The right to live independently and to be included in the community in European States
ANED synthesis report

By Neil Crowther

On behalf on the European network of academic experts in the field of disability (ANED)

LEGAL NOTICE

This document has been prepared for the European Commission. However, it reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

The European network of academic experts in the field of disability (ANED) is funded by the Rights, Equality and Citizenship Programme of the European Union.

May 2019.

Contents

Executive summary

This ANED thematic report is about the progress being made across Europe to respect, protect and ensure the rights of persons with disabilities to live independently and to be included in the community. It is based upon studies that were carried out in early 2019 by ANED country experts in 35 European States. Following a common research template, each study sought to collect data regarding:

- the current situation and trends in the living and support situation of children and adults with disabilities;
- trends in the balance of spending on institutional care versus community-based support;
- the commitments, targets and approaches of European States;
- relevant projects and initiatives;
- financial commitments towards the transition from institutional care to independent living;
- monitoring and measurement;
- involvement of persons with disabilities;
- impact and outcomes.

The challenge of data and common definitions

In common with other studies in this field, the study has faced challenges with respect to the lack of common definitions and gaps in available data. Nevertheless, available evidence does allow some findings to be reached concerning the current situation and recent trends in the living and support arrangements of persons with disabilities and with respect to the commitments and actions of European States to meet their obligations.

This report has drawn upon the authoritative guidance provided in General Comment 5 of the UN Committee on the Rights of Persons with Disabilities on the right to live independently and to be included in the community. There are inconsistencies between the Committee's advice and guidance produced by the European Expert Group on the Transition from Institutional to Community Based Care, by the European Commission concerning regulations on the use of European Structural and Investment Funds and in the way ANED countries appear to interpret their obligations. In particular, the emphasis on 'community-based care' in EU documentation is at odds with the concept of independent living, while there is also ambiguity in EU level guidance with respect to the conformity of congregate living with Article 19 of the UNCRPD. These have real and serious implications for the way in which countries interpret their obligations arising out of the UNCRPD and with respect to the acceptable use of European Union funds.

Institutional care is persistent and commonplace across Europe

Arrangements bearing the hallmarks of institutional care persist across all ANED countries, with tens of thousands of children and adults with disabilities systemically denied their human rights. Across Europe, institutional care continues to consume disproportionate levels of public expenditure, far outweighing that invested in

community- based alternatives. A number of countries have made commitments to close such institutions, have adopted policies and strategies and are implementing programmes to those ends. There is a trend, albeit slow in many cases, away from such large institutional care arrangements in many countries.

An end to institutional care, or new institutions 'in the community'?

There is extensive reliance on congregate living, of various kinds and scale, as the destination for those resettled from such large institutions. Congregate forms of living arrangement are also common in countries where large-scale institutions have long since closed, and in some countries where large-scale institutional care was never common. As a result, where people have need for support to live independently in the community, their choices of where and with whom to live are often limited to living with family or to living with, or as an immediate neighbour to, other persons with disabilities who require support. This is usually in 'specialised' housing that is not available to, and hence is segregated from, the wider community, even if located in closer proximity to it than the large institutional care facilities that are being replaced. We know little about the lived experience of choice and control that persons with disabilities are able to exercise over their daily lives when living in such settings, whether they have freely chosen to live in them or the degree of community participation and inclusion now enjoyed, because it is rarely an objective of strategies to effect the transition from institutional care, nor is data routinely collected that would permit its measurement. There is a real possibility that, rather than ending institutional care, many countries are re-imagining it instead.

Choice, control and inclusion are too often not the focus of strategies and action

Although there are some positive examples of approaches designed to expand and deepen choice and control, such as user-led personal assistance schemes, individualised budgets and peer support, these are often small scale and experimental. Peer support and self-advocacy seem generally peripheral to the strategies of many States, as does investment in building community capacity and social infrastructure generally. Current strategies, programmes and projects on deinstitutionalisation are overwhelmingly focused on resettlement of the current population of institutional care facilities, rather than on broader institutional reform and social change.

EU funding plays a pivotal role

In a number of EU Member States, these projects are heavily reliant upon European Structural and Investment Funds (ESIF), with comparatively little domestic budget commitment. On the one hand, this demonstrates the huge potential of the ESIF to advance independent living, provided the moneys are used to those ends. On the other, it raises questions about both the strength of domestic commitment to change and the future sustainability of such efforts.

Closing institutions, or opening up communities – where should countries focus their efforts?

A common challenge experienced by States that are striving to move on from institutional care appears to be that of generating sufficient community-based and person-centred support to meet self-imposed targets to reduce the institutional care population. As a result, this lack of community- based capacity acts as a barrier to resettling existing residents and fails to redirect demand for institutional care. It may also create perverse incentives towards the economies of scale offered by congregate care arrangements. States might therefore be better advised to focus strategy and targets on the development of community-based living and support, while imposing a moratorium on the building of new institutions.

In conclusion

If one regards the transition from institutional care to independent living as a process of restoring personhood, power and belonging to people hitherto denied it, as opposed only to the restructuring of the care system, then it is almost impossible to make an assessment as to the real progress being made based on the often limited evidence and data available.

However, although it is undoubtedly positive that so many European States have embarked on this journey, too many features of the alternate housing and support arrangements that have or are being implemented, while often marking progress from the large-scale institutions they replace, continue to fall significantly short of the promise of Article 19 of the UNCRPD.

Recommendations

All European States should:

- Develop rights-based, targeted and deliverable plans concerning the implementation of disabled people's rights to live independently and to be included in the community, guided by General Comment 5 of the UN Committee on the Rights of Persons with Disabilities.

- Actively involve organisations of persons with disabilities as partners in the development, implementation and monitoring of plans.

- Take measures, including support for innovation, increased investment and regulatory measures, to diversify housing and support options for persons with disabilities and to limit the development of congregate or clustered housing and care arrangements.

- Promote and invest in architecture to expand and deepen choice and control, including supporting the development of user-led personal assistance schemes, allied to individualised budgets, and through direct payment schemes and investment in peer support.

- Reform laws to accord persons with disabilities with enforceable rights to choose and to refuse where and with whom to live.

- Significantly improve systems of monitoring and data collection, based on General Comment No 5 of the UNCRPD Committee, and for example by harnessing the independent living indicators developed by the EU Agency for Fundamental Rights.

- Establish or invest in awareness-raising initiatives to promote receptiveness to the independence and inclusion of persons with disabilities by the general public.

- Engage constructively with the UNCRPD Committee and other UN Treaty Bodies, responding to and acting on concluding observations and recommendations.

The European Commission should:

- Recognise that implementation of the right of persons with disabilities to live independently and to be included in the community is a challenge for Europe and the EU as a whole, not only those maintaining large, discernible institutional care facilities. In particular, through the European Semester process and the post-2020 ESIF programming, it should seek to expand the number of Member States that commit to action on independent living in their National Reform Programmes and post-2020 Partnership Agreements and Operational Programmes.

- Take steps to ensure awareness and understanding of the UNCRPD and the right to live independently and to be included in the community across the European Commission.

- Consider how to give prominence to the concept and true meaning of independent living rather than 'community-based care' in future strategy and policy, regulation and guidance, drawing upon the CRPD Committee General Comment 5.

- Establish and promote common definitions of institutional care and independent living, drawing upon General Comment 5, including providing clearer guidelines on the need to move away from congregate living arrangements and encouraging Member States to invest in a diversity of housing and support options.

- Encourage investment, via EU funding and beyond, in architecture to expand and deepen choice and control, including the development of user-led personal assistance schemes, individualised budgets and direct payment schemes and investment in peer support and innovative practice by organisations of persons with disabilities.

- Encourage investment in social infrastructure to build community capacity, especially investment in disabled people's user-led organisations.

National human rights bodies, CRPD Independent Mechanisms and OPCAT National Protection Mechanisms should:

- Draw on the manual 'Human Rights and Disability' produced by the Asia Pacific Network of National Human Rights Institutions to ensure that in both their operations and their programmes they are advancing the rights of persons with disabilities.

- Conduct monitoring and inspection of institutional care facilities, including congregate and clustered living arrangements.

- Monitor progress towards implementation of the right to live independently and to be included in the community and report at the national level and to UN human rights treaty bodies, including the UNCRPD Committee.

- Ensure that complaints handling is accessible and conduct outreach to marginalised disabled people.

- Where available, use legal powers to support strategic litigation.

The Council of Europe Commissioner for Human Rights should:

- Continue to promote the right to live independently and to be included in the community, including via country visits.

- Address inconsistencies in opinions on independent living and on the rights of older persons concerning the compatibility of congregate forms of care with human rights standards.

- Ensure that its vital work on information and communications technology and artificial intelligence considers the particular opportunities and risks for disabled people, including with respect to supported decision making and the right to live independently and to be included in the community.

Contributors

Editors: Neil Crowther with contributions from Anna Lawson and Mark Priestley

Supported by Roy Sainsbury, Hannah Grene, Chris Hatton and Ivette Groenendijk

ANED countries

Austria	Ursula Naue and Petra Plieger
Belgium	Evelien Leyseele
Bulgaria	Slavka Kukova
Croatia	Tihomir Žiljak
Cyprus	Katerina Mavrou and Anastasia Liasidou
Czech Republic	Jan Siska
Denmark	Steen Bengtsson
Estonia	Lauri Leppik
Finland	Teppo Kröger, Katja Valkama and Hisayo Katsui
France	Serge Ebersold and Carole Nicolas
Germany	Anne Rosken
Greece	Eleni Strati
Hungary	Tamás Gyulavári
Iceland	James Gordon Rice and Rannveig Traustadóttir
Ireland	Catriona Moloney
Italy	Giampiero Griffo and Ciro Tarantino
Latvia	Daina Podzina
Liechtenstein	Wilfried Marxer and Patricia Hornich
Lithuania	Aidas Gudavičius
Luxembourg	Arthur Limbach-Reich
Malta	Lara Bezzina and Vickie Gauci
Montenegro	Nenad Koprivica
Netherlands	José Smits
Norway	Johans Tveit Sandvin
Poland	Agnieszka Król
Portugal	Paula Pinto and Yuliya Kuznetsova
Republic of North Macedonia	Zvonko Shavreski and Elena Kochoska
Romania	Loredana Totoliciu
Serbia	Kosana Beker
Slovakia	Darina Ondrusova, Daniela Keselova and Kvetoslava Repkova
Slovenia	Darja Zaviršek
Spain	Miguel Verdugo and Cristina Jenaro
Sweden	Johanna Gustafsson
Turkey	Betul Yalcin
United Kingdom	Neil Crowther

Special thanks to Nadia Hadad (EDF), Heidrun Mollenkopf (AGE Platform) and Ines Bulic (ENIL) for their input and reviewing of this synthesis report.

1 Background and purpose of this report

1.1 What this report is about

'Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is either unavailable or tied to particular living arrangements, and community infrastructure is not universally designed. Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation.'

UN Committee on the Rights of Persons with Disabilities (2017)[1]

This ANED thematic report is about the progress being made across Europe to respect, protect and ensure the right of persons with disabilities to live independently and to be included in the community.

It provides an overview of the commitments, strategies, actions and approaches of European States and considers their effectiveness. In light of these, it then considers the current status and recent trends regarding the living arrangements of persons with disabilities across Europe.

Its primary framework for analysis is Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, which all ANED countries (with the exception of Liechtenstein) and the European Union have ratified.[2]

The report considers both discrete programmes focused on closing down specific institutional care settings and resettling people to alternative arrangements, as well as broader actions to reform law, public services and to cultivate favourable social conditions for independent living.

In the European Disability Strategy 2010-20, the European Commission committed to:

> 'Promote the transition from institutional to community-based care by using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people

[1] UNCRPD Committee (2017) General Comment 5 on the Right to Live Independently and to be Included in the Community https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en.

[2] Article 19 of the United Nations Convention on the Rights of Persons with Disabilities – Living independently and being included in the community https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html.

with disabilities living in residential institutions, in particular children and elderly people.'[3]

The report also therefore considers the impact of European Union policy and action, including via the European structural and investment funds, on advancing the right to live independently and to be included in the community.

1.2 How the report has been produced

This synthesis report is based upon desk research conducted by ANED's country experts in 35 European countries.[4] The individual country studies were conducted using a common template and guidance. Each report was independently reviewed by academic experts and revised accordingly. They will be published alongside this synthesis report. Based on available data, each country study considered:

- The current situation and trends in the living and support situation of children and adults with disabilities;
- Trends in the balance of spending on institutional care versus community-based support;
- The commitments, targets and approaches of European States to implementing the right to live independently and to be included in the community;
- Relevant projects and initiatives including those supported by European Union funding;
- Financial commitments towards the transition from institutional care to independent living, including use of European Union funding;
- Involvement of persons with disabilities;
- Monitoring and data collection;
- Impact and outcomes of the strategy and actions of European States.

1.3 A note on the limitations of data and challenge of comparative analysis

This report is not able to, and does not, compare the living situation of persons with disabilities across European States, nor can it directly compare the action and performance of European States regarding their efforts to influence the transition from institutional care to independent living.

As the European Union Agency for Fundamental Rights noted in its work on independent living:

> 'The lack of an accepted definition of an institution and varied understandings of commonly used terms pose a challenge to the collection of comprehensive and comparable data on common types and characteristics of institutions in place in the EU.
>
> …Similarly to institutional services, the diversity and limited range of information on community-based services currently available in many EU

[3] European Commission (2010) *A renewed commitment to a barrier-free Europe – European Disability Strategy 2010-20*.

[4] For a list of the countries, see: https://www.disability-europe.net/about-us.

Member States does not allow for direct cross-country comparisons. This also reflects the variety of definitions employed in EU Member States to refer to community-based services.'[5]

Furthermore, data concerning the lived experience of persons with disabilities in terms of the enjoyment of choice, control and participation is extremely rare.

Although it is hoped that this study casts further light on the performance of European countries at respecting, protecting and ensuring the right of persons with disabilities to live independently and to be included in the community, the report, and the individual country reports, should be read with that in mind.

Structure of the report

Chapter 2 discusses how law, policy and guidance concerning the right to live independently and to be included in the community interprets and frames the obligations of States. It focuses on the important distinctions to be drawn between the concept of independent living and that of 'care', on the compatibility of congregate living with Article 19 of the CRPD and on the centrality of choice and control both as a vehicle for and outcome of the transition from institutional care to independent living.

Chapters 3 and 4 These chapters present key themes emerging from the ANED country studies, illustrated with examples drawn from them, while providing some overall indicators of progress. It considers the current situation and recent trends in the living situation of persons with disabilities and on expenditure on institutional care versus measures in support of independent living. It provides an overview of the relevant commitments, plans and approaches of European States, highlighting promising practices, as well as areas of concern.

Chapter 5 makes concluding remarks and proposes recommendations for the European Commission, for European countries covered by the study and for other key government and non-government actors.

[5] European Union Agency for Fundamental Rights (2017) *Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU*.

2 What is meant by 'living independently and being included in the community'?

2.1 Introduction

This chapter discusses how international law and various pieces of policy and guidance concerning the right to live independently and to be included in the community interpret and frame the obligations of ANED countries. It focuses on the important distinctions to be drawn between the concept of independent living and that of 'care', on the compatibility of congregate living with Article 19 of the CRPD and on the centrality of choice and control both as a vehicle for and outcome of the transition from institutional care to independent living.

2.2 Article 19 of the United Nations Convention on the Rights of Persons with Disabilities

All of the countries in Europe that are included in this thematic study, with the exception of Liechtenstein, have ratified the United Nation Convention on the Rights of Persons with Disabilities (CRPD), as has the European Union as a 'regional integration organisation'.

Hence, the starting point for this thematic study has been Article 19 of the CRPD, 'Living independently and being included in the community' which says that:

> '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.'[6]

This study focuses in particular on Article 19 (a) and (b). Other recent ANED studies have explored the issues connected to Article 19 (c) in depth.[7] However, this study has sought to identify and report on instances where the policies, strategies and programmes of countries concerning the right to live independently and being

[6] Article 19 of the United Nations Convention on the Rights of Persons with Disabilities – Living independently and being included in the community

[7] These studies can be accessed at the ANED website: https://www.disability-europe.net/theme.

included in the community address issues beyond housing and support arrangements.
This study of UNCRPD Article 19 has based its analysis on the authoritative guidance of the UN Committee on the Rights of Persons with Disabilities contained in General Comment 5 on living independently and being included in the community (2017). General Comment 5 elaborates the meaning and implications of Article 19 and the nature of the obligations of States Parties concerning its implementation.[8]

Other key sources of reference include the Common European Guidelines on the transition from institutional to community-based care, produced by the European Expert Group (EEG) on the transition from institutional to community-based care (2012),[9] the draft guidance fiche produced by the European Commission for desk officers on the 'transition from institutional care to community based care' (2014) which concerns the operationalisation of European Union policy on independent living via the ESIF,[10] and the research and analysis of the European Agency for Fundamental Rights concerning independent living in the EU.[11] Interpretation and analysis has been further aided by the 'Issues Paper' on the right to live independently and to be included in the community produced by the Council of Europe Commissioner for Human Rights in 2012.[12]

2.3 The rights of children with disabilities

Children with disabilities also have the right to live in the community on an equal basis with others and to grow up in a family-like environment.

Article 23(1) of the UN Convention on the Rights of the Child establishes that all children with disabilities should 'enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.'[13]

The UN Committee on the Rights of the Child has expressed its concern at the high number of children with disabilities placed in institutions and has urged States parties, through deinstitutionalisation programmes, to support the ability of such children to live in their family, extended family or foster care.[14]

---

8 United Nations Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community.
9 European Expert Group on the transition from institutional to community-based care (2012), Common European Guidelines on the transition from institutional to community-based care.
10 European Commission (2014) Draft thematic guidance fiche for desk officers on the transition from institutional to community-based care (de-institutionalisation).
11 European Union Agency for Fundamental Rights – the right of independent living of persons with disabilities https://fra.europa.eu/en/project/2014/right-independent-living-persons-disabilities.
12 Commissioner for Human Rights (2012) 'Issues Paper on the rights of persons with disabilities to live independently and to be included in the community' https://rm.coe.int/the-right-of-people-with-disabilities-to-live-independently-and-be-inc/16807bef65.
13 UN Convention on the Rights of the Child (1989) https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.
14 See: Committee on the Rights of the Child, General Comment 9 (2006) on the rights of children with disabilities, paragraph 47.

2.4 A transition to 'community-based care' or to 'living independently and being included in the community?

In General Comment 5, the UNCRPD Committee describes 'living independently' as meaning:

> '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.'[15]

With respect to 'being included in the community' the Committee advises that this includes:

> 'living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them to be fully included and participate in all spheres of social life.'[16]

The right to live independently and to be included in the community therefore reinforces and amplifies Article 29 (1) of the Universal Declaration of Human Rights, which says:

> 'Everyone has duties to the community in which alone the free and full development of his personality is possible.'[17]

In sum, the full scope of the transition from institutional care to 'living independently and being included in the community' should therefore be understood as one involving the restoration of personhood, power and belonging to persons with disabilities.

It is therefore notable that neither the current European disability strategy (which runs up to 2020), the regulations related to the European structural and investment funds, nor the European Expert Group use the language of independent living, or 'community-based living'. Rather, the language and focus in EU policy is on bringing about a shift from institutional to 'community-based care.' This reflects the fact that the relevant policy extends beyond the scope of disability rights to include children

---

[15] United Nations Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community.

[16] United Nations Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community.

[17] Universal Declaration of Human Rights https://www.un.org/en/universal-declaration-human-rights/.

with and without disabilities as well as older people, where the concept of independent living is less prominent. Nevertheless, it is language that is conceptually at odds with the meaning and scope of Article 19 and that has implications for how it is understood and acted upon by European countries.

What are now often called 'social care' systems and services can, when reformed, play a crucial role in supporting persons with disabilities to live independently and to be included in the community. Nevertheless, a central goal of the disabled people's movement in developing and advancing the concept of 'independent living' has been to challenge not only institutional care, but the very idea of 'care' itself, since it has often embodied unequal power relations and restrictive practices, has typically positioned persons with disabilities as passive objects, rather than as active citizens in control of their own lives, and has historically failed to promote full participation in community life.[18] The language and meaning of Article 19 of the CRPD embodies this 'paradigm shift' from 'care' to 'rights', emphasising the right of persons with disabilities to be in control over their own lives and to participate fully in their communities on an equal basis with others. As the Council of Europe Commissioner for Human Rights has explained:

> 'This right is violated when people with disabilities who need some form of support in their everyday lives are required to relinquish living in the community in order to receive that support; when support is provided in a way that takes away people's control from their own lives; when support is altogether withheld, thus confining a person to the margins of the family or society; or when the burden is placed on people with disabilities to fit into public services and structures rather than these services and structures being designed to accommodate the diversity of the human condition.'[19]

Furthermore, the factors involved in implementing Article 19 extend significantly beyond the design of the 'care system', including for example, reform of guardianship law and practice, the accessibility of mainstream public services, the receptiveness of the wider community and access to social networks.[20]

---

[18] For example, see:
DeJong, G., & Wenker, T. (1979) 'Attendant care as a prototype independent living service' *Archives of Physical Medicine and Rehabilitation*, 60(10), 477-482.
Kelly, C. (2016) *Disability politics and care: The challenge of direct funding*. UBC Press.
Kröger, T. (2009) 'Care research and disability studies: Nothing in common?' *Critical Social Policy*, 29(3), 398-420.
Morris, J. (1993) 'Community care or independent living?' in *Independent Lives?* (pp. 147-172). Palgrave, London.
Morris, J. (2004) 'Independent living and community care: a disempowering framework', *Disability & Society*, *19*(5), 427-442.
Priestley, M. (1999) *Disability politics and community care*. Jessica Kingsley.
Rummery, K. (2011) 'A comparative analysis of personalisation: balancing an ethic of care with user empowerment', *Ethics and Social Welfare*, *5*(2), 138-152.
Shakespeare, T. (2000) 'The social relations of care', *Rethinking Social Policy*, pp. 52-65.

[19] Commissioner for Human Rights (2012) 'Issues Paper on the rights of persons with disabilities to live independently and to be included in the community'.

[20] The full breadth of these goals is elaborated in the Independent Living Indicators developed by the European Union Agency for Fundamental Rights https://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators.

Although it may be the intention of EU policy to advance Article 19 of the UNCRPD in its broadest sense (and both the EEG guidance and European Commission regulations and guidance on the use of ESIF would suggest this to be the case), the framing of policy and regulations as a transition from one care system to another does appear both to reflect and reinforce the sometimes limited focus and scope of action by States that has been detected by this study. Specifically, a number of the ANED country studies echo the findings of previous studies in suggesting that institutional care may be being re-organised rather than replaced under the rubric of the 'transition from institutional to community based care'.[21] In particular, although there is evidence of the closure (or planned closure) of large institutions they are often being replaced with smaller modes of congregate living and there is rarely evidence that individual choice and control has been a guiding principle, either as a vehicle for this transition, or as a primary goal or measure of success. Rather, it is the mode and location of care provision, not enhanced levels of autonomy, inclusion and equality that have been or continue to be the focus of strategy and the measure of progress in a number of European States, including Hungary and Romania, for example.

While language alone will not attend to the lack of commitment and some of the systemic shortcomings in the approach taken by some European States, the framing of the policy matters in shaping how issues are understood, how strategies and plans are developed and implemented and how success is measured. It is therefore recommended that the language employed in EU policy and guidance in future makes explicit the goal of ensuring that persons with disabilities are able to live independently in the community on an equal basis with others (or 'independent living'/'community-based living' in shorthand) and both promotes and makes use of the progress indicators on independent living developed by the EU FRA to ensure that the true meaning and full scope of independent living provides the focus for action.

2.5 What is de-institutionalisation?

In its General Comment 5, the CRPD Committee advises that:

> 'To respect the rights of persons with disabilities under Article 19 means that States parties need to phase out institutionalisation. No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents' physical safety. Institutions should not be extended, new residents should not enter when others leave and "satellite" living arrangements that branch out from institutions, i.e., those that have the appearance of individual living (apartments or single homes) but revolve around institutions, should not be established.'

De-institutionalisation is the process both of resettling the existing residents of institutional care services in individualised housing and support in the community and of reorienting policy and resources from institutional care towards supporting the rights of persons with disabilities to live independently and being included in the

[21] For example: Crowther, N. et al (2017) 'Opening up communities, closing down institutions', Community Living for Europe: Structural Funds Watch.

community on an equal basis with others. According to the European Expert Group on the Transition from Institutional to Community-based Care, de-institutionalisation is:

> 'a process which includes: (1) 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. (2) The planned closure of long-stay residential institutions where children, people with disabilities (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. (3) 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.'[22]

To set about meeting this obligation, it is crucial to define what is meant by an 'institution.' The CRPD Committee's General Comment 5 does so by defining the characteristics of institutionalisation:

> **'**Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as 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; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities 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. Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings.'[23]

Some countries, such as Finland, have begun to talk about 'the second phase of de-institutionalisation', focusing in particular on how people with intellectual disabilities can move on from group housing and institution-like housing units to genuine independent living in communities. In doing so, the debate is shifting from closing

---

[22] European Expert Group on the transition from institutional care to community-based care (2014) Toolkit on the use of European Union funds for the transition from institutional to community-based care http://enil.eu/wp-content/uploads/2014/07/Toolkit-07-01-2014-WEB.pdf.

[23] United Nations Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community.

down institutions and the provision of alternative care, to how to open up and build the capacity of communities to include persons with disabilities.

2.6 Is 'congregate living' compliant with Article 19 UNCRPD?

In its General Comment 5, the UNCRPD Committee asserts that:

> 'Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood.'[24]

Similarly, in his 'Issues Paper' on the right to live independently and to be included in the community (2012), the Council of Europe Commissioner for Human Rights argued that:

> 'An incorrect understanding of the right to live in the community risks replacing one type of exclusion with another... governments increasingly recognise the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response. This is not merely a theoretical concern. Countries which have already closed down large-scale institutions are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively to people with disabilities. ... such a solution compromises the individual's ability to choose or to interact with and be included in the community.'[25]

The Council of Europe Human Rights Commissioner issues paper goes on to elaborate through the presentation of examples:

> 'A person living in a state-run group home with seven other housemates has little chance of choosing her housemates or having privacy within her home. Because the house is run for a large group, and especially if she needs support for daily living or in accessing the community, she will likely be subject to restrictions that impede possibilities for a self-directed life, including rules about when she can leave and with whom and how often, and when to retire for the night. Particularly, the possibility for her to develop personal relationships and express her sexuality will be limited. Likewise, housing communities comprised of a number of buildings designated for people with disabilities within a neighbourhood are proposed in some contexts as an alternative to segregation. By definition, however, the ability to connect from within these settings with the larger community of people with and without disabilities – chance meetings with neighbours or actively seeking out connections – is inhibited.'[26]

---

[24] United Nations Committee on the Rights of Persons with Disabilities (2017) General comment No. 5 (2017) on living independently and being included in the community.

[25] Commissioner for Human Rights (2012) 'Issues Paper on the rights of persons with disabilities to live independently and to be included in the community'.

[26] Commissioner for Human Rights (2012) 'Issues Paper on the rights of persons with disabilities to live independently and to be included in the community'.

Despite this, the ANED country studies echo the findings of previous studies in finding that among European States that are planning or implementing programmes to close down large institutional care facilities and to resettle current inhabitants, modes of congregate living, of various shapes and sizes, are a common replacement for adults[27] and for children.[28] This is the case in Estonia, Hungary and Romania for example. Even in European States in which large-scale institutions were mostly closed several decades ago, such as the United Kingdom, congregate living dominates the living arrangements of those with intellectual disabilities who require support and who are not living with family. Moreover, new forms of congregate, or 'clustered' living arrangements, sometimes under the rubric of 'supported living' have or are being developed today and there are suggestions that they may be increasing in size (for example, in Norway). It is an issue that has been repeatedly raised in shadow reports to and concluding observations by the UNCRPD Committee with respect to a number of European States.

'Community-based care' appears often therefore to be interpreted simply as 'that which is not a large institution.' This is a viewpoint that potentially has its roots in the definition employed as the basis for the seminal study of institutional care in Europe by Mansell et al. (2007), in which a 'residential institution' was defined as an establishment in which more than 30 people lived, of whom at least 80 % were mentally or physically disabled. It also appears to be perpetuated in other European Union analysis and guidance. For example, the European Union Agency for Fundamental Rights includes residential care homes under its typography of community-based services.[29]

With respect to European Union policy, the draft guidance fiche for desk officers produced by the European Commission says of the regulations concerning ESIF that:

> 'Building or renovating long-stay residential institutions is excluded, regardless of their size.' [30]

However, it goes on to say that:

> 'the size of the institution cannot be used in isolation as a criterion to judge whether the supported infrastructure can be considered as community-based service or simply a scaled-down institution. The starting point should be whether it provides a setting allowing for the possibility for independent living, inclusion in the community (including physical proximity of the location) and

---

27 For example, Crowther, N. et al (2017) 'Opening up communities, closing down institutions', Community Living for Europe: Structural Funds Watch.

28 Rosenthal, E. (2018) (Disability Rights International, Validity and TASH), 'Position paper: The right to live and grow up in a family for *all* children', December 14, 2018 https://enil.eu/wp-content/uploads/2018/12/DRI-Right-to-Family-December-2018.pdf.

29 European Union Agency for Fundamental Rights – the right of independent living of persons with disabilities https://fra.europa.eu/en/project/2014/right-independent-living-persons-disabilities.

30 European Commission (2014) Draft thematic guidance fiche for desk officers on the transition from institutional to community-based care (de-institutionalisation).

> high-quality care. However, it is clear that the larger the infrastructure the more likely it is that these criteria will not be fulfilled.'[31]

While this advice appears to discourage investment in large congregate living arrangements, there is also unhelpful ambiguity. It does not qualify what is constitutive of 'larger infrastructure' and although it says (correctly) that the size of an institution is not by itself a criterion to judge whether something amounts to community living or a downscaled institution, this is also, by default, permissive of congregate living, albeit at a smaller scale.

As this report will go on to outline, a number of European States place caps on the number of people that are allowed to be catered for in new developments (albeit ranging from 4 people in Sweden to 50 in Hungary). In its guidance, the European Expert Group says that:

> 'size is an important factor when developing new services in the community. Smaller and more personalised living arrangements are more likely to ensure opportunities for choice and self-determination of service users and to provide a needs-led service. When developing strategies for transition from institutional care to community-based services, some countries decide to limit the maximum number of users that can be accommodated in the same setting, such as number of residents in apartment or a building. This approach can help to ensure that institutional culture is not recreated in the new services. It must be noted, however, that the small size of accommodation does not in itself guarantee elimination of institutional culture in the setting. There are a number of other factors, such as the level of choice exercised by the service users, the level and quality of support provided, participation in the community and quality assurance systems used which impact on the quality of the service. In some cases, people can be coerced into taking certain treatment in order to have access to services in the community. In such cases, institutional culture prevails despite the fact that the service itself may not be institutional in character.'[32]

Again, while pointing towards a preference for smaller and more personalised living arrangements, the EEG guidance also leaves open the question of whether congregate living is of itself compliant with the CRPD.

Some ANED countries, such as Latvia, Serbia and Slovenia, have justified congregate living schemes as a transitional or temporary 'step down' arrangement from institutional care, implying that they form a stepping-stone towards full community inclusion (within the doctrine of 'progressive realisation'). However, this study has not found an example of such practice where a timeframe has been placed on their use. They remain a common living arrangement for those who were resettled from institutions some time ago (for example, in Norway and the UK) and they continue to be newly developed in States that that have largely closed down

---

[31] European Commission (2014) Draft thematic guidance fiche for desk officers on the transition from institutional to community-based care (de-institutionalisation).

[32] European Expert Group on the transition from institutional to community-based care (2012), Common European Guidelines on the transition from institutional to community-based care.

large-scale institutions (for example, in Denmark). Rather, it seems likely that such living arrangements do and can become the 'new normal' and in doing so deny 'choices equal to others', especially where countries are failing to ensure that other housing options are being made readily available.

In some instances, the severity of impairment and the scale of support need are given as a rationale for congregate living and care arrangements (for example, Liechtenstein, Poland and Spain). The UNCRPD Committee has noted in its General Comment 5 how:

> 'When persons with disabilities are assessed as requiring a high level of personal service, States parties often consider institutions as the only solution, especially when personal services are considered to be "too costly" or the person with disabilities is considered to be "unable" to live outside an institutional setting. Persons with intellectual disabilities, especially those with complex communication requirements, among others, are often assessed as being unable to live outside institutional settings.'[33]

The Committee advises that:

> 'Such reasoning is contrary to Article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements.'[34]

The emphasis of the UNCRPD is that persons with disabilities should be able to choose where and with whom to live *on an equal basis with others.* It is perhaps useful therefore to consider how rare congregate living, based on a shared personal characteristic, is among the population at large. Moreover, as the Commissioner for Human Rights has argued, such arrangements can of themselves be detrimental to living independently and being included in the community, hence urging States to:

> 'ensure that the process of transition to community-based services and supports does not fall short of achieving full implementation of the right to live in the community, recognising that smaller institutions or segregated frameworks and mechanisms, such as congregate care, even when physically placed in the community, do not satisfy the conditions set in Article 19 of the UN Convention on the Rights of Persons with Disabilities.'

The current inconsistencies between guidance at the European Union level and that contained in General Comment 5 regarding the compatibility of congregate living arrangements with Article 19 CRPD has left space for such arrangements to be regarded as the acceptable default approach to housing and support for disabled people. This study has found that, under the rubric of the 'transition from institutional to community-based care', institutional care appears often to be re-imagined rather

---

[33] UNCRPD Committee (2017) General Comment 5 on the Right to Live Independently and to be Included in the Community.

[34] UNCRPD Committee (2017) General Comment 5 on the Right to Live Independently and to be Included in the Community.

than replaced, with congregate living, albeit at a smaller scale, becoming the 'new normal.' As a result, we face a proliferation of 'hidden' or 'mini' institutions.

It is therefore recommended that the European Commission, in collaboration persons with disabilities, and based upon General Comment 5 of the CRPD Committee, revisit its guidance with respect to the development of infrastructure and support services to consider how to promote non-congregate solutions more actively and to deter reliance on congregate arrangements to facilitate the transition from institutional care to independent living.

2.7 Respecting, protecting and ensuring choice and control

The CRPD Committee General Comment 5 advises that:

> 'To choose and decide how, where and with whom to live is the central idea of the right to live independently and be included in the community. Individual choice, therefore, is not limited to the place of residence but includes all aspects of a person's living arrangements: the daily schedule and routine as well as the way of life and lifestyle of a person, covering the private and public spheres, every day and in the long term.'

Choice and control over living arrangements and over daily life is therefore the litmus test in evaluating progress on the transition from institutional care to independent living.

The evidence collected for this ANED study echoes a finding by the EU Agency for Fundamental Rights that noted how:

> 'Similar terms are used across EU Member States to describe [community-based] services with widely different characteristics, particularly in relation to the amount of control exercised by users.'[35]

In its General Comment 5 the UNCRPD Committee notes how:

> 'Providers of support service often wrongly describe their service using the terms "independent" or "community living" as well as "personal assistance", though in practice such services do not fulfil the requirements posed by Article 19. Mandatory "package solutions" which, among other things, link the availability of one particular service to another, expect two or more persons to live together or can only be provided within special living arrangements are not in line with Article 19. The concept of personal assistance wherein the person with disabilities does not have full self-determination and self-control are to be considered not compliant with Article 19.'[36]

---

[35] European Union Agency for Fundamental Rights – the right of independent living of persons with disabilities.

[36] UNCRPD Committee (2017) General Comment 5 on the Right to Live Independently and to be Included in the Community.

Similarly, in his issues paper, the Commissioner on Human Rights referred to arrangements that:

> 'rest on a mistaken notion that living in the community is solely about physical placement in the community, rather than a way of life that is intimately linked with autonomy and choice. Another troubling trend occurs when well-meaning efforts to provide individualised support fail to infuse these schemes with choice.'[37]

While this study has collected a great deal of evidence concerning the plans and actions of ANED countries to resettle people from large-scale institutions and to reform social services, this rarely appears driven by an explicit aim of strengthening and expanding individual choice and control, nor is choice and control posited as a core vehicle for the transition from institutional care to independent living. A number of ANED countries, while having embarked on a de-institutionalisation process, also simultaneously maintain guardianship regimes, denying legal personhood, and hence choice and control to some who are the intended beneficiaries of the process.

In its General Comment 5, the CRPD Committee drew particular attention to the following:

> 'Individualized support services which do not allow for personal choice and self-control are not providing for living independently within the community. Support services provided as combined residential and support service (delivered as a combined "package") are often offered to persons with disabilities on the premise of cost efficiency. However, while this premise itself can be rebutted in terms of economics, aspects of cost efficiency must not override the core of the human right at stake. Persons with disabilities should not be required by rule to share personal assistance and assistants; this should only be done with their full and free consent. The possibility to choose is one of the three key elements of the right to live independently within the community.'[38]

Respecting, protecting and ensuring the right to choice and control includes the implementation of enforceable rights to choose and to refuse particular living arrangements, on an equal basis with others, the development of mechanisms to transfer control over support to persons with disabilities to design and shape their own support, such as individual budgets and personal assistance, and the progressive generation of living and support options to choose from. With respect to the latter, it is crucial, as the Commissioner for Human Rights has advised, that:

> 'The solution lies in "unbundling" disability-related supports from certain housing units, and providing people with disabilities with individualised supports which they can take to any housing option they choose in the housing

[37] Commissioner for Human Rights (2012) 'Issues Paper on the rights of persons with disabilities to live independently and to be included in the community'.

[38] UNCRPD Committee (2017) General Comment 5 on the Right to Live Independently and to be Included in the Community.

market – whether social housing, rental, ownership, or any other form of housing tenure provided to people without disabilities.'[39]

Although there is heavy emphasis in the UNCRPD and associated guidance on individual-level measures to promote and facilitate choice and control, the disabled person's independent living movement has historically placed equal emphasis on collective measures, such as the creation of peer support platforms, user-led organisations and self-advocacy groups and there is evidence that these have greatly influenced the success of individual level measures (such as direct payments in the UK).[40] Since its inception in 1989, the European Network on Independent Living has emphasised the importance of peer support for the self-determination of disabled people.[41]

While this ANED study has found evidence of disabled people's organisations (DPOs) being engaged in the elaboration and monitoring of strategies and plans, only a few examples identified DPOs as having an express role in implementation (for example, Belgium). Confirming the findings of previous studies, such organisations also appear rarely to be the beneficiaries of European structural and investment funds that have been committed to this aim.[42]

It would be beneficial if European Commission guidance and that of the European Expert Group (EEG) were to place increased emphasis on choice and control and to elaborate the different ways it can find expression, or be denied, as well as offering advice on how it can be made a central measure of performance and progress. Moreover, it would be positive if the European Commission and the EEG were to place increased emphasis on the development of 'choice and control architecture', including law reform, public service redesign and an enhanced role for civil society, especially DPOs and self-advocacy groups, as a core building block in the transition from institutional care to independent living.

2.8 Summary and conclusions

It is certainly welcome that the European Union has adopted a policy in support of de-institutionalisation, commits significant resources towards this goal and has adopted regulations designed to prohibit expenditure of ESIF on institutional care. However, the potential of the policy and funds to advance independent living could

[39] Commissioner for Human Rights (2012) 'Issues Paper on the rights of persons with disabilities to live independently and to be included in the community'.

[40] See for example, Priestley, M. (1999) *Disability politics and community care*. Jessica Kingsley

[41] In its 'principles of independent living' (1990), ENIL asserted that 'any organization, governmental or non-governmental including organizations for disabled persons, individuals and professionals who use the term "Independent Living' in their work have to comply with the following principle: a) to use peer support as the foremost educational tool for sharing information, experiences and insights in order to make people with disabilities conscious of the audio, visual and cultural, psychological, social, economic and political oppression and discrimination that they are exposed to, b) to make persons with disabilities aware of their possibilities to reach full equality and participation, c) to empower persons with disabilities by assisting them to acquire the skills to manage their social and physical environment with the goal of full equality and participation in their families and society.

[42] See: Crowther, N. et al (2017) 'Opening up communities, closing down institutions', report by Community Living for Europe: Structural Funds Watch.

be greatly enhanced were steps taken to ensure consistency between European Union policy and guidance and the advice of the UNCRPD Committee in General Comment 5 on the right to live independently and to be included in the community. In particular, adoption of the language contained in Article 19, in place of the language of ‘community-based care’ and greater clarity about the acceptability of congregate modes of care and living would send vital signals to countries in Europe. Centring policy and associated discourse on increasing the choice, control and participation of persons with disabilities, as opposed to transforming the care system, would be advantageous and would help to promote investment in measures such as personal assistance schemes and peer support.

3 Progress towards living independently and being included in the community

3.1 Introduction

This chapter presents key themes emerging from the ANED country studies, illustrated with examples drawn from them, while providing some overall indicators of progress. It considers the current situation and recent trends in the living situation of persons with disabilities and on expenditure on institutional care versus measures in support of independent living. It provides an overview of the relevant commitments, plans and approaches of European States, highlighting promising practices, as well as areas of concern.

3.2 Where are persons with disabilities living?

As has already been outlined, definitional challenges and gaps in data mean that the evidence presented here should be regarded as indicative, rather than conclusive, concerning the scale and nature of institutional care versus support to live independently and to be included in the community.

Sometimes, the existence of institutional care arrangements is explicit and transparent. In the Republic of North Macedonia, for example, the Demir Kapija institution has 227 residents with intellectual disabilities aged 5-85. In many cases, it is not as easily discernible, as a result of definitional challenges or gaps in data. For example, in Denmark the term *botilbud* is applied both to modes of 'supported living' whereby six adults with intellectual disabilities live in a development of self-contained apartments and to a development with 100 self-contained apartments, with onsite catering available and a protected workshop attached. In some countries, it is hidden behind the misappropriation of terminology and the absence or opaqueness of data concerning the living situation of disabled people. The ANED report on Iceland notes that 'it is difficult to find data on the proportions of disabled children and adults residing in institutional or community-based settings. The first issue is that clarity is needed in drawing a clear distinction between what constitutes "institutional care" and "community-based settings."' Hence although the data presented below sometimes indicates *changes* in the living situation of or mode of service provision to persons with disabilities, it is not possible to conclude that such change is emblematic of a shift to persons with disabilities living independently and being included in the community.

3.2.1 Children with disabilities

In a number of European States, children with disabilities are disproportionately more likely to be placed in institutional care than their non-disabled peers and appear far less likely to benefit from efforts to affect a transition from institutional to family-based care.

In Serbia and Slovakia, while there has been significant progress in reducing the number of children in institutional care settings, it appears that disabled children are being left behind. In Slovakia, set against a 6 % overall decline in the number of children in institutional care between 2013-2017, there was a 10 % rise in the

number of children with disabilities in such settings, while the number of disabled children placed with foster families saw little improvement. In Serbia, which has made considerable progress in reducing the capacities of residential institutions for children and young people, over 80 % of the total number of children still in residential institutions are children with disabilities, a trend which has been increasing for several years. In Finland, it is reported that the de-institutionalisation process for children with disabilities has not progressed as well as for adults. The number of children with intellectual disabilities under the age of 18 in institutions has not decreased as planned.

In Denmark, the Ministry of Social Affairs states that around one fifth of the children in alternative care that are in an institution are disabled children.[43] By 2017, there were 2 405 children in institutions and 1 982 children in social educational establishments.[44] While only 250 children were in an institution for children with disabilities, a high proportion of children in other establishments are disabled. For example, in 2016, in 52 % of placements in institutional care, the child's 'challenging behaviour' was the principal determinant, while in 20 % of placements, autism or ADHD was recorded.[45]

A UK study in 2015 found that children with disabilities that are 'looked after' (in the care of the State) were nearly five times as likely to be in a residential placement, compared to all looked after children (59 % versus 12 %), the great majority of them in children's homes and residential special schools. In England, the number of children aged under 18 in specialist hospitals for people with learning disabilities and/or autism rose by 136 % from 110 in March 2015 to 260 in December 2018. [46] In Scotland, 39 % of young people in secure care accommodation on 31 July 2016 had at least one disability.[47]

In 2012, the UN Committee on the Rights of the Child, following its examination of Austria said that it was 'seriously concerned about the high number of children with disabilities in institutional care in the State Party.' It recommended that the State Party 'Take measures to de-institutionalize children with disabilities and further strengthen support to families to enable them to live with their parents.'[48] [49]

While it is reported that Bulgaria achieved a major reduction, of 84 %, in the number of children in institutional care between 2010-16, there is also evidence that many

---

43 https://socialstyrelsen.dk/born/anbringelse/om-anbringelse/anbringelsesformer/dogninstitution.
44 https://www.statistikbanken.dk/ table ANBAAR1.
45 https://www.statistikbanken.dk/ table BU20.
46 Department for Health (December 2018), Learning Disability Monthly Statistics Reference Data Tables December 2018 Table 2.
47 Scottish Government (2017) Children's social work statistics Scotland 2015-16 https://www.gov.scot/binaries/content/documents/govscot/publications/publication/2017/03/childrens-social-work-statistics-scotland-2015-16/documents/00515771-pdf/00515771-pdf/govscot%3Adocument.
48 Committee on the Rights of the Child (2012). Consideration of reports submitted by States Parties under Article 44 of the Convention, Concluding observations: Austria. https://www2.ohchr.org/english/bodies/crc/docs/co/CRC-C-AUT-CO-3-4_en.pdf.
49 Rosenthal, E. (2018) (Disability Rights International, Validity and TASH), 'Position paper: The right to live and grow up in a family for *all* children', December 14, 2018. https://enil.eu/wp-content/uploads/2018/12/DRI-Right-to-Family-December-2018.pdf.

disabled children have been resettled from larger institutions to group homes. For example, between 2007 and 2013, Bulgaria has built 140 group homes for 1 845 children.[50]

3.2.2 Adults with disabilities

Significant numbers of adults with disabilities continue to reside in institutional care arrangements across Europe. Evidence collated for this ANED study does however suggest a gradual shift away from large, more discernible, institutional care arrangements across a number of countries.

For example, between 2013 and 2017, Croatia saw a 33 % reduction in the number of adults with disabilities living in social welfare homes, though this was short of targets set in the country's de-institutionalisation strategy.[51] In October 2018, Inclusion Europe and the European Network on Independent Living (ENIL) together with Human Rights Watch and several Croatian NGOs wrote to Prime Minister Plenković to say that 'the process of moving people out of institutions and into the community has stalled and that no progress has been made on restoring legal capacity'.[52]

In the Czech Republic, the capacity of institutional type settings declined by around 25 % between 2007 and 2016. However, the civil society consortium JDI (Union for De-institutionalisation) has said that in the Czech Republic around 80 000 people live in residential institutions, including children and older persons, of which 79 % (63 200 people) live in large-scale institutional facilities in which people are segregated from their families, communities, public services and everyday life in general.[53]

---

50 See: 'Petition to the European Parliament concerning use of European Structural and Investment Funds to support de-institutionalisation in Bulgaria https://enil.eu/wpcontent/uploads/2019/04/CILPetiton_Fin_200918.pdf.

51 Ministry of Demography, Family, Youth and Social Policy: Monthly statistical report (December 2013) https://mdomsp.gov.hr/UserDocsImages/arhiva/files/75108/Mjese%C4%8Dno%20statisti%C4%8Dko%20izvje%C5%A1%C4%87e%20prosinac%202013.xlsx. Ministry of Demography, Family, Youth and Social Policy: Monthly statistical report (December 2014) https://mdomsp.gov.hr/UserDocsImages/arhiva/files/93576/Mjese%C4%8Dno%20statisti%C4%8Dko%20izvje%C5%A1%C4%87e%20prosinac%202014.xlsx. Ministry of Demography, Family, Youth and Social Policy: Monthly statistical report (December 2015) https://mdomsp.gov.hr/UserDocsImages/dtomasic/Statisticka%20izvjesca/2015/Mjesecno_statisticko_izvjesce_prosinac_2015.xls. Ministry of Demography, Family, Youth and Social Policy: Monthly statistical report (December 2016) https://mdomsp.gov.hr/UserDocsImages/dtomasic/Statisticka%20izvjesca/2016/Mjesecno%20statisticko%20izvjesce,%20prosinac%202016-MDOMSP.xls. Ministry of Demography, Family, Youth and Social Policy: Monthly statistical report (December 2017) https://mdomsp.gov.hr/UserDocsImages/dtomasic/Statisticka%20izvjesca/2017/Mjesecno%20statisticko%20izvjesce%20prosinac%202017.xls.

52 https://inclusion-europe.eu/wp-content/uploads/2018/10/Letter-to-the-Prime-Minister-Plenkovic_final-eng.pdf.

53 JDI- Union for De-institutionalisation (2019) *Zpráva JDI, z. s. o lidech žijících v ČR v pobytových zařízeních.*

Between 2011 and 2017, the number of adults with disabilities living in 'congregate settings' of more than 10 persons in Ireland declined by 40 %, though this again fell short of official targets.[54]

A number of the ANED country studies report either slow or slowing progress since 2013. For example, it is reported that in Italy, progress achieved between 2009 and 2012 was largely reversed in the period to 2015 and there has been no decline in the numbers of people living in institutional arrangements since then.[55] In Lithuania, where a target was set to decrease by 40 % the number of persons with disabilities entering institutional care, the numbers living in institutional care has remained constant since 2013.[56] It is reported that Cyprus and Greece saw only a 2 % decline in the number of adults with disabilities living in institutions since 2013.[57] This small decline may be attributable only to the deaths of residents, which in some countries remains the most common way that persons with disabilities leave institutional care. Following a monitoring visit to Greece in April 2018, the Commissioner for Human Rights observed:

> 'the seriously inadequate staffing of mental health institutions which results in overreliance on the use of physical restraint. It was emphasised that budget constraints should not result in the violation of human rights or marginalisation and encouraged the Greek authorities to use available resources for de-institutionalization and social inclusion of people with mental and intellectual disabilities.'[58]

In its concluding observations on the fourth report from Slovakia (2016), the UN Human Rights Committee expressed concern at the high number of institutionalised persons with disabilities, in particular women and children, and evaluated the progress on deinstitutionalisation in Slovakia as too slow and partial.[59] Similarly, with respect to Poland, where it is estimated that around 80 000 people reside in more than 800 institutions,[60] the CRPD Committee's concluding observations (issued in September 2018) express concerns with regards to the stagnation in the process of

---

54 Health Service Executive (2017) 'Time to Move on from Congregated Settings Policy Implementation Review 2012-2017', p 10.

55 See National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty, *Report to the Parliament 2018* (Garante nazionale dei diritti delle persone detenute o private della libertà personale, *Relazione al Parlamento 2018)* and *Report to the Parliament 2019*; http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub_rel_par.page.

56 Official Lithuania Statistics Portal information https://osp.stat.gov.lt/.

57 National Statistical Service, Greece (2017) (Press Release) Monitoring of Units for Social Care and Protection Table 3 (p.4); Committee for the Protection of the Rights of People with Intellectual Disabilities Annual Reports: http://www.cpmental.com.cy/epnka/page.php?pageID=29&langID=0.

58 Council of Europe, Commissioner of Human Rights (2018) 'Impact of Economic Crisis on Disabled people in Greece' pp. 34-35 https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016809024f7.

59 UN Human Rights Committee (November 2016) Concluding observations on the fourth report from Slovakia. Available at: https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CCPR/C/SVK/CO/4&Lang=En.

60 GUS (2018), Pomoc społeczna i opieka nad dzieckiem i rodziną w 2017 roku.

de-institutionalization including the absence of a strategy, action plan and funding (after termination of EU funds).[61]

Austria[62] and Latvia[63] witnessed no real change in the numbers living in institutions since 2013. There is evidence that in Austria, where 13 000 persons with disabilities live in institutions (including residential and care facilities, ranging from shared group homes for three persons to large residential homes for more than 100 persons) European funding has been used to build and to refurbish institutions for disabled adults (see 3.1.3 below).

The shadow report to the UNCRPD Committee submitted by civil society in Luxembourg says that 'only few efforts have been made to de-institutionalize the areas of housing and living of persons with disabilities. In the absence of a generalized personal assistance system and the absence of an appropriate system of care at for persons with severe physical disabilities, it is not surprising that more than a third of persons with disabilities live in specialized facilities or nursing homes.'[64]

Bulgaria has made little progress with respect to disabled adults, creating the risk that children who have been resettled from institutions to foster homes may, once they reach adulthood, face a return to institutional care, which Bulgaria is continuing to invest in.[65] [66] A similar pattern was reported in Lithuania.

In some countries, while various legal, administrative and practical measures have been put in place in support of the right to live independently and to be included in the community, institutional care continues to co-exist with community-based support and no purposive strategy exists to close such institutions down. For example, in Iceland, the national government has signalled its desire to promote the right to live independently and to be included in the community and overall the data suggests a slow shift away from small group homes with shared common spaces to more private service apartments in conjunction with the introduction of user-led personal assistance that allows some persons with disabilities to live in their own

---

61 Committee on the Rights of Persons with Disabilities (September 2018) Concluding observations on the initial report from Poland. https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fPOL%2fCO%2f1&Lang=en.

62 Federal Ministry of Labour, Social Affairs and Consumer Protection (BMASK) (2016) 'National Action Plan on Disability 2012-2020', p. 83. https://broschuerenservice.sozialministerium.at/Home/Download?publicationId=225. BMASK (2016). Bericht der Bundesregierung über die Lage von Menschen mit Behinderungen in Österreich 2016, Wien, p. 118. (in German).

63 Official statistics in the field of social services and social assistance. Annual reports. Available at: http://www.lm.gov.lv/lv/publikacijas-petijumi-un-statistika/statistika/valsts-statistika-socialo-pakalpojumu-un-socialas-palidzibas-joma/gada-dati.

64 Alternative Report on Implementation of the United Nations Convention on the Rights of Persons with Disabilities Luxembourg 2016.

65 Bulgarian Helsinki Committee (2016) *Unhappening Deinstitutionalization of Persons with Mental Disabilities*, pp.12-13, available at: http://www.bghelsinki.org/media/uploads/documents/reports/special/2016_nesluchvashtata_se_deinstitucionalizacia_na_licata_s_umstveni_zatrudnenia_v_bulgaria_[978-954-9738-37-7].pdf.

66 BG-Country report, p. 22 https://enil.eu/news/bulgaria-must-suspend-the-construction-of-68-institutions-for-the-disabled/.

homes. However, municipalities have delegated responsibilities for housing and services, with small group homes continuing to be common practice. Further, there is no indication that the small remaining number of larger institutions, such as Skálatún, near Reykjavik, an institution for people with intellectual disabilities that houses 40 individuals in a collection of 6 onsite group homes, will close. In Germany, over 350 000 people live in 'assisted living' or residential homes with the majority aged between 18-65.[67] In its concluding observations on the initial report from Germany in 2015, the UNCRPD Committee expressed concern about 'the high levels of institutionalization and the lack of alternative living arrangements or appropriate infrastructure.'[68]

Following long-term declines in the numbers of adults with intellectual disabilities in institutional care in the United Kingdom, it is reported that progress has slowed or stalled in recent years.[69] In Finland, it is reported that the objective of reaching full de-institutionalisation of persons with disabilities by 2020 is at risk.[70] In particular, the Finnish report refers to the difficulties that have been experienced in advancing independent living for people with the most severe impairments or with extensive support needs. In other European States such as Liechtenstein, Luxembourg, Poland and Spain, an explicit distinction appears to have been drawn on this basis between those deemed suitable or unsuitable for community-based living. For example, the ANED report for Liechtenstein advises that the country has concluded agreements with its neighbouring states, Austria and Switzerland, to provide special care and assistance to persons with 'very severe cases of disability' on the basis that such care cannot be fully provided nationally. The Partnership Agreement in Poland says that institutional care facilities for persons with significant intellectual disabilities cannot be included among those undergoing de-institutionalisation on grounds of cost.[71]

The Spanish campaign organisation Full Inclusion has been specifically established to challenge such positions, noting how:

> 'Expressions are often heard: "for them those models do not work", "this is fine for some, but not for ALL", "with mine this does not make sense", etc. It gives the impression that it assumes that essential issues of human dignity (for example self-determination, participation, inclusion, living according to a valuable life project ...) do not belong to them.'[72]

---

67 Children and youth statistic (Statistik der Kinder- und Jugendhilfe) 2014, social welfare statistic (Sozialhilfestatistik) 2014, care statistic (Pflegestatistik) 2013, Institut für Sozialforschung und Gesellschaftspolitik GmbH.

68 Committee on the Rights of Persons with Disabilities (2015) Concluding observations on the initial report of Germany https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/096/31/PDF/G1509631.pdf?OpenElement.

69 NHS England, LGA, ADASS (2015) 'Building the Right Support a national plan to develop community services and close inpatient facilities for people with learning disability, including those with a mental health condition'.

70 STAKES, 2001, Mietola, R. ym. (2013) Kehitysvammaisten ihmisten asumisen tulevaisuus: kansainvälisiä esimerkkejä ja vertailu Suomeen. Helsinki. Ympäristöministeriö.

71 Partnership Agreement, https://www.poir.gov.pl/media/9498/Partnership_Agreement.pdf, p. 42.

72 http://www.plenainclusion.org/informate/campa%C3%B1as/todos-somos-todos.

In Finland and Ireland, length of stay in institutional care settings, or the age of people, appears to have influenced whether or not people have benefited from measures to transition from institutional care to community-based alternatives.

In other fields, such as employment support, these patterns have been referred to as 'creaming and parking', whereby only the so-called 'easiest to reach' are targeted for particular programmes and there is evidence of this phenomenon in the context of the transition from institutional care to independent living. Such patterns also transform the population make-up of those who remain living in institutional care, including a concentration of older persons in such settings as younger residents are resettled.

Some reports indicate an upward trend in the numbers living in institutional care settings. In Romania, for example, between 2013 and 2018 there was a 5 % increase in the number of persons with disabilities housed in adult institutional care centres, set against an already high number of persons with disabilities living in such settings (18 015 people were residing in adult institutional care centres in September 2018).[73] In Estonia, over the period 2013-2017, the number of disabled service users in general care nursing homes increased by almost 20 %.[74] As with Spain, where an upward trend in numbers living in institutional settings is also reported,[75] the increase in Estonia may relate to growth in the number of older persons: over the same period the total number of persons with disabilities aged 63 or over increased by 28 %.[76]

In France, between 2010 and 2014 the number of disabled adults living in institutions increased by 6 %, from 161 284 to 172 308.[77] The insufficiency of community based services and consequent demand for institutional placements has driven families to find places in institutes in Belgium (6 109 adults and 1 444 children on 31 December 2017).[78] Following her October 2017 visit to France, the UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas-Aguilar, reported (January 2019) that France continues to promote the placement of disabled people, especially those considered to have 'severe disabilities', in institutions. She noted that the continuing high demand for places in institutions was due to 'the Government's inability to provide alternative independent living arrangements for persons with disabilities, including a sufficient number of quality support services in the cities and communities where they live, and the lack of social

---

73 National Authority for Disabled Persons. Statistical data for the 30th of September 2018. http://anpd.gov.ro/web/wp-content/uploads/2019/01/BULETIN-STATISTIC-ANPD-TRIM-III-2018-1.pdf.

74 Ministry of Social Affairs Estonia, welfare data.
María José Alonso Parreño (2015) The right to independent living and its realisation in Spain – a far horizon for persons with disabilities?
http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx.

76 Ministry of Social Affairs Estonia, welfare data.

77 DREES, Enquête ES-Handicap 2014 and 2010.

78 Interministerial Committee for Disability (Comité interministériel du handicap), https://handicap.gouv.fr/le-secretariat-d-etat/acteurs/comite-interministeriel-du-handicap-cih/

awareness of the rights of persons with disabilities to live independently in the community.'[79]

In England, levels of detention under the Mental Health Act rose sharply by 47 % between 2005/6 and 2015/16, prompting the UK Government in 2018 to commission an independent review of the Mental Health Act 2003 with a particular focus on reducing detention.[80] Of the 3 000 people with intellectual disabilities who were in specialist inpatient units on the date of the 2015 Learning Disability Census, 83 % were subject to the Mental Health Act 1983.[81] Of those in hospital at the end of December 2018 in England, 1 335 (57 %) had a total length of stay of over two years.[82] In Malta, the mental health strategy consultation document states that Malta had the largest increase in the average length of stay in hospital for persons with severe mental health problems in the EU, having risen from 34 to 47 days between 2010 and 2015.[83]

In some countries that are considered to have already made significant inroads into moving away from large-scale institutional care, there are signs of supposedly community-based living arrangements beginning to assume more institutional features. For example, the Norway report includes data showing that the proportion of people with intellectual disabilities living in large group homes (with seven or more) increased from 3 % in 1994 to 40 % in 2010, while the average size of group homes increased from 3.8 persons in 1994 to 7 persons in 2010.[84] It also reports that there is a trend in which several group homes or housing facilities for different target groups are co-located, often linked to so called 'care bases' with available personnel. Some such social housing projects consist of more than one hundred municipal rental homes (Hansen and Grødem 2012).[85] The Norway ANED report goes on to note: 'While many adults with intellectual disabilities who used to reside in institutional care settings generally celebrate the shift to group homes, it is reported that the opportunity for the persons affected by the reform to choose their place of residence and where and with whom they should live was and continues to be very limited.'[86]

---

79 https://documents-dds-ny.un.org/doc/UNDOC/GEN/G19/002/69/PDF/G1900269.pdf?OpenElement.

80 HMG (2017) Modernising the Mental Health Act – Increasing choice, reducing compulsion https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/762206/MHA_reviewFINAL.pdf.

HSCIC (2016) Learning Disability Census (2015) further analysis report https://files.digital.nhs.uk/publicationimport/pub20xxx/pub20247/ld-census-further-sep15-rep.pdf.

82 NHS Digital (December 2018) Learning Disability Monthly Statistics Reference Data Tables December 2018 Table 2 https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/provisional-statistics-at-december-2018-mhsds-october-2018-final#resources.

83 Office of the Deputy Prime Minister and Ministry for Health (2018) *Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030. Public Consultation Document*. Available at: https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx.

84 Tøssebro et al. (2012) https://onlinelibrary-wiley-com.eazy.uin.no/doi/pdf/10.1111/j.1741-1130.2012.00340.x.

85 https://www.regjeringen.no/globalassets/upload/krd/rapporter/fafo-rapport.pdf?id=2325685.

86 https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1540971.

A similar trend towards congregate or 'clustered' living arrangements has been detected in the United Kingdom.[87] This is discussed in more detail at 4.2.1. Following its examination of Denmark in 2014, the UNCRPD Committee expressed concern at the 'the increased construction, by municipalities, with State-guaranteed loans, of large institution-like residences for persons with disabilities, with thirty to sixty or even more residents, often outside city centres.'[88] It is reported that new residential housing is often built as homes for 30 or 60 persons, and a number of residential homes have their own sheltered workshops where the citizens are offered jobs. In Italy, the scale of individual residential homes is being permitted to grow in some regions. For example, the 'Decreto Dirigenziale' No 3 of the regional government of Campania, (03/01/2019), decrees that the capacity of residential facilities for disabled adults that require care and support is a maximum of 120 beds.

Across many European States, a common living arrangement for disabled adults who require support is to live with family, most often with parents. In the UK, living with family is the most common living arrangement among adults with learning (intellectual) disabilities aged 18-64 who are in receipt of long-term support from local authorities.[89] A study by the UK NGO Mencap found that around 70 % of people in this situation wanted more independence and to change their housing situation to achieve this.[90] This is also reported to be a common situation in Spain for example, particularly in rural areas, where 'long-term care…is characterized by low intensity of residential care, high levels of informal care, and low levels of community care'[91] as well as in Luxembourg. In Portugal, where it is reported that the closure of large psychiatric hospitals has not been matched by a corresponding increase in community-based services, the majority of people with psychosocial disabilities are cared for by their families. In Poland, where the dominant model of support for persons with disabilities is to live with their families, research finds that among persons with disabilities who live with their parents, 46 % declare a desire to live independently, yet only 63 % of those people believe it will be possible. The biggest obstacles to independent living identified by this group are financial issues (50 %) and support/care needs (30 %).[92] The focus of policy on a transition *from institutional care* and the lack of data on the life situation of those who no longer reside, or who have never resided in large-scale institutions, risks overlooking this significant gap in implementation of the right to live independently and to be included in the community.

---

87 National Audit Office (2017) *Local support for adults with a learning disability* https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf.

88 UN Committee on the Rights of Persons with Disabilities (October 2014) Concluding observations on the Initial Report of Denmark.

89 NHS Digital Short and Long Term Support (2018) https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-collection-materials-2018#short-and-long-term-support-salt-.

90 Mencap (2012), 'Housing for people with a learning disability'. Available at: https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf.

91 https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf.

92 Sochańska-Kawiecka et al. (2017), Badanie potrzeb osób niepełnosprawnych, https://www.pfron.org.pl/fileadmin/Badania_i_analizy/Badanie_potrzeb_ON/Raport_koncowy_badanie_potrzeb_ON.pdf.

Finally, unmet need is a growing concern in a number of European States. For example, Emerson et al. (2012) produced projections of the number of adults with learning disabilities likely to need social care support in England up to 2030. Even under the most restrictive funding scenario (with only people with critical or substantial needs getting social care support) it was estimated that by 2018 there would be 166 114 adults with learning disabilities needing social care support, compared to the 147 920 adults actually getting long-term social care support in 2017/18.[93] In Greece, based on current capacity, it is estimated that three places are available in the new sheltered living schemes for every 200 individuals with intellectual disability in Greece.[94] It is noted that in Slovenia, existing non-governmental services cannot fulfil the great need of persons with disabilities who already live in the community, not to mention people who will potentially come out of large institutions and need services (Zaviršek et al. 2015).

3.3 Expenditure on institutional care versus living independently and being included in the community

3.3.1 Balance of spending and recent trends

Institutional modes of care continue to consume disproportionate and growing levels of public expenditure, including in States where significant amounts of care and support are delivered outside of discernible institutional care settings.

Only one ANED country report, Finland, reports higher spending on assisted living than on institutional care, spending five times as much on the latter than on the former in 2016.[95]

Other countries appear to be moving in this direction, albeit gradually. For example, the ANED country report for Slovakia reports that between 2013-16, total spending on social care facilities (institutional care) declined by 15 % (from EUR 165.1 million in 2013 to EUR 139.9 million in 2016). At the same time, spending on a range of community-based care increased. For example, there was a 340 % increase in spending on day-care services between 2014-18 from EUR 2.7 million in 2014 to EUR 12 million in 2016. Expenditure on domiciliary care increased by 38 % (to EUR 18.7 million) between 2013-18, while spending on personal assistance increased by around 40 % (EUR 3.2 million to EUR 5.4 million). Despite this, spending on community-based care continues to represent a fraction of that spent on institutional care. Norway has seen a gradual reallocation of resources from traditional services towards user-controlled personal assistance (BPA), especially

---

93 Hatton, C. (2019) 'Where are we at with social care for adults with learning disabilities?' https://chrishatton.blogspot.com/2019/01/where-are-we-at-with-social-care-for.html referencing Emerson, E. et al (2012) *Estimating the need for social care services for adults with learning disabilities in England 2012-30*.
EYSEKT (2017) Study for the Support Living Shelters in ESIF 2014-2020 p. 19 based on data from the Ministry of Health, Disability Department in 2011 where the number of persons with intellectual disabilities was just over 18,000 (Table 9).

95 THL/SVT Tilastoraportti/FOS Statistikrapport/OSD Statistical Report 5/2015.
& TilastoraporttiSVT: 13/2018. THL/SVT.

after BPA became an individual right (under certain conditions) provided in the Patient and User Rights Act (§ 2-1 d) from 2015.[96]
While overall spending on care and support in Estonia has increased significantly since 2013, spending on institutional care continued to hugely outstrip spending on independent living. Between 2013-17 spending on general care in institutions increased from EUR 41.4 million to EUR 61.2 million, while spending on special care in institutions increased from EUR 19.8 to EUR 24.7 million. This compares with total expenditure on services supporting independent living that increased from EUR 11.8 million to EUR 17.1 million euros. In Slovenia, expenditure on institutional care in 2017 was EUR 295.7 million, compared with EUR 51.8 million on community-care services, a pattern that has changed little since 2013.[97] In 2016, the Commissioner for Human Rights, in a letter to the Czech prime minister, expressed his concerns about more resources being invested in institutional settings than in support services that would enable persons with disabilities to live independently.[98]

Regarding Belgium, the EU Agency for Fundamental Rights reported (2017) that in Flanders EUR 992 million went to residential services for disabled people, in comparison with around EUR 120 million allocated to services including family-type housing, assisted housing and support in the family in 2013. While comparable data are not available for 2017-18, the Belgium ANED report concludes that 'there is no downward trend in subsidising institutional care for persons with a disability.' A similar pattern was identified in the Walloon region.

Statistics Denmark reports that spending on adult institutions consumed 59 % of all spending on services for disabled people, amounting to EUR 3.12 billion in 2018. This is contrasted with EUR 812 million on personal support and care for persons with disabilities and EUR 196 million on technical aids.[99]

According to the Netherlands Institute for Social Research, total expenditure on residential long-term care was EUR 16.6 billion in 2017, compared with EUR 7.8 billion on social support in the community by municipalities for disabled people.[100] The ANED report on Italy also reports a 'structural disequilibrium' in funding, favouring institutional care.

---

96 https://lovdata.no/dokument/NL/lov/1999-07-02-63/KAPITTEL_2#KAPITTEL_2.

97 Andreja Rafaelič, Katarina Ficko in Vito Flaker (2017), 'The Transition to Community-Based Care in Slovenia' [Prehod k skupnostnim oblikam oskrbe v Sloveniji], *Social Pedagogy*, 21 (3–4): 183-210. P. 198.

98 Council of Europe Commissioner for Human Rights (2016) *Letter to the Czech Prime Minister.* Strasbourg, October 7, 2016.

98 Czech Republic, Public Defender of Rights (2018) *Dostupnost sociálních služeb pro osoby s poruchou autistického spektra.* *https://www.ochrance.cz/fileadmin/user_upload/CRPD/autismus/Vyzkum-autisti.pdf.*

99 https://www.statistikbanken.dk/ table BUDK 32, budget accounts 5.32.35-5.38.59.

100 SCP the Netherlands Institute for Social Research (2018), Evaluation report on reforming long-term care *Veranderde zorg en ondersteuning voor mensen met een beperking. Landelijke evaluatie van de Hervorming Langdurige Zorg*, (Changing care and support for people with a disability, national evaluation of the reform of long-term care), June 2018. https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2018/Veranderde_zorg_en_ondersteuning_voor_mensen_met_een_beperking.

In England, spending on residential and nursing care accounted for 64 % of expenditure on long-term support for those aged 65 plus in 2017/18.[101] With respect to adults of working age with intellectual disabilities in receipt of long-term support, residential care accounted for just over one third of all expenditure on long-term support for adults with intellectual disabilities in 2017/18 (down from 44 % in 2003/4).[102] Residential care for adults with learning disabilities in England is expensive: intellectual disability support in residential or nursing homes has the highest unit cost of all groups in receipt of residential care (GBP 1 359 per person per week for those aged 18 to 64, and GBP 868 for those aged 65 and over).[103]

Fiscal retrenchment through the 2010s, following the financial crash of 2008, has fallen disproportionately on services and support for persons with disabilities in some European States. It is reported that in Italy, some regional policies continue to promote the institutionalisation of disabled people, and in some cases their re-institutionalisation as a consequence of austerity measures. For example, in the Marche region, Resolution 1260/2013 of the Regional Council establishes that residential units for persons with disabilities must not have fewer than 20 beds and recommends the merger of 20-bed units in residential facilities accommodating no fewer than 40-60 residents. In Tuscany, two big institutions for persons with intellectual and developmental disabilities are under construction: in Empoli and Pisa, the first one providing 20 places in a residential service and more than 60 places in a day service, the second one providing 100 places in a residential service and 400 places in a day service.

In the UK, the National Audit Office (2018) reported that

> 'Continued pressures on authorities' budgets (in England) may have an adverse effect on services for people with a learning disability. Authorities face a 7.8% real-terms cut in spending power between 2015-16 and 2019-20. The Association of Directors of Adult Social Services budget 2016 survey reported that authorities are considering cutting social care services. Nearly one-third of these cuts (where identified by type of service) will affect learning disability services.'[104]

The UNCRPD Committee has conducted both an Inquiry into the impact of the UK government's 'austerity' policies on the implementation of CRPD Article 19 and examined the implementation of Article 19 via its examination of the UK in August 2017. In its Inquiry report, the CRPD Committee observed that:

> 'the interaction of various reforms on welfare schemes … have disproportionately affected persons with disabilities and hindered various aspects of their right to live independently and be included in the community.'

---

[101] NHS Digital (2018) *Adult Social Care Activity and Finance Report (England) 2017-18*
[102] National Audit Office (2017) *Local support for adults with a learning disability.* https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf.
[103] National Audit Office (2017) *Local support for adults with a learning disability.*
[104] National Audit Office (2017) *Local support for adults with a learning disability*. https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf.

The Committee went on to express concern that:

> 'the set of reforms has limited the right of persons with disabilities to choose their residence on an equal basis with others, resulting in persons experiencing increasing reliance on family and/or kinship carers, reduction in their social interaction, increased isolation and, in certain cases, institutionalization. The deinstitutionalization process in the State party has been adversely affected.'[105]

Britain's national human rights institution, the Equality and Human Rights Commission, has analysed the cumulative impact of Government spending cuts on the living standards of disabled people. It found that by 2020/21:

> 'In England, households with more disabilities (measured by the number of functional disabilities recorded across all household members) suffer much larger losses (over £2,900 per year) than those with fewer disabilities, largely because of social care cuts.'[106]

Following a country visit to Sweden, the Council of Europe Commissioner for Human Rights expressed concern that 'As a result of the decrease in state-funded personal assistance, a trend towards re-institutionalisation has been reported.'[107]

3.3.2 Use of EU Funding to develop institutional care

During the course of this study, a small number of instances have been identified where European Union funding has been used to develop or refurbish what clearly appear to be institutional care facilities.

For example, in Austria, examples have been identified where, with funding from the European Union's Agricultural Fund for Rural Development, institutions are being developed or refurbished. In Upper Austria, a new residential home is being built for 16 persons with disabilities, while a run-down old residential home for 8 persons with disabilities is being substituted by a new facility for 16 persons. In Burgenland, a residential home for 15 persons with disabilities is being refurbished and enlarged.[108]

It is reported that in Greece, the 'Strategy of the Region of Attika' is the only document available that addresses de-institutionalisation as a distinct policy

---

[105] Committee on the Rights of Persons with Disabilities (October 2016) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 6 of the Optional Protocol to the Convention – report of the committee* https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/326/14/PDF/G1732614.pdf?OpenElement.

[106] Reed, J., Portes, J. (November 2018) 'The cumulative effect on living standards of public spending changes', Equality and Human Rights Commission.

[107] Report by the Commissioner for Human Rights of the Council of Europe following his visit to Sweden 2-6 October 2016 https://rm.coe.int/commdh-2018-4-report-on-the-visit-to-sweden-from-2-to-6-october-2017-b/16807893f8.

[108] European Semester 2018/2019 country fiche on disability, p. 27, https://www.disability-europe.net/country/austria (publication date 4 March 2019).

measure, simultaneously linked with the use of ESIF. Enhancing the infrastructure and programmes of institutions is outlined as a co-existing measure, seemingly in violation of ESIF regulations and the European Union's obligations arising out of the UNCRPD.

4 What are ANED countries doing to implement the right to live independently and to be included in the community?

4.1 Commitments, goals and targets

In setting out the immediate obligations of States Parties arising from Article 19 of the UNCRPD, the CRPD Committee General Comment 5 says that States Parties must:

> 'enter into strategic planning, with adequate time frames and resourcing, in close and respectful consultation with representative organizations of persons with disabilities, to replace any institutionalized settings with independent living support services. The margin of appreciation of States parties is related to the programmatic implementation, but not to the question of replacement. States parties should develop transitional plans in direct consultation with persons with disabilities, through their representative organizations, in order to ensure full inclusion of persons with disabilities in the community.'[109]

Many ANED countries have made explicit policy commitments that are connected to the right to live independently and to be included in the community, or to family-based care for children. These overwhelmingly focus on measures to reduce the numbers of children and adults residing in institutional care and/or to increase the capacity and uptake of what are described by the countries as 'community-based services'. The ANED study did not identify any targets that focused specifically on transforming the lived experience of disabled people, though some countries have measured this in the context of specific de-institutionalisation projects.

As this report will go on to discuss, the selection and framing of targets, coupled with the challenges many States appear to be having in achieving them and pressure to spend EU funds within certain deadlines may be creating perverse incentives towards replacing large-scale institutional care arrangements with alternatives that do not fully accord with Article 19 of the UNCRPD.

A number of European States presently have no explicit goals, targets or strategies concerning independent living.

4.1.1 Targets to reduce or eliminate institutional care

In Finland, the KEHAS programme (the Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015) aims to ensure that no one lives in an institution after the year 2020. It has set targets concerning the numbers of adults with intellectual disabilities that should benefit from community-based living in order to move out of their childhood homes or institutions.[110] Latvia plans to reduce the number of persons living in institutions by 1 000 by the end of 2023 and

[109] UNCRPD Committee (2017) General Comment 5 on the Right to Live Independently and to be Included in the Community https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en.

[110] KEHAS (the Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015, *Kehitysvammaisten asumisohjelma*).

at least three state institutions are planned to be closed as a result of the project implementation.[111] In Romania, the National Interest Program (NIP) initially set a target date of the end of 2018 for the de-institutionalisation of 1 300 disabled people. The Government has since modified the NIP, changing the start date to 2018 and the target to the de-institutionalisation of a minimum of 400 young persons with disabilities by 2020.[112] Hungary originally set a target of 2041 to complete its de-institutionalisation process but has since revised it to 2036. Bulgaria has committed to eliminate all forms of institutional care for children, setting a target of 2025 to do so.[113] By way of contrast, with respect to working age and older persons with disabilities it has committed 'to close in the next twenty years all functionally outdated specialized institutions for elderly people and Persons with Disabilities, in case they do not correspond to the current needs of the target groups.'[114]

In Ireland and England, de-institutionalisation strategies and plans are focused on people with learning intellectual disabilities and/or autism. Ireland set a target to close all congregated settings for this group within a seven-year timeframe (2011-2018).[115] This target would have meant transferring 500 people per year from 2011-2018. The target was not met, however. In England, a target was set in 2015 to have closed 35-50 % of in-patient provision for people with intellectual disabilities and/or autism by March 2019, but it has recently been extended to April 2023.[116]

4.1.2 Targets to change the ratio of institutional to community-based care

Both Estonia and Slovenia have set targets concerning the ratio between institutional care and community-based living. In Slovenia, the current ratio is approximately 2:1 (two persons living in long-stay institutions and one in community-care settings). The country is aiming at 1:1 by the year 2020. In Estonia, the ratio of persons who receive 'open care services' and of persons receiving day-and-night institutional care services in 2014 was 1:4 and the target for 2023 is 2:2.[117]

---

[111] The Action Plan for Implementation of Deinstitutionalisation 2015-2020, 2015. Available at: http://www.lm.gov.lv/upload/aktualitates/4/ricplans_groz_22032016.pdf.

[112] Ministry of Labour and Social Justice, (2018) 'Inca 50 de centre de zi si 80 de locuinte protejate pentru tinerii si adultii cu dizabilitati printr-un program de interes national', press release, 4 April 2018. http://www.mmuncii.ro/j33/index.php/ro/comunicare/comunicate-de-presa/5109-cp-pin-2-dizabilitati-04042018.

[113] Government of Bulgaria, (2010) 'National Strategy - Vision for deinstitutionalisation of children in Bulgaria', available at: http://sacp.government.bg/bg/evropejski-programi-i-proekti/proekt-detstvo-za-vsichki/nacionalna-strategiya-viziya-za-deinstitucionalizaciya-na-decata/; Council of Ministers: Action Plan for implementation of the National Strategy - Vision for Deinstitutionalisation of Children in Bulgaria 2016-2020"adopted October 2016 and Council of Ministers: 'National Strategy for Long-Term Care', adopted by Decision № 2 on 7 January 2014, available at: http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=882.

[114] Government of Bulgaria (2014) 'National Strategy for Long-term Care', p.16.

[115] HSE (2011), 'Time to Move on from Congregated Settings – A strategy for Community Inclusion' 2011, p.121.

[116] NHS England (2018) NHS Long Term Plan, para 3.34.

[117] Welfare Development Plan https://www.sm.ee/sites/default/files/lisa_3_hoolekandeprogramm_2019_2022_0.pdf.

4.1.3 Targets to increase the availability of and access to 'community-based services'

A number of ANED countries have set specific targets concerning the 'community-based services' that they propose to develop and/or the number of people they expect to access such services. It is important to note that in this context 'community-based services' are those defined as such by individual countries and hence may not conform with Article 19 of the UNCRPD.

For example, in 2016, Romania set targets for the creation of 75 new protected dwellings, 76 day-care centres and 8 new respite/crisis centres. The Government has since changed the start date to 2018 and to now provide for the establishment of 80 new protected dwellings and 50 day-care centres, coupled with the de-institutionalisation of a minimum of 400 young persons with disabilities by 2020.[118]

Bulgaria aims to establish the provision of new services for more than 2 000 disabled and older persons who require care, the provision of care through social services in domestic environments for more than 17 000 disabled and older people, and the provision of quality care and support in new community services for a minimum of 750 persons with psychosocial disabilities and intellectual disabilities who have been resettled from institutional care. It also aims to improve the capacity of the staff and specialists in the system for long-term care.[119]

In Latvia, it is planned to carry out an assessment of individual needs for 2 100 adults with mental impairments and for those people to receive social care services at their place of residence by December 2023.

4.1.4 No explicit targets

Some European States, including Austria, Belgium, Denmark, Montenegro, the Netherlands, Poland and Spain, while being parties to the UNCRPD and with significant and in some cases growing numbers living in institutional care settings, do not appear to have made an explicit domestic policy commitment to de-institutionalisation. In Denmark, there is no current policy or approach related to de-institutionalisation, despite institution-like conditions persisting. Similarly, it is reported that in the Netherlands, despite high numbers of people living in institutional care arrangements, that there is no awareness among policymakers, care providers and DPOs about the imperative of Article 19 CRPD to transition from institutional care to community-based support. While the reform of long-term care was prompted by the high costs of residential care in the Netherlands, it was not an aim, nor has it been an outcome to significantly reduce the proportion of persons with disabilities living in residential care. Despite the availability of direct payments, the majority of people eligible for long-term care are offered places in group homes, with shared living rooms and the necessity to accept shared care workers without

[118] Ministry of Labour and Social Justice (2018) 'Inca 50 de centre de zi si 80 de locuinte protejate pentru tinerii si adultii cu dizabilitati printr-un program de interes national' press release, 4 April 2018. http://www.mmuncii.ro/j33/index.php/ro/comunicare/comunicate-de-presa/5109-cp-pin-2-dizabilitati-04042018.

[119] Government of Bulgaria, 'Action Plan for Implementation of National Strategy for Long-term Care (2018-2021)', p.37. http://www.strategy.bg/PublicConsultations/View.aspx?lang=bg-BG&Id=3108.

free choice. Following its examination of Luxembourg, the UN Committee on the Rights of Persons with Disabilities expressed concern at 'the lack of an action plan for the deinstitutionalization of persons with disabilities with a specific timeline and appropriate funding' and 'the absence of a clear strategy to promote and ensure the transition to full independent living for all persons with disabilities within the community, including with support of a personal assistant, and that future plans and construction projects still contain elements that limit the rights of persons with disabilities under Article 19.'[120]

While some States have made a rhetorical commitment to de-institutionalisation at a national level, it has not led to action at the local level. For example, the *National Action Plan on Disability* in Austria says: 'a comprehensive deinstitutionalisation programme is necessary in all nine Länder. In this process, large institutions need to be broken down and at the same time support services created which also enable people requiring a high level of support to lead an independent life in their own homes.' [121] However, this has led to no action to date, reflecting a challenge experienced in other States, including Iceland and the UK, where regional and municipal government enjoys a high degree of autonomy from national government.

In Poland, which is among 12 EU Member States for whom the European Commission identified a need for measures aimed at the shift from institutional to community-based care,[122] the Partnership Agreement includes sections on support for community-based services that acknowledges that institutional care dominates service provision. It mentions protected, assisted and council housing as tools for community-based support. However, it also states that it is appropriate to continue support for institutional forms of care in certain cases (e.g. children and adults with a high degree of mental disability).[123] There are no specific targets or milestones attached to these commitments. Similarly, it is noted in the country report for the Czech Republic that commitments contained in national strategies and plans are not elaborated in targets and milestones and hence it is not possible to monitor progress.

4.2 Approaches to implementation

4.2.1 Alternative living arrangements

A common approach proposed or planned by many European States is to resettle the current residents of institutional care facilities into smaller-scale modes of congregate living and support, often in the absence of parallel efforts to make

[120] UNCRPD Committee on the Rights of Persons with Disabilities (2017) Concluding observations on the initial report of Luxembourg (CRPD/C/LUX/CO/1) http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsvP%2BdTiDrgtVuqxAW%2B69tiKIXBXKWmNQXT%2Fmo%2FEyFUOnby%2FrpQIV67BUhoNbCdpCAc7SlOMvANsJafd2PwWE94G0Lo9Ob7OZ%2BGyAGRg9cMMl.

[121] Federal Ministry of Labour, Social Affairs and Consumer Protection (BMASK) (2016) National Action Plan on Disability 2012-2020, p. 84. https://broschuerenservice.sozialministerium.at/Home/Download?publicationId=225.

[122] FRA (2017), 'From institutions to community living Part I: commitments and structures', https://fra.europa.eu/en/publication/2017/independent-living-structures.

[123] Partnership Agreement, https://www.poir.gov.pl/media/9498/Partnership_Agreement.pdf, p. 42.

available the opportunity to choose an ordinary home of their own in the community or the option of choosing one's own support arrangements.

Sometimes such measures are framed as intermediate or 'step down' arrangements. For example, in Estonia, it is suggested that 'Given the difficulties in immediate integration of former residents of large institutions into communities, an intermediate step taken is the formation of smaller units located in communities, which provide a range of services and activities.' It is planned that service locations with more than 30 places are reorganised and that accommodation will be arranged in smaller units to facilitate living in a community. In Slovakia, group supported housing facilities are designed to offer a transition between residing in a large-scale institution and a person living in their own home. However, while support for independent living to enable a person to live in his or her own home also exists, it is not commonly available or provided across Slovakia's municipalities. In Serbia, an EU funded project saw 12 people move into smaller accommodation units within institutions where they received training and support with daily living skills, such as food preparation and cooking, in preparation for living independently in the community. They spent 18 months in this 'half-way house' before moving to supported living in the community. There are presently eight people in the units undergoing preparation for community-based living.

In a number of countries, it would appear that group living arrangements are conceived of as a permanent alternative to larger scale institutional care. To that end, the Czech Republic, Greece, Hungary, Lithuania, Poland and Slovenia have all developed or plan to develop group homes via programmes that are all substantially funded by ESIF. In its report, 'Opening up communities, closing down institutions' Community Living for Europe: Structural Funds Watch' argued that:

> 'high levels of investment in these smaller scale models of institutional care will act as an obstacle to further reform and continue to deny people their rights.'

In October 2018, the European Association of Service Providers for Persons with Disabilities (EASPD) published a report on the implementation of the European Pillar of Social Rights in Austria, noting that: 'The nine Länder responsible for legislation and funding of social services have a different understanding of what community-based services mean. Some of them are now replacing bigger institutions by smaller ones (e.g. institutions of 120 persons are transformed into 4 institutions for 30 persons).'[124]

In Finland, the KEHAS programme[125] aimed to bring about community-based living with necessary support for 3 600 persons with intellectual disabilities between 2010 and 2015, enabling them to move out of their childhood homes or institutions. However, an evaluation of the programme found that the new community-based

[124] EASPD (2018) 'Support services as key players in the implementation of the European Pillar of Social Rights', EASPD report on the European Semester and the European Pillar of Social Rights, 4 http://www.easpd.eu/sites/default/files/sites/default/files/Publications/easpd_report_on_es_and_epsr_-_october_2018.pdf.

[125] KEHAS (the Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015, *Kehitysvammaisten asumisohjelma*).

housing largely consisted of group homes with places for 15 or more residents, while the development of more decentralised housing solutions had been modest.[126] According to SOTKAnet statistics, two thirds of housing alternatives for persons with intellectual disabilities are group homes.[127]

In the Republic of North Macedonia, during the first phase of de-institutionalisation, a number of people were resettled in individual apartments with individualised support, based on the will and preferences of the individuals involved. In the second phase all persons were resettled in the group homes in Radishani and Volkovo, villages on the edge of Skopje urban area. In the shadow report[128] sent by DPOs and CSOs from the Republic of North Macedonia to the UN CRPD Committee it was argued that:

> **'**The so-called "independent living with assistance" services are group homes concentrated in two municipalities. Unfortunately, these services are considered as final solution, instead of being intermediary structures that later would be transformed into real independent living.'

In Lithuania, in 2017, 5 group homes accommodated 108 residents, and 23 group homes in the community for disabled people accommodated 469 residents. In Greece, in 2017, 267 individuals with intellectual disabilities were accommodated in 42 units across Greece.[129] In Slovenia, people have been resettled from larger institutions to 'dislocated units' of 20-25 persons or group homes (4 to 8 persons). Turkey has been developing 'Hope Houses' where up to 6 people with disabilities live together as an alternative to financial support being directed towards care undertaken by families. It is reported that 'the majority of the newly offered residential system is nothing but the reproduction of previous institutional culture on a smaller scale, i.e. group housing units.'[130]

To facilitate this 'downscaling' from larger institutions to smaller scale congregate living arrangements, a number of ANED countries have set caps on the numbers of persons with disabilities that can reside in the same setting. These caps range from 4 to 50 persons. Others discourage congregate living without specifying any upper limits.

Hungary has the most generous upper limit, permitting 50 persons per building where the people concerned are being resettled from large-number residential

---

[126] Karinen et al. (2016) Yksilölliseen ja monimuotoiseen asumiseen: Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta. Helsinki. Ympäristöministeriön Raportti 18/2016.

[127] Pitkänen, Sari, Huotari, Kari & Törmälä Sinikka (2018) Lisää asumisvaihtoehtoja ja valinnanvapautta. Kehitysvammaisten ihmisten yhdenvertaisuus valtion tukemassa asumisessa. Ympäristöministeriön raportteja 12/2018. Page 86 http://urn.fi/URN:ISBN:978-952-11-4790-6.

[128] Summary report of the state responses to the questions related to the initial report of the Republic of North Macedonia on the implementation of the Convention on the Rights of Persons with Disabilities, page 12, 2018 Available at: https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fMKD%2f31979&Lang=en.

[129] EYSEKT (2017) 'Study for the Support Living Shelters in ESIF 2014-2020', p. 18 http://www.esfhellas.gr/el/Pages/eLibraryFS.aspx?item=2087.

[130] RUSIHAK ILNET Project. The Project deliverables are not available online. Please use the rusihak@gmail.com for further information and documentation.

institutions. Where new group homes are being developed, the maximum capacity is 12. Hungary however also permits existing institutions with a current capacity of less than 50 persons to expand up to 50 places.[131]

In Poland, the guidelines for the implementation of projects in the area of social inclusion and poverty eradication funded by the ESF and ERDF 2014-2020 permit expenditure on institutions of up to 14 places, in the case of children (in line with national law)[132] and up to 30 places for adults. With respect to 'protected houses' the number of persons living in protected housing cannot be higher than 12 by 31 December 2019, than 10 by 31 December 2021, and 7 post-2021. However, the legislation does not impose a limit on the number of protected houses in a single building.

Ireland defines congregate living only as that where 10 or more persons with disabilities reside in a single unit or where the living arrangements are campus-based, although it aims to ensure that persons with disabilities are resettled from institutional care to housing units of 4 persons or less.

In Slovakia, the Act on social services states the maximum number of recipients per one supported living flat is 6 persons, and per one block of flats is 12 disabled persons.[133]

In the Czech Republic, the Criteria of Community-based Social Services and Criteria for Transformation and Deinstitutionalisation (2013) stipulates that up to 6 persons may reside in a single group home, 1 or 2 people can reside in the individual homes and that there can be no more than 12 service users in any one apartment building. If more than 150 people (including those without disabilities) live in any one residential building, the number of services users can be higher, but the number of service users must not exceed 8 % of the total number of people. These criteria are mandatory only to EU funded projects.[134]

In England, guidance issued in 2015 to National Health Service and local authority commissioners regarding the de-institutionalisation programme 'Transforming Care' says that:

> 'Housing with occupancy of six or more people can quickly become institutionalised. New campus sites should not be created. Commissioners should carefully consider the service design when contracting with care and support providers or housing providers to create schemes of multiple units within close proximity, to ensure the service enables the tenants to have control over where they live and who provides their support.'

---

[131] Act III of 1993 on Social Administration and Social Services (hereinafter Social Act) 66/A. paragraph (1)-(3).

[132] Poland, Act of 9 June 2011 concerning Family Support and Foster Care (Text No. 887) ISN: POL-2011-L-89639.

[133] Slovakia, Act No. 448/2008 on Social Services, as amended.

[134] MoLSA/TRASS (2013), 'The Criteria of Community Cased-services Social Services and Criteria for Transformation and Deinstitutionalisation' http://www.trass.cz/wp-content/uploads/2016/05/kriteriaSSKCH-a-TaDI.pdf.

The Care Quality Commission, which registers and regulates care providers in England, has adopted a policy to support this position.[135]

Similarly, in Norway, in response to a trend towards the colocation of group homes or housing facilities often linked to so-called 'care bases', the Housing for Welfare strategy states that:

> 'Co-located housing units should not have institutional-like features and the number of residential units should not be too large. The accommodation units should be located in ordinary living environments, so that the principles of normalization and integration are maintained. Different user groups should not be co-located in an unfortunate manner.'[136]

In Sweden, only three to five persons are permitted to live in any group accommodation.[137]

In Iceland, the Regulations on services for persons with disabilities in their homes no. 1054/2010[138] said that the number of apartments for persons with disabilities that are next to each other in the same apartment building should be four to six, with a maximum of ten in the same building, and that the number of apartments, where people use joint facilities, should not be higher than four to six. A newer Regulation on housing for persons with disabilities[139] now allows for a slightly higher number of apartments, allowing 'not more than six' but the maximum number of ten apartments remains the same. Although not representing a major increase, it is considered that this change could be interpreted as a negative development, in light of the fact that the numbers of people living together have been decreasing.

In a number of cases, it is proposed that the downsizing of congregative living arrangements should be achieved via supporting the providers of large-scale institutional care arrangements to re-organise the way they deliver care, rather than by replacing such providers. For example, in the Republic of North Macedonia, 'transformation plans' are to be developed with each residential home to transform them into 'community-care services' including via the retraining and 'professional reorientation' of staff.

There are risks inherent to such an approach. For example, Slovenia lists among planned 'community-based services' 'living units' and 'sheltered workshops', yet closer inspection reveals that the former are already part of long-stay institutions, built by the institutions and involving the same staff, while sheltered workshops are partially part of existing long-stay institutions, or are themselves long-stay institutions. In Portugal, much of the contracts to provide the new centres for independent living have gone to providers of residential homes, raising fears that traditional care approaches will be maintained.

---

[135] Care Quality Commission (2017) 'Registering the right support' https://www.cqc.org.uk/sites/default/files/20170612_registering_the_right_support_final.pdf.
[136] https://www.regjeringen.no/globalassets/upload/krd/rapporter/fafo-rapport.pdf?id=2325685.
[137] The National Board of Health and Welfare's regulations and general advice [SOSFS 2002: 9].
[138] Reglugerð um þjónustu við fatlað fólk á heimili sínu 1054/2010.
[139] Reglugerð um þjónustu við fatlað fólk á heimili sínu 396/2016.

Even where living arrangements are relocated away from prior institutional care facilities, managers, staff and systems can struggle to relinquish the power structures that define institutions, with institutional care replicated, albeit at a smaller and more dispersed scale. This is especially the case where such strategies do not include measures to restore legal, financial and administrative power to persons with disabilities over where and with whom to live and over who supports them and in what fashion. For example, it is reported that in Slovenia, staff working in the new smaller scale 'dislocated units' and group homes were not re-trained, and no evaluation was carried out about the quality of services from the perspective of persons with disabilities and from the perspective of independent living philosophy.

Some ANED countries have taken specific measures to diversify the range of housing and support options available to persons with disabilities who require support to live independently and to be included in the community.

In England, 'Building the Right Home' commits GBP 100 million (EUR 117 million) capital funding to support the development of bespoke housing options based on the principle of supported living (that choice of housing should be unbundled from choice of care and support provider). It proposes supported housing, home ownership, bespoke rental properties and 'community living networks', which 'work by connecting people in their own homes within a particular area. The model can enable people to live in a network of houses or flats to support each other, as well as to receive support. A support worker lives as part of the community and provides small amounts of support to each network member.'

In Ireland, the National Housing Strategy for People with Disabilities 2011-2016 includes measures for the development of accessible dispersed (non-congregate) housing options.

Finland has committed to build on the KEHAS programme with an aim to promote the abolition of institutional housing and the development of individual housing solutions in line with the UNCRPD. It aims to ensure that enough different housing solutions that fulfil the needs of persons with disabilities are available, particularly as part of the ordinary housing stock.

In response to trends towards congregate living in Norway, Housing for Welfare: The National Strategy for Social Housing (2014-2020, p. 20),[140] reaffirms the goal, developed since the 1990s, that:

> "most people should be able to live in their own homes and receive necessary services there. The goal of normalization means that people should as far as possible live in ordinary homes in ordinary living environments and have the opportunity to live independent and active lives."

One of the objectives in the National Strategy for Development of Social Services 2016 – 2025 and the recently completed Housing Strategy of the Czech Republic

140 https://www.regjeringen.no/globalassets/upload/kmd/boby/nasjonal_strategi_boligsosialt_arbeid.pdf.

2020[141] is to generate conditions to ensure decent and adequate and accessible housing usable regardless of age, gender or health restrictions (disability).

In Iceland, the Regulation on housing for disabled people no 370/2016[142] stipulates that housing options for persons with disabilities must be community based and that each apartment should be a minimum of 40 square metres (Article 4). New housing options have to meet these requirements.

In the Netherlands, the CRPD implementation plan (*Onbeperkt Meedoen*) aims to coordinate actions by local municipalities, NGOs, DPOs, organisations of employers and trade unions, including with a view to stimulating municipalities and housing corporations to plan innovative social housing projects in which renters can also be provided with care.

4.2.2 Building the capacity of community-based services

A number of European States have developed and are implementing plans to build the capacity of community-based social services, both generally, as well as specifically towards the goal of de-institutionalisation. Some related programmes are financially supported by ESIF.

For example, Croatia is aiming to improving the accessibility, affordability and quality of social services by developing and expanding the network of services in the community and intensifying the process of transformation and de-institutionalisation of social welfare homes.

In Lithuania, during 2016-17, while carrying out the reform of institutional care, a programme of professional development was implemented across all regions. It included conferences focusing on inter-institutional, interdepartmental and cross-sector cooperation, round-table discussions and seminars on the theoretical and practical aspects of teamwork when modelling the system of integral community-based services, and training for senior staff on managing the development of community-based services in municipalities.[143]

In Latvia, the Framework for Development of Social Services 2014-2020[144] includes 'objectives and measures [that are] aimed at ensuring the provision of social services that are relevant to the needs of the individual, to maximise his or her self-care capacity and independent life opportunities' and sets forth three areas of action: deinstitutionalisation, community-based and successive social services appropriate to needs of customers, and effective social services management.'

---

[141] Czech Republic (2016) *Koncepce bydlení ČR do roku 2020*. (The Czech Republic Housing Strategy up to 2020) http://www.mmr.cz/getmedia/f97ad787-1512-4b28-bf57-04973d772c27/KB-R_VIII-2016_web-min_3.pdf.

[142] Reglugerð um húsnæðisúrræði fyrir fatlað fólk.

[143] Ministry of Social Security and Labour 2016/2017 Social report - https://socmin.lrv.lt/uploads/socmin/documents/files/pdf/13545_social-report-2016-2017.pdf.

[144] Cabinet Decree No. 589 "Framework for Development of Social Services 2014-2020, 2015". Available at: https://likumi.lv/doc.php?id=262647.

In Serbia, the strategy for the development of mental health protection aims to create and strengthen mental health services in the community, and to improve the responsiveness of primary health care to people with mental health problems as a precursor to de-institutionalisation of large psychiatric hospitals.[145] Similarly, in Malta, the *Mental Health Strategy Consultation Document* 'embraces a modal shift in the locus of care away from institutions towards community-based mental health care' (p. 9).[146] In Ireland, the review of the country's mental health policy 'A vision for change' identified some promising practices such as progress 'based on floating support services that help people with mental health difficulties find suitable housing. This includes transition to independent living and support in managing tenancy-related aspects.'[147] The support offered through HAIL includes: 'settlement planning and support; tenancy sustainment; mental health recovery; improving independent living skills; sourcing education, employment and training; accessing and signposting to statutory and community services; and integration into the new or existing community.'[148] In the Czech Republic, with financial support from the European Social Fund, the Psychiatric Care Reform Strategy 2017 aims to promote the full integration of persons with mental health problems into society and to reorganise psychiatric care.[149]

4.2.3 Personal assistance

Some European States have developed or propose to develop schemes described as offering 'personal assistance'. Personal assistance schemes, as conceived by the independent living movement and described in the UNCRPD Committee General Comment 5 are designed to accord persons with disabilities more control over both their support and their day-to-day lives. In particular, it is anticipated that persons with disabilities are empowered to employ their own personal assistant and to be in control of how support is provided.

In Iceland, a pilot project on user-led personal assistance (*Notendastýrð persónuleg aðstoð* - NPA) was established in 2012 by the Ministry of Welfare and the municipalities in Iceland. User-led personal assistance was subsequently made a legal entitlement in April 2018 with the passage of the Act on services for persons with disabilities with long-term support needs 873/2018.[150] Article 11 of this act is specifically devoted to user-led personal assistance and states that individuals are entitled to this service option if they can demonstrate a significant and sustained

---

[145] Strategy for development of mental health protection, "Official Gazette of the Republic of Serbia", no. 8/2007.

[146] Office of the Deputy Prime Minister and Ministry for Health (2018) 'Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030'. Public Consultation Document. Available at: https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx.

[147] Kevin Cullen and David McDaid, (2017) 'Evidence Review to Inform the Parameters for a Refresh of A Vision for Change'. Available at: https://health.gov.ie/blog/publications/evidence-review-to-inform-the-parameters-for-a-refresh-of-a-vision-for-change/ p. 10.

[148] See, Kevin Cullen and David McDaid (2017) 'Evidence Review to Inform the Parameters for a Refresh of A Vision for Change', p.54.
Czech Republic. Ministry of Health (2016). *Psychiatric Reform Strategy 2017.* http://www.reformapsychiatrie.cz/proc_reformujeme/.

[150] Lög nr. 38/2018 um þjónustu við fatlað fólk með miklar stuðningsþarfir.

need for assistance with daily activities. The assistance scheme is to be organised and managed by the user.

In Malta, the Personal Assistance Fund (PAF), established in 2017, subsidises the cost of carers for adults who need more than 30 hours weekly of on-going 'personal assistance.'[151]

In Portugal, following a pilot project in Lisbon, the Independent Living Support Model (MAVI) is to be developed nationally over three years, with financial support from the European Social Fund. It will pilot a network of independent living support centres (CAVIs) throughout the country that will implement personal assistant projects by serving as the so-called 'contact points' to receive requests from persons with disabilities who need personal assistance and allocate the required personal assistance services. The provision of personal assistance will follow an individual plan. This plan will be defined by the disabled person in collaboration with the CAVI and it will identify: the specific assistance needs of the person; how support activities are to be carried out; how the assistance will be monitored and evaluated. The individual assistance plan will state the number of hours of weekly support the person is entitled to. Each person can receive up to 40 hours of support per week. Exceptionally, more hours of support can be provided — up to 24 hours a day. However, each CAVI can only provide more than 40 hours a week of support to a maximum of 30 % of its clients.

According to the MAVI official announcement,[152] the funding available for the current support to independent living programme is set at EUR 23.5 million for three years. Funding from the ESF amounts to 85 % of this total, while the national contribution is 15 %.

Concern has been expressed that many of the organisations awarded funding to provide CAVIs are residential service providers rather than organisations led by disabled people (as was the case with the initial pilot) and hence there is a risk that they will continue to provide services in a very traditional way. It is understood that for DPOs to provide CAVIs they must register as a social care institution. Further, as personal assistants are provided only through the CAVIs, persons with disabilities do not have total control over the service provided and do not have access to a personal budget.[153]

In Croatia, two projects supported by the European Social Fund projects - development of personal assistance service for persons with disabilities, phase 1[154] and phase 2[155] - aim to extend the availability of personal assistance to a wider

[151] Aġenzija Sapport (2018) *Biennial Report 2016-2017*. Available at: https://sapport.gov.mt/en/Downloads/Documents/A%C4%A1enzija%20Sapport%20Biennial%20Report%202016-2017.pdf.

[152] http://poise.portugal2020.pt/documents/10180/73143/AAC_TO+3.18_POISE-38-2018-04_v1_20180313.pdf/0bd18758-5f42-4238-8daa-f9907a64351d.

[153] See 'Independent living in Portugal' https://enil.eu/news/independent-living-in-portugal/.

[154] https://strukturnifondovi.hr/natjecaji/razvoj-usluge-osobne-asistencije-za-osobe-s-invaliditetom/.

[155] https://strukturnifondovi.hr/natjecaji/razvoj-usluge-osobne-asistencije-za-osobe-s-invaliditetom-faza-ii/.

range of beneficiaries than the State-supported scheme, for example to persons with intellectual and mental disabilities.

In Denmark, the citizen-led personal assistance scheme, established in 2012, replaced an earlier scheme established in 2006. It is funded by the Satspulje (Social Ministry). In 2019, a project was developed to provide advice to persons with disabilities who employ their own personal assistants.

In Luxembourg, a national working group is currently preparing the second national action plan (2018-2019) on the implementation of the UNCRPD, which identifies among current priorities the implementation of personal assistance.

It is crucial not to regard the mere existence of a personal assistance scheme as evidence of progress towards independent living. In 2018, the European Network on Independent Living conducted a survey concerning such schemes in eight European countries, using a checklist, to measure the degree to which personal assistance schemes accord users control over their lives. It found that people who use personal assistance in Sweden were able as a result to make the most decisions about their lives, whereas users of personal assistance in Bulgaria can make very few decisions about their lives.[156]

In Slovakia, the number of persons with disabilities in receipt of the cash benefit for personal assistance grew from 8 583 in 2013 to 10 173 in 2018.

4.2.4 Individualised budgets and direct payments

A number of European Countries are implementing or experimenting with individualised budgets (sometimes referred to as 'personal budgets') whereby the person is advised of the financial value of the support that they are entitled to and is then able to make choices about how the money is spent on securing their support. In some countries, this money is given to the individual in the form of a 'direct payment' enabling them to purchase support, or to employ a personal assistant, directly.

The ANED report on Italy says that the only tool that has proven to be actually effective in advancing the right to live independently and to be included in the community is the personalised budget, in different fields including health and social care. However, only pilot personal budget projects currently exist in Italy, and these are in only some regions. Ireland is also piloting personal budgets, with positive results. People with disabilities who took part in the pilots expressed their 'satisfaction with the level of flexibility and subsequent choice that comes with the Direct Payments model' and their 'sense of confidence and empowerment as well as helping them to achieve social integration, personal life goals and economic independence and participation.'[157] Luxembourg is reported to be exploring the

[156] Mladenov T. et al (February 2019) PA Checklist – a tool for assessing personal assistance schemes.

[157] Keogh, S. and Quinn, G. (2018) Independent Living: An Evaluation of the Áiseanna Tacaíochta model of Direct Payments p.6. Available at: http://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf.

introduction of a general personal budget in the context of its next national action plan on implementation of the UNCRPD.

Personal budgets have been a legal right in Germany since 2008 and in the UK since 2014 in the field of social care. Rights to personal health budgets are gradually being introduced in the UK as part of the 'comprehensive model of personalised care.'[158]

However, the availability of individualised budgets may not, of itself, mark major progress on the right to live independently and to be included in the community. For example, in the Flanders region of Belgium, a vast majority of recipients of personal budgets choose a voucher, which means they fully use the budget to 'buy' support modules in disability-specific services/institutions. Only 7 % use personal assistants to meet their support needs. In England, 97 000 people receiving long-term social care support outside of residential or nursing care use direct payments, whereas 111 000 people have their personal budget managed by their local authority.[159]

Siska, J et al (2017) report in their paper on social inclusion through community living that

> 'the availability of personal budgets, direct payments and other individualised funding systems were reported (in nine countries across Europe) as core facilitators of community living. However, where personal budgets existed, they were often made very complex to access, only available to some people, limited by a lack of available services to purchase and were sometimes seen by government's as a way to save money.'[160]

In the Netherlands, of the total of 295 115 people receiving long-term care, 22 985 people opt for a direct payment with which they can organise either care in their own home or pay for a place in a residential home. According to the Ministry of Health, Welfare and Sport one in five people with an intellectual disability opt for a direct payment.[161]

4.2.5 Peer support

As noted in chapter 2.5 above, collective measures involving DPOs have often been important to the success of individual level measures on choice and control, such as direct payments and personal assistance.

---

[158] NHS England (2019) The Comprehensive Model of Personalised Care, see: https://www.england.nhs.uk/personalisedcare/comprehensive-model-of-personalised-care/.

[159] Source: Adult Social Care and Finance Report 2017-18 https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2017-18#resources.

[160] Šiška, J et al (2017) 'Social Inclusion through Community Living: Current Situation, Advances and Gaps in Policy, Practice and Research' *Social Inclusion* (ISSN: 2183–2803) 2018, Volume 6, Issue 1, pp. 94–109.
Noted in the report Volwaardig Leven by Ministry of Health, Welfare and Sport, page 56. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/09/30/programma-volwaardig-leven/Programma+Volwaardig+leven.pdf.

In Belgium, 'user-assistance organisations' give advice and help to people with a personal budget or to those who have applied for one. Persons with disabilities are supported to start working with the budget, to search for appropriate services or to organise assistance themselves. One of these organisations grew from the local independent living organisation in Flanders.[162] In Walloon, users of a personal assistance budget can turn to EVA, a local independent living organisation for support.[163]

In France, the national government has committed EUR 7.7 billion over two years to create mutual support groups for people with mental health problems, aimed at supporting their inclusion in society.

In England, the North West Care Cooperatives is a two year pilot, led by Cheshire Centre for Independent Living in collaboration with four other DPOs, which aims to support persons with disabilities[164] who wish to have as much control as possible over their support provision but who do not want to become a direct employer, by creating the means to become shared employers of personal assistants.

In Iceland, NPA miðstöðin[165] (the centre for user-led personal assistance) is a collective operated by persons with disabilities for the purposes of providing assistance for the application, administration and monitoring of user-led personal assistance contracts. The centre can also provide assistance with hiring and managing assistants, shifts and hours, and budgets as well as providing counselling.

4.2.6 Legal rights to, choice and control

This study has identified only one example of Article 19 UNCRPD being codified into domestic law.

In Iceland, the Law on services for disabled people with long-term service needs no. 38/2018 came into force on 1 October 2018.[166] It has the stated aim to implement the UNCRPD into Icelandic law and policy. According to the first paragraph of Article 1, the act is aimed at providing persons with disabilities with the necessary support to enable them to enjoy full human rights on an equal footing with others and thereby create the conditions for independent living on their own terms. It is also noted that in carrying out services for disabled people, respect for human dignity, autonomy and independence should be respected. Article 9 states that persons with disabilities have the right to choose where and with whom they live and are not required to reside in a particular living arrangement. A preliminary clause in the law states that persons with disabilities currently living in institutions and group homes should be offered other living arrangements that are in line with Article 9 of the legislation (community-based living). The law also makes user-led personal assistance legally binding as one of the services available to persons with disabilities, including disabled children (Article 11). The law also states (in Article 36)

[162] Onafhankelijk Leven (2019) Wie zijn we?, www.onafhankelijkleven.be.
[163] EVA stands for 'Ensemble pour une vie autonome' (together for an autonomous life), http://www.eva-bap.be/.
[164] See: http://www.drilluk.org.uk/north-west-care-cooperative-social-enterprises/.
[165] NPA Miðstöðin www.npa.is.
[166] Lög nr. 38/2018 um þjónustu við fatlað fólk með miklar stuðningsþarfir.

that a committee shall be established to be a collaborative body for state, municipalities and interest organisations, the majority of which should be made up of disabled people. The role of the committee is to advise the minister on policy making.

In England, the Law Commission, when preparing draft legislative proposals for reform of England's care law, rejected calls for Article 19 UNCRPD to be reflected in the new legislation, on the grounds that it would 'create a bias towards home-based care.' In Wales, though not included in the primary legislation, the statutory code of practice for local authorities concerning implementation of the Social Services and Wellbeing (Wales) Act 2015 says that local authorities must have due regard to the UNCRPD when implementing the Act. In its concluding observations on the initial report of the UK, the UNCRPD Committee expressed concern about the absence of legal recognition of independent living as a human right.[167] Similarly, in its concluding observations on the initial report of Turkey, the Committee expressed concern at 'The absence of a legislative framework recognizing the right of persons with disabilities to live independently and choose their place of residence.'[168]

4.2.7 Budgets committed to advancing a transition from institutional care to community-based alternatives

Many of the individual ANED country studies provide information on the budgets committed to programmes and projects on the transition from institutional care to community-based alternatives. It is not possible, within the scope of this study and based upon available data, to accurately account for total expenditure by European States. Nevertheless, it is clear that billions of Euros have and continue to be invested in programmes and projects that are described as aiming to effect a process of deinstitutionalisation.

Given the heavy reliance by a number of European Union Member States on the ESIF to support this process, it is clear that the funds have the potential to play an indispensable role in advancing the rights of persons with disabilities to live independently and to be included in the community. For example, it is noted in the ANED country study on the Czech Republic that:

> 'since 2009, EU funds (with the associated domestic contribution) have been the primary source of financing for the deinstitutionalisation process and the development of community-based services.[169]

---

[167] UNCRPD Committee (October 2017) Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2fCO%2f1&Lang=en.

[168] UNCRPD Committee (April 2019) Concluding observations on the initial report from Turkey https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/TUR/CO/1&Lang=en.

[169] Czech Republic. MoLSA (2015). Národní strategie rozvoje sociálních služeb na období 2016 – 2025. (National Strategy for Development of Social Services for the Period 2016 – 2025). Usnesení vlády ČR č. 245/2016 ze dne 21. 3. 2016 https://www.mpsv.cz/files/clanky/29624/NSRSS.pdf.

In Portugal, 85 % of the funding for the development of a national network of centres for independent living (see 4.2.3 above) will come from the European Social Fund. This situation might be construed as a 'double edged sword': on the one hand, in the absence of ESI funding, little if any progress may be being made in some countries, and on the other, as noted by Community Living for Europe: Structural Funds Watch in 2017, in some countries:

> 'the quality of proposed measures, coupled with patterns of investment, suggest that change is being driven overwhelmingly by EU policy and ESIF funding, with the transition to community-based living enjoying low support or prioritisation at the domestic level.'

In the absence of greater domestic-level support and prioritisation, questions are likely to emerge about the long-term sustainability of strategies and programmes concerning the right to live independently and to be included in the community.

The heavy reliance on ESIF in support of such initiatives also confirms the importance of regulations governing their use in conformity with Article 19 of the UNCRPD, of adequate monitoring and enforcement where such regulations are violated.

As well as questions concerning the overall commitment of funds towards related programmes and projects is the issue of how efficiently such funds are spent or indeed whether they are spent at all.[170] The ANED country study on Croatia reports that in 2014, Croatia received a loan for de-institutionalisation from the World Bank totalling EUR 70 million, however, by the end of 2018 only EUR 6 million had been spent, mostly on consultants. At the end of 2018, the loan was cancelled and the remaining amount - EUR 63 million - was not received.[171]

4.3 Involvement of disabled people

In many European States, disabled people's organisations (DPOs) have had some involvement in the elaboration of strategies and plans concerning or related to the transition from institutional care to living independently and being included in the community. However, it is not possible to report upon the depth of this involvement, or on its impact on policy and action.

In Slovakia, the Committee of Experts for Deinstitutionalisation was established in 2012. Two of the committee's 13 experts are representatives of persons with disabilities and/or older persons. In England, National Health Service England has a Learning Disability and Autism Advisory Group, involving adults with a learning disability and/or autism who are involved in the scrutiny and oversight of

[170] See for example ENIL (2018) Briefing on the use of EU Funds for Independent Living https://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing_web0903.pdf.

[171] Report on financial audit carried out by the Ministry of Demography, Family, Youth and Social Policy for 2017 (2018).
Izvješće o obavljenoj financijskoj reviziji Ministarstva za demografiju, obitelj, mlade i socijalnu politiku za 2017 (2018)
http://www.revizija.hr/datastore/filestore/135/MINISTARSTVO_ZA_DEMOGRAFIJU_OBITELJ_MLADE_I_SOCIJALNU_POLITIKU.pdf.

Transforming Care and Building the right support.[172] In Ireland, the Time to Move On policy was developed by a working group with membership including 'representatives of key stakeholders including voluntary and statutory service providers, representatives and advocates for persons with disabilities including a self-advocate with intellectual disabilities'.[173]

In Finland, DPOs were closely involved into the preparation of the 2018-2019 action plan on the implementation of the UNCRPD through VANE, the Advisory Board for the Rights of Persons with Disabilities. VANE's previous general secretary was a disabled woman, and its vice chairperson and five of its members are representatives of the Finnish Disability Forum. DPOs are also engaged in the promotion and monitoring of the implementation of the UNCRPD, via the Disability Rights Committee, which is a permanent division of the Human Rights Centre. In Malta, the national policy on the rights of persons with disability 2014 was written with the Kumitat Azzjoni Lejn Soċjeta' Ġusta[174] (Committee Action Towards a Just Society), which is made up of a majority of disabled people, with the remainder being parents of disabled people, activists and academics.

In Latvia, a range of civil society organisations that focus on disabled people, including the Latvian Umbrella Body for Disability Organisations and the Association of Latvian Movement for Independent Living have been involved in the elaboration of relevant policies and regulations, including the framework for the development of social services 2014-2020 and the framework for the implementation of the UNCRPD 2014-20.

According to the North Macedonian National Strategy for De-institutionalisation,[175] the involvement of DPOs and persons with disability is planned within the monitoring unit, as a part of the national monitoring body for CRPD implementation and in the advisory body that will be established.

It is reported that persons with disabilities and their representative organisations are not involved in planning the de-institutionalisation process in Lithuania.[176]

In Iceland, the obligation to involve persons with disabilities is codified in national law in the Act on services for people with disabilities with long-term support needs no. 38/2018.[177] Article 36 of the law states that the minster responsible must create a committee of consultation (*samráðsnefnd*). The consultative committee will be composed of two representatives from the ministry, one representative from the Ministry of Finance, two representatives from the municipalities and four

[172] See: https://www.england.nhs.uk/learning-disabilities/about/get-involved/advisory-group/.
[173] HSE (2011), 'Time to Move on from Congregated Settings – A strategy for Community Inclusion' 2011, p. 25.
[174] https://activeageing.gov.mt/en/News/Pages/Jitwaqqaf-il-Kumitat-Azzjoni-Lejn-So%C4%8Bjeta'-%C4%A0usta.aspx.
[175] National Strategy for deinstitutionalization 2018-2027, Ministry of Labour and Social Policy Available at: http://mtsp.gov.mk/content/pdf/strategii/Strategii%202018/Strategija_deinstitucionalizacija_Timjanik_2018-2027.pdf.
[176] http://lnf.lt/deinstitucionalizacija/.
[177] Lög nr. 38/2018 um þjónustu við fatlað fólk með miklar stuðningsþarfir.

representatives from disabled people's organisations. The ministry will ensure that persons with disabilities are in the majority of the committee. The role of the consultative committee is to advise the minister on the policy on persons with disabilities.

A significant gap is the lack of involvement of DPOs in implementation. In its report 'Opening up communities, closing down institutions', Community Living for Europe: Structural Funds Watch reported that civil society faced significant barriers in accessing ESIF to these ends.

As has already been reported, in Portugal, a pilot project in Lisbon to develop a Centre for Independent Living to support the development of personal assistance was led by a DPO. However, in the national roll-out of the model, with finance from ESIF, many of the contracts have gone to residential care providers rather than to DPOs, which some fear will undermine the impact of the programme. The current review of the European Code of Conduct on Partnership provides an opportunity to address this issue.[178]

Since 2018, Icelandic law requires that municipalities collaborate with disabled people's organisations in policy-making and service planning.[179]

4.4 Monitoring and data collection

A number of the ANED country reports have raised issues concerning the lack of transparency and accountability of European States on the progress of strategies, plans and projects. These relate to the bodies and mechanisms established to provide oversight to programmes, strategies and projects, as well as the availability and quality of data.

4.4.1 Monitoring systems and structures

European Union regulations stipulate that Monitoring Bodies are established by European Union Member States with respect to the Operational Programmes for the expenditure of ESIF. It is important to note that the Operational Programmes typically span the full range of programmes and projects funded under each 'thematic objective', or across a range of thematic objectives, meaning that oversight of any specific programmes on the 'transition from institutional to community-based care' is likely to be superficial. Moreover, these bodies are broad in their membership and areas of expertise. For example, in the Czech Republic, a monitoring committee has been established consisting of 28 members. It is reported that only one committee member directly represents DPOs, although a few committee members are indirectly associated with disability issues.[180] In Greece, the

[178] European Commission (2018) Review of the Code of Conduct on Partnership https://ec.europa.eu/esf/transnationality/filedepot_download/1145/1749.

[179] Lög um breytingu á lögum um félagsþjónustu sveitarfélaga, nr. 40/1991, með síðari breytingum (innleiðing samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks, stjórnsýsla og húsnæðismál).

[180] Evropská Unie. ESF. Operační program. Zaměstnanost. *Složení monitorovacího výboru OP Zaměstnanost.* https://www.esfcr.cz/monitorovaci-vybor-opz/-/dokument/797536.

monitoring body for the use of ESIF is the Special Service for the Coordination and Monitoring of ESF funded actions (EYSEKT).[181]

Some European States have established dedicated monitoring bodies with respect to their de-institutionalisation strategies and programmes. For example, in Hungary, the National Committee for the Coordination of the Replacement of Institutions (Intézményi Férőhely Kiváltást Koordináló Országos Testület or IFKKOT) was first established in 2011 and re-established in 2017. Its role is to:

- monitor changes in the quality of life during resettlement from institutional care;
- evaluate plans for de-institutionalisation submitted by the candidates involved in the process;
- comment on measures for the development of rehabilitation institutions;
- monitor the organisation and implementation of state-operated services.

Its membership includes DPOs, the National Human Rights Institution, NGOs, church bodies and government. However, concern has been expressed about the independence of this body.

In Ireland, a number of mechanisms have been implemented to support the implementation of the 'Time to Move on from Congregate Living' policy. Under the Transforming Lives programme, six working groups have been established. The Time to Move On subgroup is tasked with implementing initiatives 'which underpin and enable a new model for residential support in the mainstream community, where persons with disabilities are supported to live ordinary lives in ordinary places.'[182] The subgroup carries out its role according to an annual work plan, focusing on deliverable actions and monitoring progress.[183] Membership consists of a multi-stakeholder and cross–departmental group.[184] However, it is unclear how many DPOs or individual persons with disabilities are represented.

In Latvia, the 'Action Plan for the implementation of de-institutionalisation 2015-2020' sets up a chain of command through monitoring at the level of the Ministry of Welfare, regions and municipalities.[185]

In Bulgaria, permanent expert working groups are expected to report annually on the de-institutionalisation process as it relates to children and to disabled adults. However, it is reported that no monitoring reports have been published since 2013.[186]

In the Republic of North Macedonia, implementation and monitoring of deinstitutionalisation has been embedded in the implementation and monitoring of

[181] http://www.esfhellas.gr/el/Pages/EYSEKT.aspx.
[182] HSE (2018), 'Time to Move on From Congregated Settings, Annual Progress Report', p. 9.
[183] HSE (2018), 'Time to Move on From Congregated Settings, Annual Progress Report', p. 9-10.
[184] HSE (2018), 'Time to Move on From Congregated Settings, Annual Progress Report', p. 75.
[185] Action Plan for the implementation of deinstitutionalisation for 2015-2020, p.17. Available at: http://www.lm.gov.lv/upload/aktualitates/null/2015_15_07_ricplans_final.pdf.
[186] Government of Bulgaria, (2016) 'Updated Action Plan for Implementation of the National Strategy - Vision for deinstitutionalization of children in Bulgaria', October 2016, p.50.

the UNCRPD.[187] The National Coordination body for CRPD implementation is tasked with securing political support for the de-institutionalisation process, to facilitate inter-ministerial coordination, to assure that the implementation of the measures are in line with CRPD, and to give directions for improvements. The Ombudsman Office, in its capacity as the Independent Mechanism under Article 33 of the UNCRPD, will be responsible for monitoring of the implementation of the strategy. The Government will also establish an advisory body from representatives of public institutions, international organisations, CSOs, disabled people, beneficiaries of social services, and experts, to critically monitor and evaluate the implementation of the strategy.

In Croatia, the dedicated Ombudsperson for Person with Disabilities, which is independent of the Government, actively monitors de-institutionalisation. His team has commissioned research into the placement of disabled people into 'family homes' and 'foster families'. They Ombudsman has an advisory council made of DPOs.

Many States are not actively monitoring implementation of the right to live independently and being included in the community.

4.4.2 Data collection

As outlined in the introduction and as has been highlighted by the EU Agency for Fundamental Rights, descriptors and definitions vary considerably, making definitive conclusions about performance and comparisons between States impossible. Where data does exist, it is overwhelmingly quantitative data, focused on the numbers of people leaving existing institutional care facilities, rather than on the destination or the degree to which individuals are enjoying greater choice, control and participation as a result of their changed living situation.

In Latvia, the action plan for the implementation of de-institutionalisation for 2015-2020 provides for the implementation of the development of an information system for monitoring the DI process, with a view to establishing an informational technology-based system to monitor de-institutionalisation. It proposes developing a harmonised set of indicators and a single data entry system to be used in each municipal social service office. Data collected will complement existing national statistical reports on social services and social assistance, with new sections describing the provision of community-based services. This will link to the information systems of the Ministry of Welfare and local governments, creating a single de-institutionalisation monitoring system.[188]

In Ireland, a master data set (MDS) tool is used to measure transitions and collect key data on annual progress.[189] An MDS questionnaire is circulated to collect data

[187] National Strategy for deinstitutionalisation 2018-2027, Ministry of Labour and Social Policy Available at: http://mtsp.gov.mk/content/pdf/strategii/Strategii%202018/Strategija_deinstitucionalizacija_Timjanik_2018-2027.pdf.

[188] Action Plan for the implementation of deinstitutionalisation for 2015-2020, pp.45-46. Available at: http://www.lm.gov.lv/upload/aktualitates/null/2015_15_07_ricplans_final.pdf.

[189] HSE (2017), 'Time to Move on From Congregated Settings, Annual Progress Report', p. 20.

on the changes in the circumstances of all those living in congregated settings, such as information related to the population remaining in congregated settings, transitions into the community and the status of congregated settings. This information is reported in the annual progress reports for the Time to Move On policy.

In England, NHS England publishes two sets of monthly statistics on the number of people with learning disabilities and/or autism in inpatient units in England. One data set is based on information provided by English commissioners, while the other is based on data provided by providers of inpatient services. The data also provides information on the age and gender of inpatients and on length of stay. Until 2014, the Department for Health in Northern Ireland published a monthly monitoring report concerning delivery of the Bamford Vision action plan 2012-15, which included data on the numbers of people with a learning disability in inpatient units.[190] NHS England also commissioned an independent evaluation of 'Building the right support' which was published in October 2018.[191]

Positively, some European States collect qualitative and quantitative data on the lived experience of de-institutionalisation programmes by disabled people. In the Czech Republic, a study on the impact of de-institutionalisation on disabled people's freedom to decide how to live their life was conducted between 2012 and 2015 as part of the EU funded project transformation of social services. Ten institutions participated in the project.[192] The results found that the opportunities to make decisions significantly increased during the project lifespan. That was particularly the case for decisions related to leisure time, to being with someone privately, and to regimen. In contrast, choices related to where to live, to legal issues and to medical care remained significantly limited. The outcomes demonstrate that empowerment of service users is not merely about changing their place of living.[193]

A number of European States have developed or are developing indicator sets to measure progress on de-institutionalisation. In France, indicators have been developed to measure progress on the implementation of the 'Strategy of transformation of the socio-medical specialist provision', including a reduction in the number of young adults residing in institutions and an increase in inclusive services.

In Finland, the action plan of the Finnish Government for the implementation of the CRPD in 2018-2019 requires the ministries responsible to set indicators for their objectives by the end of the term. However, that had not been completed at the time of writing. Institutional care is highly regulated in Finland, hence the number of people with intellectual disabilities in institutions is reported in the official statistics, SOTKAnet. Further, the Ministry of Environment has evaluated the de-

[190] Available at: https://www.health-ni.gov.uk/publications/bamford-action-plan-2012-15.
[191] The Strategy Unit (2018) 'Evaluation of building the right support – findings to date' https://www.strategyunitwm.nhs.uk/index.php/publications/building-right-support.
[192] European Social Fund. *Employment. OPLZZ 2007 – 2013. Project Transformation of Social Services. CZ.1.04/3.1.00/04.00009* https://www.esfcr.cz/projekty-oplzz/-/asset_publisher/0vxsQYRpZsom/content/transformace-socialnich-sluzeb?inheritRedirect=false.
[193] MoLSA (2015) Souhrnná zpráva z evaluace nového stavu uživatelů v 10 vybraných zařízeních sociálních služeb. Zpracováno v rámci projektu Ministerstva práce a sociálních věcí. Transformace sociálních služeb. Praha, prosinec 2015.

institutionalisation process and published reports[194] on its progress and ideas for further development. The data are collected with different methods, depending on the research questions.

A number of European States collect data on quality of life among disabled people, including measures of choice and control. For example, in Finland, VANE (the Advisory Board for the Rights of Persons with Disabilities), a coordination body for the implementation and monitoring of the CRPD, conducted an online survey among persons with disabilities in autumn 2017 to understand the daily realisation of disability rights and 577 persons with disabilities or their families, their representative organisations and members of disability councils responded to the it.[195] According to the results of the survey, the majority of people (54 %) thought that the freedom of choice for persons with disabilities pertaining to their right to live in a place and live with a person of their choice is currently poorly realised in practice. A similar result was also found in relation to the availability of necessary services for enabling their independent living in communities.

In Denmark, the Handicapbarometer[196] (a website launched by the Institute of Human Rights in 2018 which follows the development of the conditions for persons with disabilities in 10 areas on the basis of large survey studies conducted by VIVE every four years) highlights how many people are experiencing having a great influence on their own lives. It shows that 43 % of the disabled respondents have great influence on their own lives, while 67 % of the other respondents experience a high degree of influence.[197] The survey data *may* include people living in institutions, but this group are likely to be underrepresented and the report does not look at their situation specifically.

Similarly, the Netherlands Institute for Human Rights monitors implementation of the CRPD including Article 19 of the CRPD, by collecting statistical data.[198] Indicators used are the number or percentage of persons with disabilities owning their own house; who can choose their house; who can choose the people to share housing accommodation; who have adaptations in their house, who have applied for and received adaptations in their house, who have adequate income or benefit to live independently, who have access to public buildings and provisions (such as sports-clubs) in their neighbourhood, and who are accepted as a client to buy insurance. The institute found that 41 % of people with a moderate intellectual disability were not allowed to choose their living arrangement both in 2012 and in 2016.

---

[194] Karinen, Risto, Laitinen, Lasse, Noro, Kirsi, Ekholm, Elina & Tuokkola, Kati. (2016) Yksilölliseen ja monimuotoiseen asumiseen; Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta. Ympäristöministeriön raportteja 18/2016 http://urn.fi/URN:ISBN:978-952-11-4607-7; Pitkänen, Sari, Huotari, Kari & Törmälä Sinikka (2018) Lisää asumisvaihtoehtoja ja valinnanvapautta. Kehitysvammaisten ihmisten yhdenvertaisuus valtion tukemassa asumisessa. Ympäristöministeriön raportteja 12/2018 http://urn.fi/URN:ISBN:978-952-11-4790-6.

[195] Hoffren, Tea. (2018) *Kysely oikeuksien toteutumisesta vammaisten henkilöiden arjessa: raportti keskeisista kyselytuloksista*. VANE. Helsinki. Available at https://vane.to/documents/2308875/2395516/Raportti+kyselyn+tuloksista.pdf/e6bd3b12-1554-43b4-8f6a-38a21143e419/Raportti+kyselyn+tuloksista.pdf.pdf.

[196] https://handicapbarometer.dk/ 5. Selvstændigt liv og samfundsinklusion.

[197] In the population 16-64 years old 30 % report having a disability or a mental health problem.

[198] National Institute of Human Rights, (2018) *Report Inzicht in inclusive,* September 2018. https://www.mensenrechten.nl/nl/node/2281.

Figures from Statistics Norway (2018) show that young people with disabilities have much lower quality of life compared to peers in the general population. Although 75 % of people aged 25-44 are largely satisfied with life and think what they are doing is meaningful, the proportion of young people with disabilities with the same view is as low as 40 %.[199] Regarding a sense of belonging, 19 % of young people with disabilities say that they struggle with social contact due to health problems, compared with only 4 % of young people in general and twice as many young people with disabilities say they have barely participated in social activities in the last week (15 % and 7 %, respectively). Likewise, 30 % of persons with disabilities aged 25 to 44 have psychological difficulties, as compared to 9 % of the general population of the same age.

Several ANED countries do not appear to be either collecting or making publicly available data on performance and progress. For example, relevant data are unavailable in Liechtenstein, Malta and Serbia. In response to requests from the Slovenia ANED country expert, the office for the implementation of the cohesion politics at the Ministry of Labour, Family, Social Affairs and Equal Opportunities said that the results of the evaluations and reports of the projects funded by the EU are not publicly available. No answers were given upon a written request regarding the funds and measures in the area of de-institutionalisation. The Department of Social Affairs was also approached, and it advised that funded projects are not evaluated.

4.5 Performance against goals and targets

As noted in 4.4.2 above, data on the impact of strategies and programmes are not always available, and several countries do not have dedicated strategies or programmes on the right to live independently and to be included in the community.

The table below therefore provides a summary of available data on the overall performance of European countries against their published national level strategic goals and targets.

Country	Impact of strategies and programmes
Bulgaria	By the end of 2015, all institutions for children with intellectual disabilities had been closed. However, six of these turned into institutions for adults as the children who were placed in them turned 18.[200] The implementation of the Updated Plan for De-institutionalisation of Children (2016-2020) is lagging behind as admissions to children's institutions remain open. The share of the institutionalised children that were disabled was nearly 1.4 times higher in 2017 compared to 2010. The deficit of early intervention and prevention of abandonment leads to the fact

[199] https://www.ssb.no/helse/artikler-og-publikasjoner/unge-med-nedsatt-funksjonsevne-har-darligere-livskvalitet.

[200] Bulgarian Helsinki Committee (2016), *Unhappening Deinstitutionalization of Persons with Mental Disabilities*, pp.12-13, available at: http://www.bghelsinki.org/media/uploads/documents/reports/special/2016_nesluchvashtata_se_deinstitucionalizacia_na_licata_s_umstveni_zatrudnenia_v_bulgaria_[978-954-9738-37-7].pdf.

Country	Impact of strategies and programmes
	that 57 % of all admissions in IMSCC in 2017 are disabled babies and children. De-institutionalisation of adults is lagging. There is no report yet on the implementation of the Action Plan for De-institutionalisation of Adults (2018-2021). The number of residential, day care and personal assistance services is gradually growing while waiting lists for placement in institutions are also longer each year. The demand for community-based services is much greater than the current provision.
Croatia	Goals from the *Plan of Transformation and De-institutionalisation of Social Welfare Homes and Other Legal Entities Performing Social Welfare Activities in the Republic of Croatia for the Period 2011-2016 (2018)* have not been fully achieved. By 2016, 48 % of disabled children were supposed to be in institutions, and according to the latest data (from 2016) 73 % of disabled children are still in institutions. Similarly, 49 % of adults with physical, intellectual and sensory impairments were supposed to be in social welfare homes. According to data from 2016, 56 % of adults from that population are still in social welfare homes. In 2015 and 2016 382 adults were de-institutionalised, and during the same period approximately the same number of new users, 337 were placed in institutions. Among persons with mental impairments 70 % are in social welfare homes, and the plan was for there to be no more than 68%.
Czech Republic	Data indicates that the capacity of large social care facilities for persons with disabilities decreased by 26 % during the period 2007 – 2017. In contrast, the number of places in the sheltered housing services increased by 96 %. Increase of persons residing in homes with a special regime also increased. The monitoring report conducted in 10 institutional care facilities which participated in the Project 2 shows that the capacity decreased by 13.57 % from 3 649 beds (31 December 2013 - project commencement) to 3 154 (31 December 2015 – the project completion). Alternatives to the institutional care facilities increased by 18.14 % which equates to 431 beds (31 December 2015) [201]
Estonia	According to the Ministry of Social Affairs, Estonia has achieved and even slightly exceeded the target set for persons with special care needs. The 2017 target was 1:6 supporting

[201] MoLSA (2015) *Mapování průběhu transformace v organizacích zapojených v projektu Transformace sociálních služeb 2013 – 2015*.

Country	Impact of strategies and programmes
	services users per one 24-hour institutional care service user. The actual ratio was 1:7. A challenge is applying the approach to long-term care services that are targeted for elderly persons. It seems that the number of older persons in institutional care and financing thereof increases faster than services provided for community living.
Finland	Over the last decade there has been an observable decrease in the number of disabled residents in institutions. Accordingly, an increasing number of people with intellectual disabilities live in communities. The progress during the last few years, however, has been stagnating. The objective of reaching full de-institutionalisation of persons with disabilities by 2020 is at risk. At a time of austerity with major changes in disability services, the future of the DI process remains uncertain.
Ireland	Overall, the targets have not been met under the time to move on strategy. However, the review of policy implementation highlights the progress regarding the target of closing all congregated settings and transferring 500 people per year from 2011 to 2018. In the period 2012-2017, 661 people have been supported to transition into community-based independent living.[202] In 2014, 67 people transitioned, in 2015, 150 people transitioned and there was a drop in 2016 with only 74 transitions, followed by another increase in 2017 with 144 people transitioning into the community.[203] During the same period 592 residents passed away and 222 were admitted or re-admitted to congregated settings.[204] The discrepancy between the target of 500 people per year and the actual transitions of 661 people over five years shows a stark failure of the Irish government to meet its commitments.
Latvia	According to data from the Ministry of Welfare (November 2018), social services funded by the ESF are provided to 153 adults with mental impairments, with an average of 66 persons per year leaving the long-term care institutions between 2012-2017. Compared with 2012, one long-term social care institution has been closed; the total number of places in long-term care institutions has decreased by 283 places, while the share of community-based services has increased from 20 % to 23 %.
Lithuania	The number of people who are living in institutional care

[202] HSE (2017), 'Review of the Implementation of Time to Move On 2012- 2017', p.10.
[203] HSE (2017), 'Review of the Implementation of Time to Move On', p.11.
[204] HSE (2017), 'Review of the Implementation of Time to Move On 2012- 2017', p.10.

Country	Impact of strategies and programmes
	remains almost unchanged from 2013, despite a target to decrease by 40 % the number of adult people with disabilities who are entering institutional care.
Netherlands	The National Human Rights Institute states in its monitoring report[205] on implementing Article 19 of the CRPD, that the most important principle of Article 19 is the respect for personal autonomy, including the right to determine where to live and with whom to live and that an important part of Article 19 is the aim to provide support not in residential settings but in one's own environment. The Human Rights Institute concludes in its monitoring report that no progress has been made on both aspects in the Netherlands between 2012 and 2016.
Romania	Progress in achieving targets and milestones has been slow and nonlinear, at times even regressive. The adoption of the strategy along with its corresponding action plan was frequently postponed until it was finalised eight years after the initial pledge. It is also difficult to measure progress because targets are vague and non-specific. The strategy provides a list of specific objectives to be accomplished by 2020 but in the absence of clear indicators and monitoring, it is difficult to measure the progress of its implementation.
Slovenia	Despite the targets and milestones described in the resolution, the actual activities in this area are moving away from the targets (Flaker 2017: 202-204; Zaviršek 2018). Institutional care and community-based systems are growing in parallel. The management of long-stay institutions and social workers prioritise institutional living and oppose de-institutionalisation; the structure of social welfare funding shows that the priority is given to long-stay institutions; there are no social housing funds for people to move out of the long-stay institutions; the Ministry of Labour, Family, Social Affairs and Equal Opportunities promises de-institutionalisation but in reality invests money to reconstruct closed wards of long-stay institutions.
UK (England)	Targets were set in 2015 to close at least 35-50 % of inpatient provision for people with learning disabilities and/or autism by March 2019. The National Health Service long-term plan, published in January 2019, extended the target date to March 2023.

4.6 Summary and conclusions

[205] See paragraph 3.4.2.

Arrangements bearing the hallmarks of institutional care are prevalent and persistent across all European States. Commitments to end or reduce reliance on institutional care have been made by a number of ANED countries. Policies have been adopted and programmes have been initiated that have begun to effect a gradual move away from large-scale institutional care arrangements. However, the process of change is often slow and faltering. Public expenditure on care and support in the majority of ANED countries continues to be disproportionately consumed by institutional care. European Union funding plays a pivotal role in supporting projects focused on de-institutionalisation, which, though welcome, also raises important questions about future sustainability and domestic level political commitments.

Among people with disabilities who do not live with their families, smaller scale congregate forms of care and living arrangements are commonplace, including in those ANED countries that have already closed down large institutions. These are frequently the alternative living and support arrangement that are being developed to resettle persons with disabilities from large institutions. Although some countries have implemented measures designed to accord persons with disabilities choice and control, such as personal assistance schemes and individualised or personal budgets, these are often limited in scope, or pilot schemes, which while benefiting the existing participants, do not appear to have had a large scale impact so far. Taken together, the evidence collected confirms the finding of previous studies that rather than being replaced, in many cases, institutional care may simply be being re-imagined.

As a result, hundreds of thousands of children and adults with disabilities in Europe continue to be denied their human rights, including the right to liberty, to live independently and to be included in the community.

5 Concluding remarks and recommendations

5.1 Concluding remarks

The first ANED study on independent living was carried out 10 years ago, in 2009.[206] The findings of the 2019 study are strikingly similar: high-level policy commitments are commonplace but their ambition is rarely matched by implementation on the ground; there remains a lack of common definitions of 'independent living' and 'institutions'; institutional care is prevalent and persistent and where 'community-based care' is being developed, it bears hallmarks of institutional care, such as the high reliance on modes of congregate living and care arrangements; the under-development of community based infrastructure acts to undermine efforts to wind down institutional care provision, including user-led personal assistance; there is sometimes a belief that independent living is not achievable for people with significant support needs and a perception that independent living is prohibitively expensive; there is a lack of research into outcomes for persons with disabilities; and although persons with disabilities and their organisations are perhaps more involved in the elaboration of policies and strategies than was reported in 2009, they are infrequently involved in implementation.

There is evidence of progress since 2009, in particular a gradual shift away from large-scale institutions and the elaboration of detailed strategies and plans in some countries. It is also too early to account for the result of a number of independent living projects established with support from the ESIF 2013-20 funding round, some of which are ongoing or have only recently begun. However, the findings of this 2019 ANED study can be summarised with the conclusions of the authors of the ANED synthesis report in 2009:

> 'Progress is hugely varied with arguably too few countries offering good community options or effective support for independent living (with a small number of exceptions). Progress still risks excluding some specific groups. One key question is whether there is a clear, shared vision of independent living – above and beyond the detail of how to make it happen? More work remains to be done to put disabled people at the heart of decision making about independent living at every level.'

5.2 Recommendations

5.2.1 Recommendations to European States

All European States should:

- Develop rights-based, targeted and deliverable plans concerning the implementation of disabled people's rights to live independently and to be included in the community, guided by General Comment 5 of the UN Committee on the Rights of Persons with Disabilities.

[206] Townsley, R. et al (2009) *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report*, ANED.

- Actively involve organisations of persons with disabilities as partners, in the development, implementation and monitoring of plans.

- Take measures, including support for innovation, increased investment and regulatory measures, to diversify housing and support options for persons with disabilities and to limit the development of congregate or clustered housing and care arrangements.

- Promote and invest in architecture to expand and deepen choice and control, including via supporting the development of user-led personal assistance schemes, allied to individualised budgets and direct payment schemes and investing in peer support.

- Reform laws to accord persons with disabilities enforceable rights to choose and to refuse where and with whom to live.

- Significantly improve systems of monitoring and data collection, based on General Comment No 5 of the UNCRPD Committee, and for example by harnessing the independent living indicators developed by the EU Agency for Fundamental Rights.

- Establish or invest in awareness-raising initiatives to promote receptiveness to the independence and inclusion of people with disabilities by the general public.

- Engage constructively with the UNCRPD Committee and other UN Treaty Bodies, responding to and acting on concluding observations and recommendations.

5.2.2 Recommendations to the European Commission

The European Commission should:

- Recognise that the implementation of the right of persons with disabilities to live independently and to be included in the community is a challenge for Europe and the EU as a whole, not only for those countries maintaining large, discernible institutional care facilities. In particular, through the European semester process and the post-2020 ESIF programming, it should seek to expand the number of Member States that commit to action on independent living in their national reform programmes and post-2020 partnership agreements and operational programmes.

- Take steps to ensure awareness and understanding of the UNCRPD and the right to live independently and to be included in the community across the European Commission.

- Consider how to give prominence to the concept and true meaning of independent living rather than ‘community-based care’ in future strategy and

policy, regulation and guidance, drawing upon the UNCRPD Committee General Comment 5.

- Establish and promote common definitions of institutional care and independent living, drawing upon General Comment 5, including providing clearer guidelines on the need to move away from congregate living arrangements and encouraging Member States to invest in a diversity of housing and support options.

- Encourage investment, via EU funding and beyond, in architecture to expand and deepen choice and control, including the development of user-led personal assistance schemes, individualised budgets and direct payment schemes and investment in peer support and innovative practice by organisations of people with disabilities.

- Encourage investment in social infrastructure to build community capacity, especially investment in disabled people's user-led organisations.

5.2.3 Recommendations to national human rights bodies

National human rights bodies, CRPD independent mechanisms and OPCAT national protection mechanisms should:

- Draw on the manual 'Human Rights and Disability' produced by the Asia Pacific Network of National Human Rights Institutions to ensure that they are advancing the rights of persons with disabilities in both their operations and programmes.

- Conduct monitoring and inspection of institutional care facilities, including congregate and clustered living arrangements.

- Monitor progress towards implementation of the right to live independently and to be included in the community and report at the national level and to UN human rights treaty bodies, including the UNCRPD Committee.

- Ensure that complaints handling is accessible and conduct outreach to marginalised disabled people.

- Where available, use legal powers to support strategic litigation.

5.2.4 Recommendations to the Council of Europe Commissioner for Human Rights

The Council of Europe Commissioner for Human Rights should:

- Continue to promote the right to live independently and to be included in the community, including via country visits.

- Address inconsistencies in opinions on independent living and on the rights of older persons concerning the compatibility of congregate forms of care with human rights standards.

- Ensure that its vital work on information and communications technology and artificial intelligence considers the particular opportunities and risks for disabled people, including with respect to supported decision making and the right to live independently and to be included in the community.