy or a plan that is detailed and structured, and that includes timelines and allocation of resources. States must dedicate as many resources as they can to implement this plan. They should coordinate among Ministries, as often more than one Ministry will oversee different parts of the plan (for instance, ministries in charge of social protection, health or education). Finally, States must involve disabled people and their representative organisations at all stages.

The *Guidelines* make it clear that directors of institutions, or others working in institutions, should not be in charge of deinstitutionalisation. Instead, people with disabilities and survivors of institutionalization should be in the leadership roles.

→ See Section III of the *Guidelines*

7. What are the most common mistakes made by States when it comes to deinstitutionalisation?

Often, governments refuse to admit they are financing institutions and that they are not respecting Article 19 of the CRPD. In some cases, they may find various reasons to keep institutions open, or run settings and services that they call something different, but which are institutions. The *Guidelines* list some of the arguments that States use to justify these practices and call for them to end.

- **Creating establishments that are not called institutions but are in fact institutions**

For instance, putting people leaving an institution together in communal housing or a specific neighbourhood; into small group homes with shared assistants; or placing children into family-type homes.

- **Arguing that disabled people “choose” to live in institutions**

This is a common argument to defend institutionalization. However, it is worth noting that many people do not have other viable options or may have lived in institutions for a long time and do not feel empowered to live independently.

- **Justifying institutionalisation under the reference to residential services in Article 19**

Article 19 refers to the availability of residential services. The *Guidelines* clarify that this does not give countries a permission to build institutions. In fact, providing residential services means that States must ensure access to housing to disabled people. Examples of residential services are social housing, self-managed co-housing, free matching services and assistance in challenging housing discrimination.

- **Creating additional barriers by assessing capacities for independent living**

When transitioning to independent living, States may assess people's capacity, to determine who they think can live independently and who cannot. This is discriminatory and it should be considered that every person can live independently. Furthermore, States should not claim that some disabled people are too "vulnerable" or "weak" to live independently.

- **Considering institutions as support to the family**

The *Guidelines* say that if a disabled adult chooses to be supported by their family, the States should provide adequate financial, social and other assistance. However, being in an institution is not a form of support to the family.

→ See Sections [II](#) and [IV](#) of the *Guidelines*

8. What is meant by transition from institutions to living in the community?

Successful deinstitutionalisation requires individualised planning while the person is still in the institution. However, this "transitioning" period creates confusion, as some think it justifies the placement of people in small group homes or other forms of communal housing. The *Guidelines* clearly say that this is not allowed, but instead, people should receive support, so they are prepared to leave the institution.

These are the actions States should take to make sure disabled people are prepared to leave institutions:

- **Create individualized planning for each person, with peer support as part of the planning process and be respected as decision makers**

The staff in the institutions need to be trained in deinstitutionalisation with an approach that respects human rights and is focused on the person. Disabled people must be respected as decision-makers and be at the core of the process. Those close to the disabled person (friends, family, other trusted people) should be involved, if the disabled person wants them to. Peer support for people in institutions and survivors is a key part of the transition. It is important that disabled people are given time and opportunities to prepare emotionally and physically for living in the community.

- **Receive information**

Disabled people must be respected as survivors and be provided information. States must provide information about all aspects of living in the community, to ensure an adequate standard of living. This includes information about employment, housing, education, transport, and funding they can access. Family members should also receive information and guidance so they can best support their relative when leaving an institution.

- **Offer experiences in the community**

The best way to ‘learn’ to live independently is by having access to different services and opportunities in the community. This way those that leave institutions can feel empowered as they become part of the community. After leaving the institution, disabled people should not continue to depend on support from those running or working in institutions.

- **Ensure access to documentation**

Countries must remove barriers to birth registration and acquisition of citizenship. Disabled people leaving institutions must be able to access all necessary documentation, such as passports, identity or social security cards, also in situations of emergency.

- **Remove financial barriers**

Countries need to ensure that any financial services, such as banks or insurance companies, allow disabled people to access the services they need. Inquiries, interrogations and background checks based on their past stay in an institution are discriminatory.

→ See Section [VII, A](#) of the *Guidelines*

9. What should a deinstitutionalisation strategy or a plan include?

For deinstitutionalisation to have good results, in line with the Convention, a good strategy and/or an action plan is needed.

The key components of a high-quality and structured strategy and/or an action plan for deinstitutionalisation are:

- A detailed action plan with timelines, benchmarks and an overview of the necessary and allocated human, technical and financial resources;
- A clearly stated declaration of what is to be achieved through the deinstitutionalisation process;
- A cross-governmental approach, meaning that all the relevant ministries, agencies or other departments are involved in the implementation;

- High-level political leadership and coordination at ministerial level. The reason for this is that whoever is in charge of the strategy or the action plan should have the needed authority to initiate the change in laws and policies, the assign funding and approve plans;
- Disabled people and their organisations (including those involving disabled children) must be involved and consulted at all states of implementation. Survivors of institutionalization should be given priority.

A deinstitutionalisation strategy should also include plans for emergency situations, to make sure that the process does not stop or becomes delayed.

→ See Section [V.C](#) of the *Guidelines*

10. How can States ensure that disabled people are able to live independently in the community?

All disabled people, including those that are leaving institutions, have the right to live independently in the community. Closing institutions is not enough to ensure this. Disabled people need a range of experiences and opportunities, with respect to their right to accessibility, personal mobility, privacy, physical and mental integrity, legal capacity, liberty, education, participation in cultural life and recreation, participation in political life, as well as freedom from violence, abuse and exploitation and from torture and other ill-treatment.

The *Guidelines* recommend a number of actions for governments to take so disabled people can have access to all they need to live independently in the community. These actions are:

- **Awareness raising activities**

These activities will be in support of the environment of the person, including their family and neighbourhood, to be well aware of how inclusion works in practice. Disabled people and DPOs, but specially survivors of institutionalisation, must be involved in these activities.

- **Accessibility of transport and public spaces and information**

An accessible environment is key to live independently, so disabled people can move freely and navigate around urban and rural areas. This means that public transportation needs to be accessible and affordable, that public spaces are designed with accessibility in mind, and that information is accessible.

- **Access to healthcare, rehabilitation and assistive technology**

Health services, rehabilitation and assistive technology must be accessible and affordable, and respectful of the choices, will and preferences of disabled people. They

should not follow the medical model, and treatment can only happen on the basis of free and informed consent by the disabled person.

- **Access to employment**

Those that can and wish to work should have access to employment away from sheltered or segregated environments. People who need support to be able to work should receive it, including supported decision making.

- **Social protection packages**

As a person leaves an institution, their risk of homelessness and poverty is high. They may not have savings, job experience, or an alternative for housing. Therefore, governments should provide social protection packages for this transitional time, and long-term economic and social support. Disabled people should also be able to access other social protection measurements, such as rental benefits or subsidized public transport.

- **Access to inclusive education**

It is possible that persons leaving institutions may not have completed education or may only have experienced segregated education. Therefore, they should be able to access inclusive education, even if they are adults, including opportunities for higher education.

→ See Section [VII, B](#) of the *Guidelines*

11. How do we make sure that all disabled people, in all their diversity, can live independently?

Disabled people are all different and may experience other forms of discrimination. For instance, a disabled woman will be discriminated against because of her gender and her disability. We are not simply adding up multiple forms of discrimination, but we are looking at how those forms of discriminations interact and intersect. This is called an intersectional approach.

The *Guidelines* ask States to adopt this intersectional approach. Taking an intersectional approach to deinstitutionalisation is important because the barriers that limit independent living can be related to intersecting forms of discrimination the person experiences.

The *Guidelines* explore three types of intersecting discrimination:

- **Women with disabilities**

Women with disabilities are more at risk of experiencing violence, especially if they live in institutions. This violence can take the form of sexual abuse, forced abortions or sterilizations, or forced contraception. They are also more often deprived of their legal capacity.

- **Children with disabilities**

All children have the right to grow up in a family, including children with disabilities. Being placed in an institution, including large or small group homes, is dangerous for children. Children should not be separated from their families based on their disability or the disability of their parents.

The *Guidelines* define a family as married and unmarried parents, single parents, same-sex parents, adoptive families, kinship care, sibling care, extended family, substitute families or foster care.

Children with disabilities have the right to be heard in all matters that affect them, and they should be provided the support and accommodations they need to do so. However, children and adolescents cannot choose to live in an institution.

Children may also be separated from their families because of poverty, ethnicity or for another reason, and they are likely to acquire impairments because they are placed in an institution. To ensure that children with disabilities stay within their families, support services, accessible information, inclusive education and peer support must be ensured.

International donors should not give funds to orphanages, residential care, group homes or children's villages.

- **Older persons with disabilities**

Deinstitutionalisation efforts should also include older persons with disabilities, including those with dementia. They should target both disability-specific settings and settings for older people.

→ See Section [IV](#)

12. How can States create an enabling environment?

When the *Guidelines* refer to an enabling environment, this means changing the system, so it allows deinstitutionalisation to happen. If the deinstitutionalisation process starts but the rest of the system stays the same, disabled people who leave institutions will find barriers that will not allow them to live independently.

There are a few elements the *Guidelines* refer to so this enabling environment can be created:

- **Change existing laws**

The legal system should be changed to ensure that it is respectful of the rights of disabled people.

A key change is ensuring the right to legal capacity. When a person is under guardianship, their guardian can make decisions for them, such as managing their money, accepting forced medical treatment, or placing them in an institution. Laws that allow guardianship should be eliminated, and the person must give their free and informed consent before receiving any treatment. Different types of support must be provided to those who need it, in order to exercise their right to legal capacity.

Disabled people face barriers to access justice, in particular women and girls who have experienced gender-based violence. To eliminate these barriers, governments must provide reasonable accommodations, such as information in Easy to Read, and the provision of free and accessible legal aid. Disabled people must also be allowed to testify in court, call the police and report a crime, even if they are living in an institution.

Governments should abolish laws that allow to detain someone based on disability, such as forced psychiatric hospitalization, as this is a violation of the right to liberty and security.

Finally, countries should put a prohibition of discrimination based on disability in law.

- **Map existing laws, institutions, services, workforce and support systems**

To understand the legal framework in a country and create reform, governments must map out the existing laws and policies. They should find what laws allow or enable institutionalization, so they can be abolished; laws that are in breach of related rights, such as legal capacity; and whether legal remedies are available to disabled people.

Countries should further identify existing institutions and the funding they are receiving; community-based services; and the workforce. To create new support systems, countries must identify the gaps in the system, and develop a wide range of services that respond to the will and preferences of disabled people. Disabled people should have a real choice to select the services they want, so they are not forced to use segregated services.

- **Ensure access to mainstream services**

Other than specific services disabled people may need, they should also be able to access mainstream services. These can be transportation, health, education and others. Governments must ensure that disabled people can access a variety of services, and that these are all accessible and affordable.

→ See Section [V](#) of the *Guidelines*

13. What are the elements needed to create support systems?

Support systems are networks of people who act as emotional or physical support. They include the relationships that a person has with their family, friends, neighbours, or any trusted person, that can support in their daily life and decision-making. Everyone needs a support system, but for disabled people, they can play a role in facilitating their inclusion in the community.

To create support systems, governments must:

- Invest in peer support, self-advocacy, circles of support and other support networks, as well as Centres for independent living;
- Let persons with disabilities choose their support system and services;
- Ensure that peer support is self-directed and independent of institutions and medical professionals;
- Provide assistance to families acting as support, together with providing other options for support, so family support is not the only option (for adults);
- Ensure support services at community level have a human-rights based approach;
- Develop specific support services for children with disabilities;
- Make sure that people returning to their family after living in an institution are still eligible for independent housing;
- Ensure access to personal assistance. This applies even for people living in institutions, who should be eligible for personal assistance, so they can move out of the institution and into the community;
- In addition to personal assistance, provide other support options, such as support persons, support workers, direct support professionals;
- Increase and ensure access to affordable assistive technology;
- Provide individualized and direct funding to cover basic income security, healthcare and disability-related costs. Provide support with administering user-led funding, so that disabled people are encouraged to use it;
- Ensure there are financial incentives in place and support for people to purchase and manage services in the community. This means that people should have a personal budget high enough to allow them to live in the community.

Governments must **not**:

- Develop assessment tools that rely mainly on medical criteria and are run by medical professionals, to decide on access to support. Instead, they should prioritise self-assessment tools;
- Develop segregating or isolating services, such as day-care centres or sheltered employment. Such services do not comply with the Convention;

- Limit access to support for older disabled people, including access to personal assistance. Instead, the level of support should increase as people age, if that is what is needed;
- Limit access to income support for disability-related costs based on income (individual or household)

→ See Section [VI](#) of the *Guidelines*

14. How should States implement deinstitutionalisation in situations of emergency?

Situations of emergency refer to natural disasters – such as earthquakes or tsunamis; armed conflicts, famines, and pandemics. Examples of emergency situations can be the COVID-19 pandemic, the Chernobyl nuclear disaster, or the Syrian civil war.

In situations of emergency, States need to act fast, and they often prioritize resources for the focus of the emergency. Consequently, they will perceive deinstitutionalisation as less important in these times. However, as the COVID-19 pandemic or the war in Ukraine showed, people living in institutions are more affected than the rest of the population. They are more vulnerable to attacks or the spread of disease, and it is more difficult for them (or impossible) to leave to safer place. Therefore, during situations of emergency, the need to implement deinstitutionalisation is higher.

The *Guidelines* remind the States that during emergencies, they must continue and reinforce deinstitutionalisation. After the emergency is over, they should not rebuild or repopulate institutions. Deinstitutionalisation needs to be integrated in emergency protocols.

The first thing to do is to identify the situation of disabled people in the context: counting those in institutions, displaced, or unaccompanied children.

Then, all humanitarian actors must make sure that all actions are inclusive, including evacuation (moving people from a dangerous place to a safe one), humanitarian relief (actions taken during the emergency to reduce the impact of the disaster), and recovery (actions taken after the emergency to replace and restore infrastructure, assets and livelihoods).

In addition, times of emergency often justify taking some extreme measures that otherwise governments would consider unacceptable. But some international standards still apply, those considered to be so essential that they are always in force. In the case of disabled people, this can mean preventing isolation, eliminating disability-based discrimination, or avoiding preventable deaths. The *Guidelines* clarify that the right to legal capacity and the prohibition of detention based on disability still apply during emergencies.

Finally, an intersectional approach to emergency preparedness, response and recovery is crucial. This is because people experiencing intersecting forms of discrimination are at higher risk of the impact of an emergency. Disabled women, for instance, are at a higher risk of violence. Persons with the highest risks should be prioritized.

→ See Section [VIII](#) of the *Guidelines*

15. Are survivors of institutionalization entitled to reparations?

When a person is a victim of a violation of human rights, they are entitled to reparations. Reparations try to remedy the damage done by the violation. The main forms of reparations are:

- Restitution: the State ensures that the situation goes back to how it was before the violation happened;
- Compensation: providing money to the victim to cover for costs caused by the violation. Moral damage can also be compensated;
- Rehabilitation: the person can receive physical and psychological support to deal with the consequences of the violation;
- Satisfaction: the State recognizes the damage that has been done and puts efforts to amend it, such as truth-seeking or giving a public apology;
- Guarantees of non-repetition: the State commits to prevent that the violation will not happen again. This can be done by training public officials or reforming the system.

Each victim can receive more than one reparation measure, depending on the situation.

Reparations are important for two main reasons: one, because the State recognizes that a violation has taken place; second, because the victim can feel like their situation is repaired and it can bring them a sense of justice and peace.

The *Guidelines* consider that survivors of institutionalization are entitled to reparations. This is very significant, because it means that the Convention recognises that institutionalization is a violation of human rights and encourages States to do the same.

Some of the reparations suggested by the *Guidelines* include:

- Recognizing institutionalization as a violation of the CRPD and acknowledge all violations that happen as the consequence of institutionalization;
- Ensuring access to justice for disabled people seeking reparation;
- Putting in place a mechanism for formal apologies and for providing automatic compensation for survivors;

- Provide other possible reparations beyond financial compensation: restitution, rehabilitation, non-repetition, criminalize disability-based detention, establish truth commissions that investigate what happened in the institutions, and investigate and prosecute perpetrators.

All these reparations should be done in consultation and with the involvement of disabled people, in particular of survivors of institutionalization.

→ See Section [IX](#) of the *Guidelines*

16. What role can international cooperation play?

The CRPD calls for international and regional cooperation actors to support the implementation of the Convention. The *Guidelines* specify their role in regard to deinstitutionalisation.

The key obligation is to stop investing in institutions, even if they are small or if it is an emergency context. All investments in institutions are a breach of the CRPD.

International cooperation actors should establish transparent processes to ensure that there are no investments in institutions. Transparency can be achieved through data collection, monitoring, or complaint mechanisms. They should also be consulting DPOs, in particular persons living in institutions and survivors.

Since achieving the right to independent living does not end at deinstitutionalisation, it is important that international cooperation actors ensure that all their projects are inclusive of disabled people.

To have effective international cooperation, coordinating all efforts is essential. The *Guidelines* suggest establishing a platform for sharing good practices.

→ See Section [XII](#) of the *Guidelines*

17. How can we make sure the *Guidelines* are respected?

Implementing the *Guidelines* requires planning and continuous action, to make sure that progress is achieved. Tracking this progress is essential to know how states are advancing.

Data collection can greatly support this process, to know before starting how many disabled people live in institutions and what is their situation. Therefore, governments must collect data and disaggregate it by various factors, including: race, ethnic origin, age, gender, sex, sexual orientation, socioeconomic status, type of impairment, reason for institutionalization, date of admission, expected or actual date of release and other. Disabled people and their representative organizations must be part of the data collection process.

When counting the number of people in institutions, governments must include all forms of public, private and church run institutions. They should use the definition of an institution from the *Guidelines*, to cover all residential settings where disabled people live, not just those that are above a certain size.

Governments should put in place mechanisms for monitoring of the deinstitutionalisation strategy. The role of these mechanisms would be to identify, prevent and remedy human rights violations, to recommend best practices, and to ensure that Article 19 of the CRPD is implemented. They must involve disabled people and their organisations and exclude those running or working in institutions.

Independent monitoring must also be in place, with sufficient resources and access to all relevant documentation and to the institutions they are investigating. When human rights violations are identified through independent monitoring, governments should address them quickly and effectively.

In this process, the data of survivors must be respected. For this, survivors of institutionalisation can request any personal data, and their records should be handed to them as they leave the institution and/or destroyed, based on their preference.

Other than monitoring mechanisms established by governments, independent monitoring should continue until all institutions are closed, also in times of emergency.

→ See Sections [X](#) and [XI](#) of the *Guidelines*

18. What is the role of disabled people and DPOs?

The deinstitutionalisation process must include disabled people and DPOs at all stages. They should be prioritized before service providers, charities, professionals and religious groups. Among DPOs, it is important that priority is given to survivors and persons living in institutions and their representative organizations. For this, governments must give survivors, persons living in institutions, at others that are at higher risk of institutionalization, support and information so they can participate in the process.

As DPOs are to participate at all stages, this includes monitoring mechanisms, also independent ones led by civil society (see question 16).

If necessary, DPOs or national human rights institutions can represent survivors to ensure access to justice. But this can only be with the person's free and informed consent, or if the rights of the person are at stake and it is not possible to obtain their consent.

→ See Sections [III](#), [G](#) of the *Guidelines*

19. How can the *Guidelines* support your advocacy?

The *Guidelines* define the actions governments must take. However, as an advocate, you can support the implementation of the *Guidelines*, and the *Guidelines* can also support the advocacy you may be already doing.

These are some things you can do:

- **Awareness raising**

All stakeholders should be familiar with the *Guidelines* and their content. For this, you can organize workshops, webinars, or trainings with government officials, service providers, disabled people and DPOs, family members of disabled people and other stakeholders that play a role in making deinstitutionalisation work. You can spread the word on social media action; you can publish articles; you can translate the *Guidelines* in your local language and make sure it is available in plain language or in Easy to read. What action might work better depends on your context, your capacity, and who you think should know about the *Guidelines*.

- **Dialogue with decision-makers**

Governments are the ones responsible for implementing the *Guidelines*. Identify who in your government would be the pertinent Ministry (for example, the Ministry of Social Affairs, the Ministry of Health...). You may also want to target representatives of international and regional organizations, such as the European Union, or United Nations regional and country offices. You can write your target a letter, ask for a meeting, or invite them to a workshop you may already be organizing. This may be an opportunity to find out their plans to implement the *Guidelines* and explore how you can collaborate.

- **Use the *Guidelines* to support your advocacy objectives**

If you have already some advocacy objectives, or an ongoing campaign, you can integrate the *Guidelines* therein. You can take out key messages from the *Guidelines*, use them as a supporting document, or use it as an entry point to meet with decision-makers.

- **Work together with survivors of institutionalization**

As is explained in the *Guidelines*, survivors of institutionalisation play a key role in making sure everyone can live in the community. It is therefore important to involve survivors in the work of your organisation and to support efforts of survivors to self-organise. When speaking about the *Guidelines* to outside stakeholders (during

workshops, presentations), you can make sure to involve a survivor to share their experiences, for example.

- **Be involved in monitoring and implementation**

The *Guidelines* call for disabled people and DPOs to be part of the monitoring and implementation of any deinstitutionalisation process. Therefore, make sure to participate in any monitoring mechanisms, or set up an independent one; support the collection of data; carry out monitoring visits; publish reports and carry out other watchdog activities.

20. Where can you find the *Guidelines*?

The text of the *Guidelines* is available from the Committee's website in the following languages: official UN languages (English, French, Spanish, Russian, Arabic and Chinese), English ETR, German, Italian, Bulgarian, Czech, Czech ETR, Hungarian, Hungarian ETR, Slovenian, Slovenian ETR, Romanian and Portuguese: <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalisation-including>

Videos explaining the Guidelines in Easy to read language are available from Inclusion International: <https://inclusion-international.org/resource/guidelines-on-closing-institutions/>

Additional resources are available from the website of the Global Coalition on Deinstitutionalisation: <https://gc-di.org>

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination. For more information, see: www.enil.eu Contact person: Rita Crespo Fernandez, Human Rights Officer



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