Independent Living Survey

Summary report, December 2020

ENIL's 1st Independent Living Survey Summary report

1. Introduction

On 30 June 2020, the European Network on Independent Living launched its first Independent Living Survey, with the aim of collecting general information about access to Independent Living of disabled people[1] across Europe, and detailed information about Personal Assistance schemes or systems. The online survey targeted countries within the Council of Europe area and was disseminated to ENIL members, as well as to the general public, through our Newsletter, website and social media.

The Independent Living Survey followed Personal Assistance (PA) tables, published by ENIL in 2013 and 2015, which included a smaller number of questions in relation to the provision of Personal Assistance. This time, a total of 97 questions were included, 22 in **Section I (General section on Independent Living)**, and 75 questions in **Section II (General information about the PA scheme/policy)**. The latter section covered the following areas: a) funding; b) eligibility and needs assessment; c) provision; and d) recruitment and working conditions of PAs. Section II was aimed exclusively at those countries which had some form of PA available. All the questions were available in English, German and French[2].

A total of 143 responses were received, 116 in English, 7 in French and 20 in German. The majority came from disabled people (including PA users) and organisations of persons with disabilities (see Annex I). In the end, responses from 43 countries were included in the analysis (see below, Table 1). A detailed description of the PA scheme/policy – i.e. the country sheets - is available for 30 countries. A response from the Russian Federation could not be verified, therefore it was not included in the analysis. No responses have been received for Andorra, Liechtenstein, Monaco and Switzerland.

[1] ENIL prefers the term 'disabled people' over 'persons with disabilities' or 'people with disabilities', in order to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society. This is in line with the social model of disability.

[2] To access the questions included in the survey, please go to: https://enil.eu/news/enil-launches-independent-living-survey/

Table 1: List of the countries included in the IL Survey

Albania	Denmark	Latvia	Romania
Armenia*	Estonia	Lithuania	San Marino*
Austria	Finland	Luxembourg*	Serbia
Azerbaijan	France	Malta	Slovakia
Belarus*	Georgia	Moldova*	Slovenia
Belgium	Germany	Montenegro	Spain
Bosnia and Herzegovina*	Greece*	Netherlands	Sweden
Bulgaria	Hungary*	North Macedonia	Turkey*
Croatia	Iceland	Norway	Ukraine*
Cyprus	Ireland	Poland	United Kingdom
Czech Republic	Italy	Portugal	

*Countries for which there is no description of the PA scheme/policy (Section II of the survey)

2. Development of the survey

Questions in **Section I of the survey** were based on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD)[3] (see Box 1). Consideration was given to the fact that 46 out of the 47 Council of Europe countries, the European Union and all its 27 EU Member States have ratified the CRPD, therefore were required to provide disabled people with the right to live independently and to be included in the community. Our aim was to establish not just the level of implementation of the article, but also if any progress has been made in the last five years.

The survey focused on the level of choice disabled people have in deciding where and with whom they live, the prevalence of institutionalisation of disabled adults and children, the existence and quality of deinstitutionalisation strategies, availability of PA, and the level of access to mainstream services. An additional question was added to find out whether funds provided by the European Union were being used to support institutions or other segregated services. The reason for this question is the prohibition of investing in institutions under the General

[3] See: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Comment 5[4], and the fact it is an area that ENIL works on. Most of the questions were multiple choice, with space to provide additional information or comments.

Section II of the survey was based on ENIL's Personal Assistance Checklist[5], developed by Dr Teodor Mladenov in 2019, as part of a three-year Marie Sklodowska-Curie individual research fellowship. The PA checklist is a tool designed for assessing PA schemes from the perspective of independent living. Its defining features are that it was co-produced with PA users and independent living advocates, it measures the degree to which PA schemes support independent living, and it enables international comparisons. As with Section I, most of the questions were multiple choice, with space to provide additional information or comments.

Box 1: Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

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[4] Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en

[5] European Network on Independent Living (2019), PA Checklist – A Tool for Assessing Personal Assistance Schemes, available at: https://enil.eu/wp-content/uploads/2019/02/Mladenov_Pokern_Bulic-PA_Checklist.pdf

3. Methodology and limitations

The survey targeted disabled people and their representative organisations. Section II of the survey required detailed knowledge of the PA scheme/policy, which is why ENIL strongly suggested that it should be completed by PA users, or in close consultation with PA users. The survey was sent to members of ENIL, and shared in the Newsletter, on the website and via social media. Recognising that English may not be accessible to all, it was translated into French and German, and was available both online and in Word.

Because of the technical nature of the survey (i.e. Section II), and the fact that it required very good knowledge of the PA scheme/policy, ENIL did not aim for a large number of responses per country. Rather, we tried to ensure that only those familiar with the system answered the questions. In some countries, where ENIL does not have members, this was not possible, however.

ENIL's aim was to get more than one response per country, to improve accuracy, and we were mainly successful in achieving this. Where only one response was received, attempts were made to verify it with other members or DPOs. Only one response, for the Russian Federation, submitted by a local authority, could not be verified with a DPO and it was therefore not included in the analysis.

The information gathered was used to complete 43 individual country sheets. In the case of Belgium, United Kingdom and Spain, the country sheets cover different constituent territories/autonomous provinces separately.

The analysis of the data was made difficult by the following limitations, which should be taken into account when reading this summary report and the 43 country sheets.

3.1. Subjectivity of responses

A number of questions ask respondents to rate the level of access, or the quality of policies or provision. Where respondents from the same country provided a different rating, the average value was used. However, it is clear that some respondents were more critical than others, or have higher expectations. Therefore, countries considered as having made considerable progress in Independent Living in the past (such as the Scandinavian countries or the UK), may have fared worse than countries where access to Independent Living is more limited. ENIL is of the view

that this is because of the level of expectation and awareness of independent living in some countries. Where people have spent decades fighting for independent living and other rights, and have achieved these, they expect the situation not to go backwards. With many countries affected by cuts to disability services in the last decade, and more recently COVID-19, it is understandable that many disabled people are disappointed with the direction their countries are heading in.

3.2. Regional differences and postcode lottery

A question was included in the survey whether the responses relate to the entire country or a particular region. In some cases, respondents stated that they were answering for the entire country, whereas their response was in fact limited to their local authority or the region. This was made clear by the fact that another person from the same country provided conflicting information.

It is evident that, in many countries, provision of social care services, which includes PA, is the responsibility of local and/or regional authorities. Therefore, access may vary greatly from one local authority/region to another. In the case of Spain, Belgium and the UK, the constituent territories/autonomous provinces have very different levels of PA provision. Such regional differences, as well as the existence of so-called 'postcode lottery' (where access varies from one local authority to another), make it difficult to present the situation in some countries in a coherent way. We have noted such regional differences in the country sheets, whenever this was clear from the responses provided.

3.3. Misunderstanding of Personal Assistance

There continues to be a lack of awareness about what differentiates Personal Assistance from home care services, even among some disabled people and their representative organisations. In addition, according to the Independent Living movement, a system or a policy that does not have certain characteristics (such as adequate level of funding, being able to hire one's PA etc.) should not even be referred to as Personal Assistance. The full list of criteria is set out in the definition of PA in General Comment 5, and is included in Annex II of this summary report. For the purposes of this survey, we have included all the information about PA schemes/policies provided by respondents. However, it is worth noting that many of the schemes/policies described do not fulfil some or many of the criteria listed in the definition of PA. These issues will be addressed in Chapter II of this report.

To address the limitations outlined above, more research is needed in the countries to identify all characteristics of PA schemes/policies at local, regional and national levels. Such research should encompass interviews with disabled people, family members, DPOs, providers of PA (such as user-cooperatives and Centers for Independent Living, but also other service providers), and should include research into legislation, policy and funding. It would be important to ensure a cross-disability approach, including people with psychosocial and intellectual disabilities, children, women and girls, and disabled people over the age of 65. Research should be carried out by disabled researchers and led by DPOs, to ensure a user-led approach.

4. Organisation of the report

This summary report is divided into two chapters:

Chapter I: This chapter includes findings from the General section on Independent Living, followed by recommendations. In addition to quantitative data, written comments by the respondents were used to provide more detailed information about deinstitutionalisation strategies and initiatives.

Chapter II: This chapter covers the Section on PA schemes/policies, with the data presented under the following headings: a) PA scheme: general information and corresponding legislation; b) funding of personal assistance; c) eligibility and needs assessment procedures; d) characteristics of PA provision and recruitment; and d) working conditions of assistants. These are followed by recommendations. [To be added in January 2021.]

Annex I: This annex includes a table with the number and type of respondents by country.

Annex II: This annex includes the definitions of key terms.

In addition to the summary report, 43 country sheets will be available from ENIL's website by the end of January 2021: www.enil.eu.

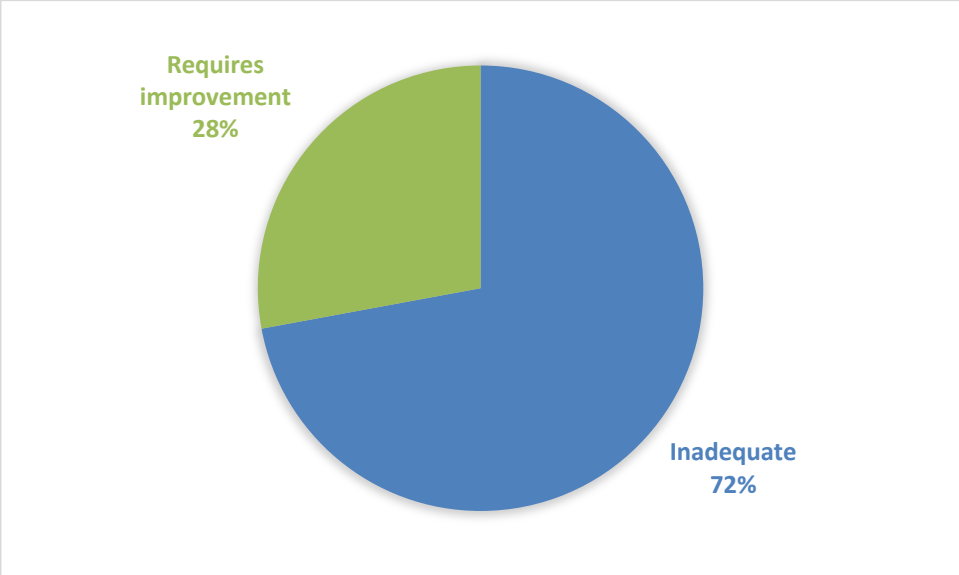
Should you notice any inaccuracies in the summary report or the country sheets, please let us know and we will correct them. Please email us at secretariat@enil.eu, with a subject line 'Independent Living Survey correction'.

Chapter I: General section on Independent Living

The aim of this section is to understand overall access of disabled people to the right to live independently and to be included in the community, as set out in Article 19 CRPD.

1. Transition from institutional care to independent living

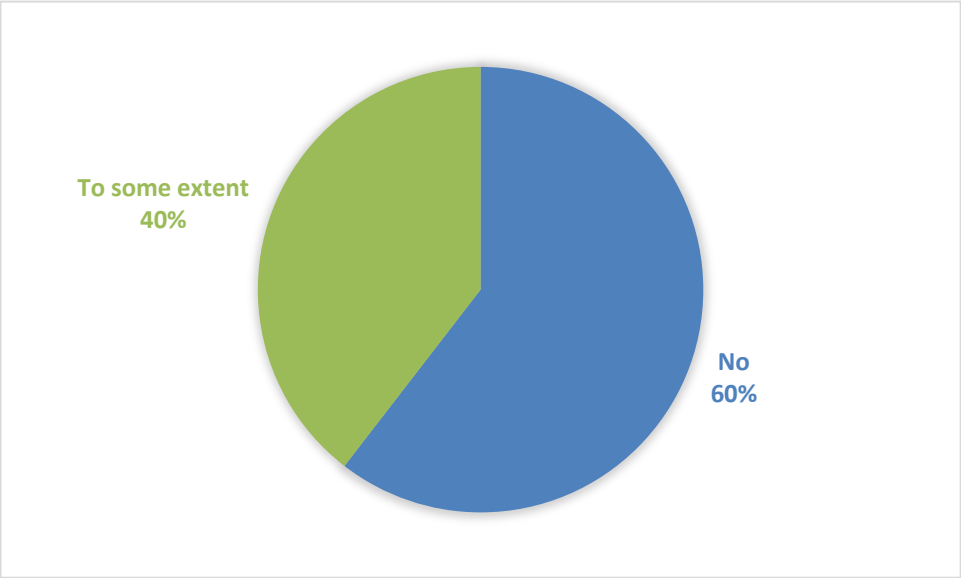
Q1: How would you describe the implementation of Article 19 of the UN CRPD in your country?



Respondents from 31 countries consider implementation of Article 19 to be inadequate, and from 12 countries as requiring improvement. None of the countries are considered to be doing enough to implement the right to live independently and being included in the community.

Q2: Can all disabled adults choose where and with whom to live, without being forced into a particular living arrangement?

In the majority of countries (26), respondents state that disabled people have no choice about their living arrangements, while in some countries (17) they consider that disabled people are able to choose to some extent. There is no country where all disabled people have a real choice about where, with whom and how to live. These responses can be explained by the fact that while some may have choice, others do not. This can be due to their impairment, age, place of residence or other characteristics, and motivated by the prevailing medical model of disability, stigma, inadequate funding for community-based services and other reasons.



For example, the situation in Denmark was explained as follows:

> "It is not possible for any person with more demanding/complex or even sometimes minor disabilities to choose where to live and with whom. If you're dealing with persons with physical impairment, the majority are able to choose where to live and with whom, but if you are in need of more space or particular furnishment/possibilities within your place of living, it can be challenging to get the support for adaptation of your living accommodation. If you are a person with more complex and demanding intellectual, cognitive or even psychosocial disabilities, one can be provided with a single solution/possibility to live together with others, not chosen by oneself and in a place not supported/chosen by oneself."

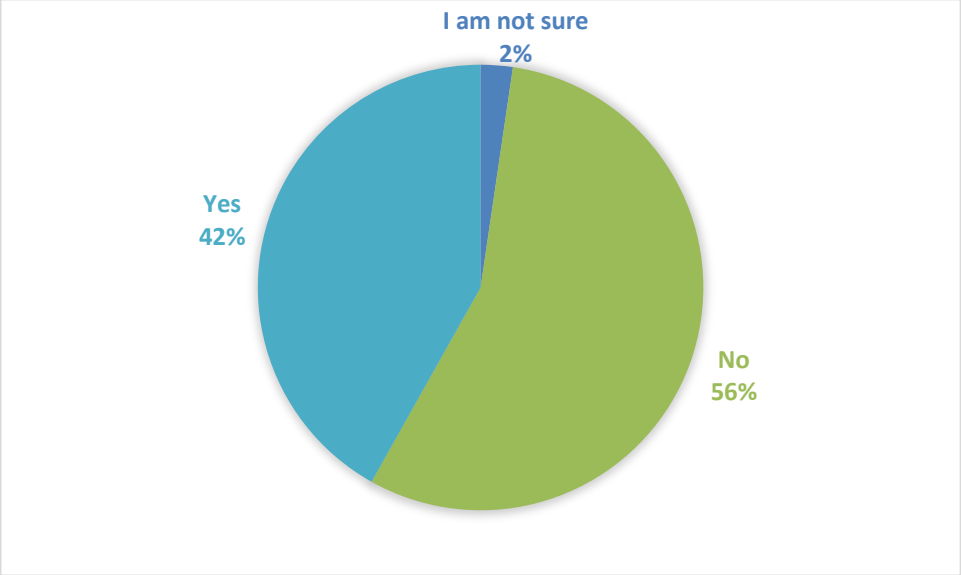
Q3: Are there still segregated settings (social care institutions, psychiatric hospitals, group homes and other) for disabled adults (incl. older people with disabilities).

All 43 countries (100%) still have segregated settings for disabled adults. This includes social care institutions, psychiatric hospitals, group homes, but also sheltered workshops and day care centres for disabled adults.

Q4: Are there still segregated settings (social care institutions, family-type homes, residential schools and other) for disabled children?

The majority of the countries – 42 out of 43 – have segregated settings for disabled children. This includes social care institutions, institutions under the health authorities, family-type homes, residential schools and other. San Marino is the only country, according to the response provided, where all disabled children live with their families or in family-based care, and go to mainstream schools.

Q5: Does your country have a deinstitutionalisation strategy?



A total of 18 countries have a deinstitutionalisation strategy, while 24 are yet to adopt one. There is no information for Azerbaijan.

The countries with a deinstitutionalisation strategy are: Armenia, Bulgaria, Croatia, Cyprus, Estonia, Finland, Hungary, Ireland[6], Latvia, Lithuania[7], Moldova, North Macedonia[8], Norway, Poland, Romania, Slovakia, Slovenia and Ukraine. Parts of the United Kingdom, such as England, Scotland (see Case study) and Northern Ireland[9] also have a strategy, though the UK as such does not.

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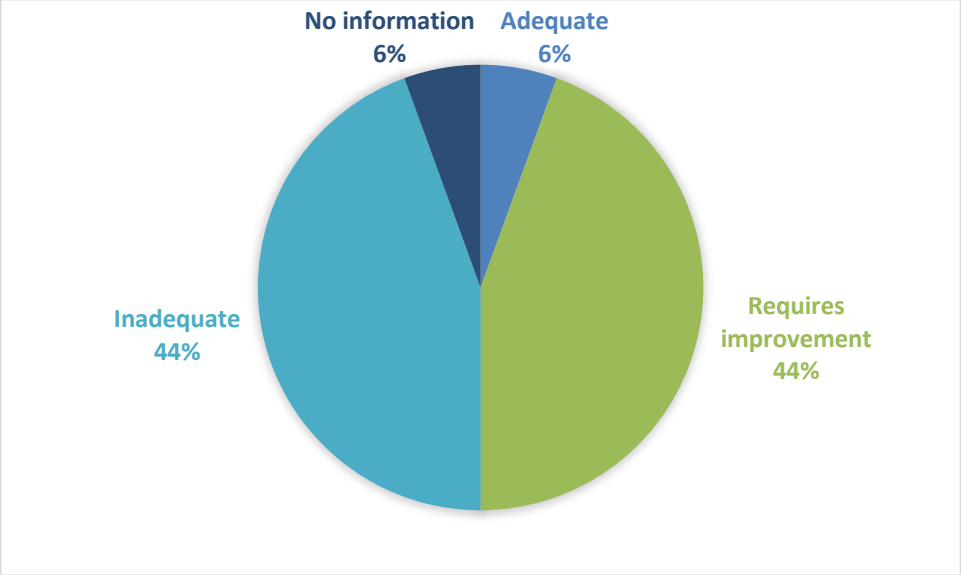
[6] See: https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf
[7] See: http://perspektyvos.org/images/failai/dei_report_3.pdf
[8] See: http://www.mtsp.gov.mk/content/pdf/2019pravilnici/23.4_National%20Deinstitutionalisation%20Strategy%20and%20Action%20plan.pdf
[9] See: https://www.health-ni.gov.uk/articles/community-care

Poland has a new strategy, from August 2020. Two countries – Greece and Malta – are in the process of developing a strategy. In Greece, working groups have been established by the Ministry of Labour and Social Affairs, and the process is supported by the EU.

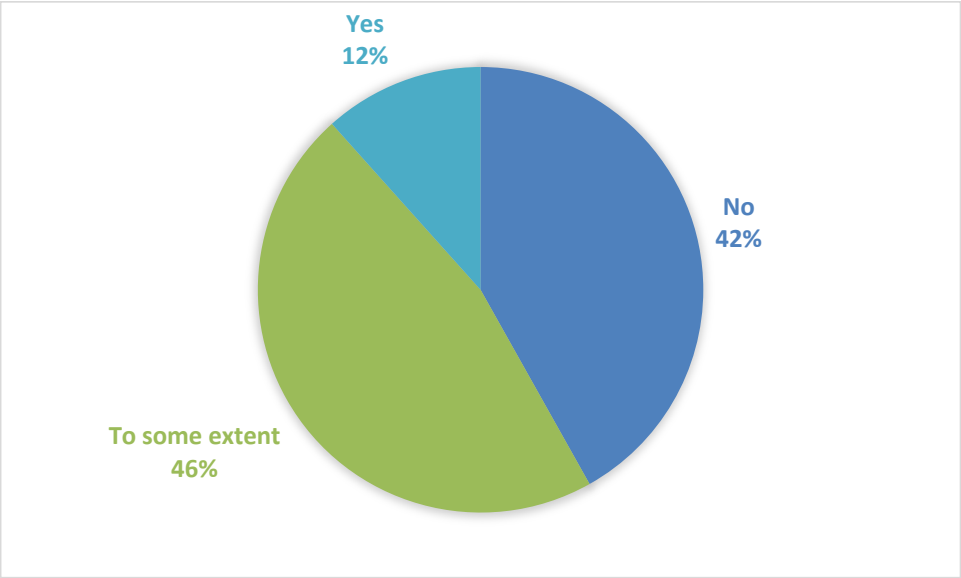
In Belarus, although there is no deinstitutionalisation strategy, the government is taking certain non-systemic measures, aimed at introducing services at one's home. In Serbia, the Strategy on the Improvement of Status of Persons with Disabilities contains a part on deinstitutionalisation.

Q5.1: If yes, how would you describe this deinstitutionalisation strategy?



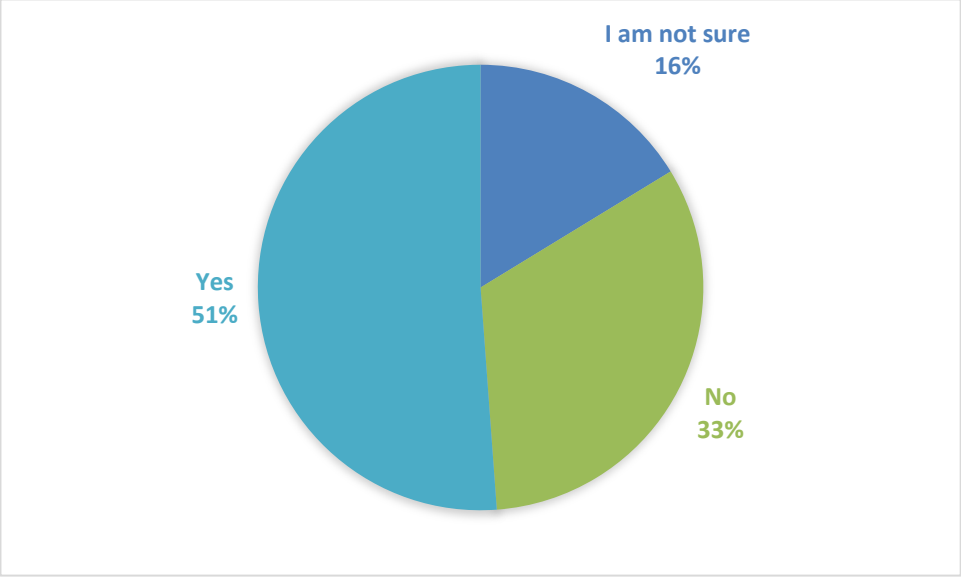
Out of the 18 countries that have a deinstitutionalisation strategy in place, only one country – Moldova – has one that is considered by the respondents as fit for purpose. The majority of countries have a strategy that is either inadequate (8), or requires improvement (8). There is no information for Poland, because the strategy was adopted very recently, in August 2020.

Q6: Has there been any progress in the last 5 years when it comes to deinstitutionalisation?



Most of the countries (20) have made limited progress in the last 5 years. A similar number (18) have made no progress at all, while in 5 of the countries - Azerbaijan, Cyprus, Georgia, Moldova and Slovenia - respondents have been positive about the progress made.

Q7: Are you aware of funds provided by the European Union being invested into the renovation or building of new institutions for disabled people in your country?



In most countries (22), respondents are aware of the EU Funds being used to build or renovate institutions (i.e. large institutions or group homes), or other segregating services (i.e. sheltered workshops, residential schools, day care centres and other) for disabled children and adults. The countries

for which this information was reported are: Austria, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Estonia, Hungary, Italy, Lithuania, Luxembourg, Malta, Moldova, Montenegro, the Netherlands, North Macedonia, Poland, Portugal, Romania, San Marino, Slovenia, Spain and Turkey.

In 14 countries, EU Funds are not being used for this purpose, while in 7 countries, respondents replied that they were not sure. Considering the difficulty in accessing information about projects co-funded by the EU, such high number is not surprising.

2. Key characteristics of DI strategies and the process of deinstitutionalisation

A number of respondents described the main problems with the implementation of the deinstitutionalisation strategy, or the process of deinstitutionalisation (where it is not based on a strategy) in their country. They can be summarised under the following headings:

2.1. The strategy/process provides for alternatives to institutions that do not support independent living

In several countries, respondents have highlighted the trend of moving disabled people from large into smaller institutions, rather than providing everyone with the opportunity to live independently in the community (also referred to as 're-institutionalisation'). In some countries, disabled people are placed into residential care, when providing support in the community is considered to be 'too expensive'.

In **Bulgaria**, the deinstitutionalisation strategy is focused on the closure of large institutional care facilities, without providing for independent living. Residents are resettled and relocated into group homes, without any change in their ability to make decisions about their lives, their social inclusion and participation. The situation of disabled children who have been moved into so-called family-type homes (i.e. group homes), as part of Bulgaria's closure of large institutions for children, has been well document by NGOs[10] and the media[11].

[10] Disability Rights International, 2019. *A Dead End for Children – Bulgaria's Group Homes, a*vailable from: https://www.driadvocacy.org/wp-content/uploads/Bulgaria-final-web.pdf
[11] BBC, Bulgaria's Hidden Children, see: https://www.bbc.co.uk/programmes/m000c1ds

In **Norway**, the deinstitutionalisation strategy dates back to the 1990s, and has led to positive changes in the past. However, the respondents noted that, in the last 10 years, there has once again been a rise in state-funded institutions. These institutions are typically smaller, such as group homes, to avoid negative public opinion, and have just below the maximum number of residents allowed by law. In theory, every individual should have a right to choose where they live; however, the state has discretion in deciding whether that is possible. Mostly it comes down to costs; if the city council considers it more cost effective to place someone in residential care, they can do so against the person's will.

In **Scotland**, there has been a longstanding process of de-institutionalisation and closure of long stay hospitals, but some group living settings persist, particularly for people who are described as 'challenging' or having more complex needs. There are also still a number of people 'placed' away from their home areas in group settings in other parts of the United Kingdom.

In **Cyprus**, the state operates 'houses' in the community, where disabled adults are transferred from large institutions, and where they live with other adults with disabilities, with support. Adults with more complex needs, as well as disabled children, are still placed in large institutions and in boarding schools.

In **Estonia**, the strategy targets only people with intellectual disabilities, who are being moved into settings with prevailing institutional characteristics.

In **Sweden**, group homes and nursing homes are, in theory, optional and are supposed to provide opportunities for independent living. However, because community-based services are under constant threat, due to attempts to reduce public spending, this leads to people who could have lived with personal assistance being forced to move into group homes or nursing homes. In these facilities, shortages of staff are a problem and constantly subject to regression. Thus, people living there are becoming socially isolated. At the same time, the Government claims that there are no institutional care facilities in Sweden.

Many people in Sweden are denied access to personal assistance by the municipality or the state. It is possible to challenge this in court, but it is a long process. For those unable to go to court, there is no other choice but a group home, nursing home or home care services, which is what is often being offered.

2.2. The strategy is not comprehensive

In **Croatia** and **France**, the process of deinstitutionalisation discriminates on the basis of the type of disability. For example, in Croatia, people with psychosocial disabilities are marginalised in the strategy, the measures aimed at their deinstitutionalisation are heavily delayed or not implemented at all. Similarly, in **England**, the strategy does not require an end to involuntary treatment in psychiatric hospitals, to involuntary treatment of detained patients, and to community treatment orders under the Mental Health Act.

The **Hungarian** strategy does not contain any guarantees that EU funds will not be used to create solutions that are not CRPD compliant. It continues to maintain the underfunded social system, which is unsuitable for supporting disabled people. Its aim is not real social inclusion. In turn, the strategy contains only generalities and avoids specifying deadlines and appointing those responsible. Thus, although it refers to Articles 12 and 19 of the CRPD as a starting point, its provisions go against the principles and spirit of the CRPD.

In **Turkey**, prevention of institutionalisation is based on a monthly cash payment to a disabled person's family member, who stays at the same home address. Even this, however, is means tested and only provided to those people whose household income does not exceed a certain amount. It is not available to disabled people who are employed, for example.

2.3. There are delays in the implementation of the strategy

In a number of countries, delays have been reported with the implementation of deinstitutionalisation strategies. In **Croatia**, for example, the implementation is considered too slow. In **Ireland**, the strategy was adopted in 2011, but very little has changed for disabled people since then. There are numerous young people living in institutional care with very little prospect of living independently in the community, with the support of a Personal Assistance service.

In **Italy**, the laws are applied differently depending on the region, and on the resources that are available (with significant differences across the country). Respondents from **Serbia** noted that the action plan for implementation of deinstitutionalisation reforms has still not been developed. Similarly, in **Malta** and **Finland**, the process of deinstitutionalisation is not being implemented effectively, despite the strategy in Finland having been adopted 10 years ago. In Malta, the

respondents pointed to a lack of involvement of DPOs in discussions and decisions related to disability rights.

In **Moldova**, there is still reportedly a lot of resistance to the changes, which makes the work of those advocating for implementation of the deinstitutionalisation strategy very difficult. In **Slovenia**, despite the strategy, disabled people continue to be placed into psychiatric hospitals and social care institutions, which receive significant funding.

2.4. There is still no deinstitutionalisation strategy

Several respondents provided additional comments, even though their countries do not have a deinstitutionalisation strategy in place.

For example, in the **Czech Republic**, it was pointed out that funds were still going into renovation of institutions. Whether someone lives at home depends very much on the level of support they need and whether they have family to assist them. This is because the budget provided to disabled people for personal assistance is not high enough in many cases and makes it difficult to hire assistance from the open labour market.

In **Azerbaijan**, "the State Programme for the placement of children living in state-owned child institutions in families (Deinstitutionalization) and alternative care" was implemented between 2006 and 2015. A total of 604 children were prevented from entering state-owned special child institutions in the country, including 12 children in 2015. A total of 364 children were reintegrated into their biological families and placed with close relatives by the order of district and city authorities. This process has continued thanks to new legislation, but a new deinstitutionalization strategy has not been adopted after 2015.

In **Denmark**, there is no strategy and the development is going backwards, especially when it comes to persons with intellectual or cognitive disabilities.

In **Germany**, there is officially a commitment to deinstitutionalisation; however, there are significant shortcomings in the implementation. Institutions are not being closed, but rather extended, or new ones created. Residential care homes can accommodate up to 24 individuals, although they are often built in the middle of towns or villages.

One respondent from Germany also noted that there is a move back to institutional care and the medical model, which results in the placement of disabled people into large or smaller institutions. There is insufficient

access to personal assistance, in particular outside of the big cities. Also, many people are afraid of losing their current status quo - including PA hours that they have been granted - if they “activate” themselves (i.e. if they start working or form a family).

Case study 1: Ukraine

Ukraine started the process of deinstitutionalisation of the child care system in 2016. At the moment, it is still among the European countries with the highest number of children in institutions, many of which are in boarding schools.

In January 2016, the Government signed a decree “on a working group for reforming the system of institutional care and education of children”, which launched the reform. After that, the National Strategy of Institutional Childcare System Reform, and the National Action Plan for 2017 - 2026 were also adopted. The planned reform consists of three components: a) rapid development and availability of services at community level for children and families, which will contribute to a gradual closure of boarding schools; b) using released funds to create new and expand existing services in the community; and c) transformation of institutions into centers for providing specialized services, educational institutions and other, to help meet the needs of the community.

The reform will span over 10 years. The plan is to reduce the number of children in boarding schools by 90%, and to ensure that in each community, there are affordable and high-quality services to support families with children, according to their individual needs.

In 2020, the second stage of reforming the state-run boarding schools began. Among the key indicators of this process, according to official information, is the development of social work specialists in local communities, increasing the number of foster families, reducing the number of children in boarding schools. In reality, however, the process is not going well. At the end of 2019, a representative of the Office of the Presidential Commissioner for Children's Rights noted that 26 boarding schools have closed down through liquidation or transformation into an educational institution. She added, however: "At the same time, another 47 institutions have changed only the type of institution, without abandoning the boarding school system”, concluding that this approach is “a pseudo-reform”.

The worst situation is found in psychiatric institutions (referred to as “psychoneurological dispensaries”) for adults. There are 145 of these institutions in Ukraine, accommodating 27,8 thousand individuals with intellectual and/or psychosocial disabilities (data as of 2018). The state of these institutions in Ukraine is, as in most post-Soviet countries, appalling, as human rights are violated on a daily basis. Psychiatric institutions are recognized as places of detention. However, there is currently no comprehensive policy for reforming the system.

Case study 2: Scotland

In 2013, the Scottish Government, the Scottish Health Service and the Convention of Scottish Local Authorities signed, alongside the Scottish Coalition for Independent Living, "A Shared Vision for the Future of Independent Living in Scotland"[12]. While this is not a distinct deinstitutionalisation strategy, it has as its aim ensuring access of disabled people to independent living.

In the same year, the Social Care (Self-Directed Support) Scotland Act gave disabled people four options to use a direct payment: a) employ their own PA; b) pay a care agency to provide support in their own home; c) give payment back to local authority in exchange for a service; d) a combination of previous options[13].

In 2019, the Scottish Government gave the Scottish Independent Living Movement (SILM) funding to become actively involved in their Adult Social Care Reform Programme[14]. With this funding, SILM set up a virtual group of disabled people who make online comments, or complete online surveys, on the work of the Government's Reform Programme. From this virtual group, the members of which come from urban, rural and island communities, and a range of other demographics, a smaller group comprise the People-Led Policy Panel, and have regular meetings with the other stakeholders. The funding from the Government not only created this structure, but allows the panel sufficient time and resources to make a meaningful contribution to this coproduction process.

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[12] See: https://www.webarchive.org.uk/wayback/archive/20150220144551/http://www.gov.scot/Publications/2013/04/8699/0

[13] See: https://www.legislation.gov.uk/asp/2013/1/contents/enacted

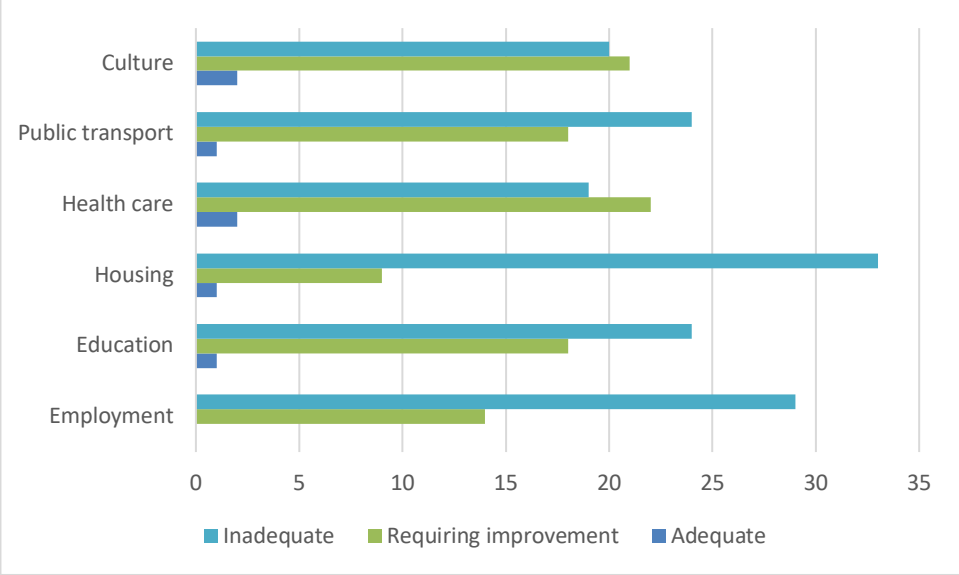
[14] See: https://www.gov.scot/policies/social-care/reforming-adult-social-care/

Despite optimistic publications by Scottish Government[15], the implementation of this strategy is piecemeal, as it depends on the irregular and unsystematic implementation of the 32 local 'Health and Social Care Partnerships' throughout Scotland. There is also the effect of Michael Lipskey's 'street-level bureaucracies'[16], in which the attitudes of front-line professionals affect public policy. So, there is a tendency to persuade people that a direct payment is too difficult to manage, and that they should just rely on publicly controlled home care services.

Once again, there is a growing tendency to implement an unofficial policy of institutionalising those whose support package exceeds the weekly cost of a care home. As one front-line bureaucrat has, unreported, said: "We can no longer afford your human rights". Therefore, there is a large disconnect between the inclusion of the Scottish Government and the exclusion of local government.

3. Access to mainstream services

Q8: How would you rate disabled people's access to mainstream services? ['Adequate' means that these services are available on an equal basis to disabled people and are responsive to their needs.]



The question on access to mainstream services covered: employment in the open labour market; education (primary, i.e. elementary schools);

[15] See: https://www.gov.scot/publications/self-directed-support-strategy-2010-2020-implementation-plan-2019-21/pages/2/
[16] See: https://en.wikipedia.org/wiki/Street-level_bureaucracy

education (secondary; i.e. high schools); education (higher/tertiary, i.e. universities, colleges, vocational training); housing; health care; public transport and culture.

In the majority of countries (33), access to housing is considered as inadequate, followed by employment (29 countries), public transport and education (24 countries), culture (20 countries) and health care (19 countries).

Access to health care is found to require improvement in 22 countries, followed by culture (21 countries), education and public transport (18 countries), employment (14 countries) and housing (9 countries).

There are no countries where access to employment is considered to be adequate. In San Marino and Cyprus, respondents are satisfied with access to health care, while in Georgia and Luxembourg, access to culture is considered as adequate. In Georgia, access to all levels of education is found to be adequate, and in San Marino that applies to access to housing and public transport. Overall, access to mainstream services appears to be the best in San Marino and Georgia, which had the highest number of 'adequate' responses in the survey.

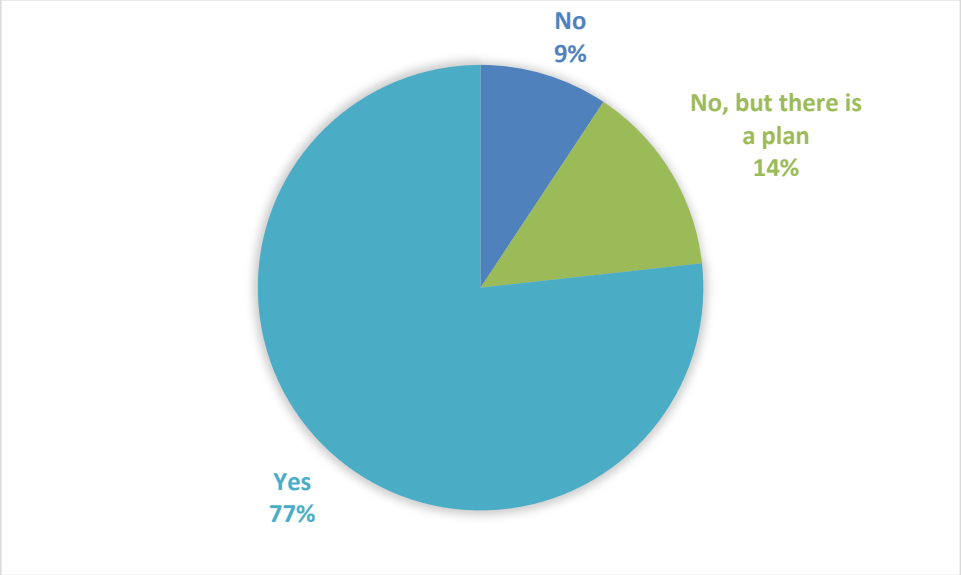
Q9: Does your country have legislation that protects disabled people from discrimination in the labour market?

The vast majority of the countries – 40 in total - have legislation that protects disabled people from discrimination in the open labour market. In Austria and Bosnia and Herzegovina, respondents reported no such legislation, while we do not have information for Lithuania.

Q9.1: If yes, how would you describe the impact of this legislation?

In contrast with answers to the previous question, which were largely positive, the majority found this legislation to be inadequate (18 countries) or requiring improvement (23 countries). This means it is not considered to be effective in preventing and tackling discrimination of disabled people in employment. There are no countries where respondents found legislation to protect from discrimination in employment to be sufficiently good.

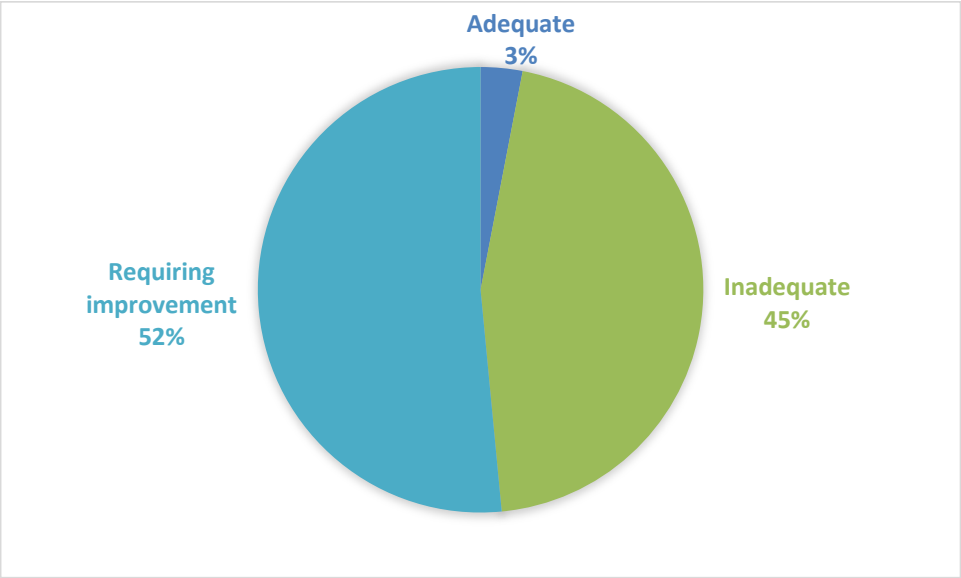
Q10: Can disabled people access personal assistance (PA)?



In most countries – 33 in total – disabled people can access personal assistance to at least some extent. In Bosnia and Herzegovina, Armenia, Greece, San Marino, Albania and Luxembourg, there is no PA scheme/policy, but there is a plan to introduce it in the near future. There are only 4 countries – Hungary, Turkey, Ukraine and Belarus – where there is neither access to personal assistance, nor a plan to introduce it.

This is, overall, a positive result, although the quality of PA schemes varies greatly. This is summarised in Q11 and further analysed in Chapter II of the summary report.

Q11: If yes, how would you describe access to personal assistance (PA) in your country?



Out of the 33 countries that have some form of personal assistance scheme/policy, it is considered adequate in only one country – Slovenia. In the rest of the countries, respondents find PA schemes/policies to be either requiring improvement (17 countries) or inadequate (15 countries). The reasons for such assessment can be found, as noted above, in Chapter II of this summary report, but also in the individual country sheets, where access to PA is described in considerable detail.

4. Recommendations on access to Independent Living

Based on the information provided in the Independent Living survey, ENIL calls on the Governments to take the following actions:

- Ensure that all disabled people are provided with a **genuine choice of where and with whom they live**, regardless of their impairment, the level of support needs or the cost of providing community-based services;
- Ensure that **families of children with disabilities have all the support they need** to raise their child at home, including access to personal assistance if required, peer support, adequate housing and income, as well as inclusive childcare and education;
- Adopt a **comprehensive deinstitutionalisation strategy**, as a matter of priority, based on Article 19 CRPD and the guidance set out in the General Comment 5, and in close consultation with disabled people and their representative organisations;

- Accelerate the **closure of all segregated settings** and a facilitate transition to independent living and being included in the community, through access to personal assistance, peer support and other community-based services, as well as full access to mainstream services and facilities;
- Adopt or review existing **personal assistance legislation**, in line with Article 19 and the General Comment 5, and in close consultation with disabled people and their representative organisations;
- Make sure that **personal assistance is adequately funded** and provided in a way to facilitate choice and control of disabled people over their lives, and in the case of children a right to grow up in a family;
- Support **research initiatives into PA**, led by disabled people and their representative organisations, to identify all characteristics of PA schemes/policies at local, regional and national levels, with the aim of bringing them in line with the CRPD.

We also call on the European Commission to:

- Ensure that **EU funds are used in line with the CRPD, the EU Fundamental Rights Charter and other EU laws**, and prohibit and sanction investments into any form of segregation of disabled children and adults;
- **Investigate reports** of EU funds being used to build or renovate institutions for disabled people in the Member States, as well as other European countries benefiting from EU funding, and put in place an efficient and transparent monitoring and complaints system accessible to non-governmental organisations and the general public.

Annex I: Overview of responses

Country	Responses by individuals (out of which PA users)	Responses on behalf of an organisation	Names of organisations
Albania	1	1	Fondacioni "Së Bashku"
Armenia	1	1	Unison NGO
Austria	2 (2)	1	Independent Living Austria
Azerbaijan	0	1	Union of Disabled People Organisations of Azerbaijan
Belgium	10 (4)	4	GRIP, EVA asbl
Belarus	0	1	Office for the Rights of Persons with Disabilities
Bosnia and Herzegovina	2	0	
Bulgaria	1	1	Centre for Independent Living
Croatia	1	1	SOIH
Cyprus	0	1	Cyprus Paraplegics Organisation
Czech Republic	3 (3)	0	
Denmark	2 (1)	0	
Estonia	1	0	
Finland	2 (2)	1	Threshold Association
France	5 (2)	2	CHA, Gré a Gré
Georgia	1		
Germany	16 (11)	3	Rhein-Main-Inklusiv e.V., ZSL e.V. Erlangen/EUTB North-East Middle Franconia, Phoenix e.V. Tegensburg
Greece	2 (1)	1	i-living Independent Living Organisation
Hungary	2	1	MEOSZ
Iceland	1 (1)	1	NPA miðstöðin
Ireland	8 (5)	0	
Italy	1	2	ENIL Italia onlus, Assoziacione Vita Indipendente
Latvia	0	1	SUSTENTO
Lithuania	0	2	Association of Independent Living, NGO mental Health Perspectives
Luxembourg	1	0	
Malta	5	1	Malta Federation of Organisations of Persons with Disabilities

Moldova	1	1	NGO of people with disabilities Vivere
Montenegro	2 (1)	0	
Netherlands	3 (1)	0	
North Macedonia	0	1	Polio Plus
Norway	1	1	ULOBA – Independent Living Norway
Poland	2 (1)	0	
Portugal	4 (2)	0	
Romania	2 (2)	0	
San Marino	0	1	Attiva-Mente
Serbia	3	2	Centre Living Upright, CIL Serbia
Slovakia	2 (1)	0	
Slovenia	7 (6)	1	YHD
Spain	4 (2)	3	FEVI, Vigalicia
Sweden	0	2	STIL/Independent Living Institute, JAG
Turkey	1	1	Engelli Kadin Demegi
Ukraine	1	0	
United Kingdom	18 (4)	6	Disability Rights UK, CILNI, In Control Scotland

Annex II: Definitions of key terms

Independent Living

The right to living independently and being included in the community is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and further defined in the General Comment No 5[17]:

> "Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities."

Personal assistance

The General Comment 5[18] defines personal assistance as "person-directed/"user"-led human support available to a person with disability" and "a tool for independent living".

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[17] Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para 16(a).
[18] *Ibid, para 16(d).*

According to the General Comment 5, the following characteristics distinguish PA from other types of assistance:

- Funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualized services must not result in a reduced budget and/or higher personal payment;
- The service must be controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom design their own service, i.e., design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;
- Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be "shared" without the full and free consent of the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community;
- Self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of "the employer" are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected. The control of personal assistance can be exercised through supported decision-making.

Group homes/Institutional care

The term 'group homes' refers to buildings, houses or apartments where disabled people live together. Some countries will use other terms, such as protected homes, sheltered homes, organised housing or even supported or assisted living.

If group homes have *one or more* of the following 'institutional care' characteristics, they can be considered as institutional in character and not compliant with Article 19 CRPD[19]:

- obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from;
- isolation and segregation from independent life within the community;
- lack of control over day-to-day decisions;
- lack of choice over whom to live with;
- rigidity of routine irrespective of personal will and preferences;
- identical activities in the same place for a group of persons under a certain authority;
- a paternalistic approach in service provision;
- supervision of living arrangements;
- a disproportion in the number of persons with disabilities living in the same environment.

General Comment 5 goes on to state that institutional settings with these characteristics "may offer disabled people a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions".

With regard to children, the General Comment 5 states that anything other than a family is considered an institution, as there can be no substitute for growing up with a family.[20]

Deinstitutionalisation

ENIL defines 'deinstitutionalisation' as:

> "a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalisation occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalisation in

[19] *Ibid*, para 16(c).
[20] *Ibid*, para 16(c).

the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care."

The Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care[21] describes 'deinstitutionalisation' as a process which includes:

- the development of high quality, individualised services based in the community, including those aimed at preventing institutionalisation, and the transfer of resources from long-stay residential institutions to the new services in order to ensure long-term sustainability;
- the planned closure of long-stay residential institutions where children, disabled people (including people with mental health problems), homeless people and older people live, segregated from society, with inadequate standards of care and support, and where enjoyment of their human rights is often denied;
- making mainstream services such as education and training, employment, housing, health and transport fully accessible and available to all children and adults with support needs.

[21] European Expert Group on the Transition from Institutional to Community-based care, *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based care,* 2012, available at: https://enil.eu/wp-content/uploads/2016/09/Toolkit-10-22-2014-update-WEB.pdf

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About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL has Participatory Status with the Council of Europe, Consultative Status with ECOSOC, is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform, and on the Advisory Council on Youth at the Council of Europe.

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