Role of the European Union funding in supporting deinstitutionalisation around the world: A Call for Change

Joint report by EDF and ENIL

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The European Disability Forum

The European Disability Forum is an independent NGO that represents the interests of 100 million Europeans with disabilities. EDF is a unique platform which brings together representative organisation of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

The European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organizations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalization, democracy, self-representation, cross disability and self-determination.

Acknowledgements

Executive Summary

This report, written by the European Network on Independent Living for the European Disability Forum, looks at the use of the European Union (EU) funding for external action. The report sets out to establish if the EU funding supported the process of deinstitutionalisation (DI) globally during 2014 – 2020. This includes the closure of institutions and the development of community-based supports and services, and the prohibition of building or renovating institutions.

Information for the report was collected between July and November 2021, through desk research, access to information requests to the European Commission, an online survey, two focus groups, as well as several interviews. The report makes it clear that more extensive research is needed to get a full picture of EU's support for DI globally.

Chapter I: Scope of the report begins by explaining that the EU is the biggest development and humanitarian aid donor in the world, and as such, is in a prime position to address the ongoing social exclusion and segregation of children, adults and older persons with disabilities in institutions. However, due to the complexity of EU funding and a lack of transparency, it is very difficult to understand to what extent the EU facilitates access to the right to live independently and being included in the community around the world.

Chapter II: The case for deinstitutionalisation notes that the EU is the only regional integration organisation which ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), in 2010. However, despite broad ratification of the Convention world-wide, it is estimated that between 5 and 6 million children live in institutions. No overall figure exists in relation to adults and older people with disabilities. There are still many barriers to implementation of Article 19 CRPD (living independently and being included in the community), from the denial of legal capacity, the lack of supports and services, to misconceptions about the right to independent living. The COVID-19 pandemic has made the situation worse for persons with disabilities, especially those in institutions.

Chapter III: Overview of funding instruments in the European Union explains the main elements of EU external action funding and how they are delivered. While the focus is on 2014 – 2020, changes in the current programming period (2021 – 2027) are also discussed. Although the EU received a recommendation from the Committee on the Rights of

Persons with Disabilities, in 2015, to use international development funding in compliance with the Convention, very few funding instruments refer explicitly to the CRPD or the need to support DI. Humanitarian aid is dealt with in a separate section, and it is explained how non-governmental organisations work in partnership with the Commission to implement projects on the ground. Since 2019, there is guidance in place on how to include persons with disabilities in EU-funded humanitarian aid projects.

Chapter IV: EU funding in practice summarises existing research on the use of EU funding to support DI globally. Such research is very limited and focuses mainly on children. To understand the situation better, requests for information were submitted to the European Commission, but the response was also limited. In some cases, the Commission did not have the requested information, or had refused to provide it.

Chapter V: Views of DPOs and CSOs on EU's role in supporting deinstitutionalisation provides extremely useful information on the key barriers to independent living in the context of EU external action funding. These are: a) lack of projects on DI funded by the EU; b) DI understood as moving residents from large to small institutions; c) lack of clear criteria for the selection of projects; d) contracts awarded to beneficiaries with lack of expertise on DI; e) lack of sustainability of the newly-developed services; f) difficulty of accessing comprehensive information about the projects funded; and g) lack of involvement of DPOs in the programming, implementation and monitoring of EU funds.

Chapter VI: Recommendations sets out actions that must be taken by the European Union institutions, with a view to ensure better support for DI reforms globally. Among the key recommendations is the need for significantly more investment in disability-specific projects, in particular in support of DI reforms and the development of community-based supports and services. Furthermore, there is a need for clear guidance and criteria by the European Commission on CRPD-compliant deinstitutionalisation, and an intersectional approach in the use of funds. Several recommendations focus on improving the monitoring of funds use, through indicators linked to the closure of institutions and prevention of institutionalisation, as well as improved transparency of EU funding for external action. Finally, this report calls for the full involvement of persons with disabilities and their representative organisations, including persons with disabilities in institutions and survivors of institutionalisation.

Easy to Read version of the Executive Summary is available online.

List of abbreviations

CSOs	Civil Society Organisations
DGs	Directorates-General
DG ECHO	Directorate-General for European Civil Protection and Humanitarian Aid Operations
DG INTPA	Directorate-General for International Partnerships
DG NEAR	Directorate-General for Neighbourhood and Enlargement Negotiations
DI	Deinstitutionalisation
DPO	Disabled persons' organisation
EDF	European Disability Forum
EEAS	European External Action Service
ENIL	European Network on Independent Living
ESIF	European Structural and Investment Funds
IPA	Instrument for Pre-Accession Assistance
NDICI	Neighbourhood, Development and International Cooperation Instrument
NGOs	Non-governmental organisations
ODA	Oversees Development Assistance
OECD	Organisation for Economic Co-operation and Development
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities

Glossary

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) recognises the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives.

Directorates-General (DGs) are policy departments which develop, implement and manage EU policy, law, and funding programmes.

DG European Civil Protection and Humanitarian Aid Operations (ECHO) ensures rapid and effective delivery of EU relief assistance. Its main mission is to preserve lives, prevent and alleviate human suffering and safeguard the integrity and dignity of populations affected by natural disasters and man-made crises.

DG Neighbourhood and Enlargement Negotiations (DG NEAR) is responsible for EU policy on enlargement and the EU's eastern and southern neighbours**.**

Disable People's Organisations (DPOs) are organisations led, directed and governed by persons with disabilities, including family members, which represent the interests and defend the human rights of persons with disabilities through self-representation and advocacy.

European Union (EU) is a unique economic and political union between 27 European countries, as it stands at the time of the creation of this publication.

EU Charter of Fundamental Rights was declared in 2000 and brings together the most important personal freedoms and rights enjoyed by citizens of the EU into one legally binding document.

The 2030 Agenda for Sustainable Development refers to Resolution 70/1, unanimously adopted by the United Nations General Assembly in September 2015. It sets out 17 Sustainable Development Goals, which aim to mobilise global efforts to end poverty, foster peace, safeguard the rights and dignity of all people and protect the planet.

UN Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty that reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms. It recognises that all persons with disabilities have the right to participate in civil, political, economic, social and cultural life of the community, just as anyone else.

Chapter I: Scope of the report

This chapter explains the scope of the report, its methodology and limitations. It ends by setting out the structure of the report.

1.1. Introduction

As the biggest development and humanitarian aid donor in the world, the European Union (EU) is in a prime position to address the ongoing social exclusion and segregation of children, adults and older persons with disabilities in long-stay residential institutions. Despite the adoption and broad ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), including by the EU, persons with disabilities around the world continue experiencing institutionalisation, poverty, denial of education, exclusion from the labour market and inability to access mainstream services, among other.

The COVID-19 pandemic has exacerbated the already existing inequalities and exposed horrific human rights violations in institutional care settings. It has brought to fore the need to accelerate deinstitutionalisation reforms, to ensure that all persons with disabilities are able to live in their own homes with the support they need, and to make choices and decisions about their lives.

The aim of this report is to look at whether the EU, through its external action funding, supported the process of deinstitutionalisation during 2014 – 2020. The report deals with two main questions:

- To what extent has the EU supported the closure of institutions and the development of community-based support infrastructure, in line with Article 19 (Living independently and being included in the community) of the CRPD?
- Is there any evidence that EU funding contributed to maintaining the system of institutional care, through renovation or building of institutions, for instance?

The report was commissioned by the European Disability Forum (EDF) and researched and written by the European Network on Independent Living (ENIL). Its aim is to improve the understanding of the EU institutions, other funders, development organisations, persons with disabilities and their representative organisations (DPOs), service providers and the general public on the role of the EU in supporting deinstitutionalisation of persons with disabilities globally. The report also

provides recommendations on changes which should be considered to ensure that funding provided by the EU improves opportunities for persons with disabilities of all ages to enjoy their right to live independently and to be included in the community.

1.2. Methodology and limitations

Research for this report was carried out between July and November 2021. Due to the limited time for writing of the report and the limited resources, its aim is not to provide a comprehensive picture of EU support to deinstitutionalisation around the world. The expectation is, however, that more extensive research may be done in the future to better understand the needs for financial support by the EU in this area.

Information for the report was gathered through desk research, access to information requests (to the European Commission Directorates-General and the European External Action Service), an online survey, two focus groups, as well as several interviews with the European Commission officials and NGOs.

The online survey was disseminated by ENIL, EDF and the International Disability and Development Consortium, and was available in English, Russian, French, Spanish and Arabic[1]. A total of 14 responses were received, mostly in English. Taking into consideration the low response rate to the survey, which may be linked to the lack of information that is available to DPOs, two focus groups were organised in November, one for the countries in the Western Balkans and one for other countries in the EU neighbourhood. The first meeting was attended by representatives of DPOs and CSOs from Serbia (2 organisations), Montenegro (2 organisations) and North Macedonia. The second meeting was attended by participants from Albania (2 organisations), the Republic of Moldova, Georgia, Armenia, Turkey and Serbia. The input from these focus groups has been very important for understanding the key issues in relation to EU funding of deinstitutionalisation projects, considering that the majority of participants had either taken part or were consulted in relation to DI projects implemented in their countries. In addition to the focus groups, interviews were held with two organisations, namely Humanity & Inclusion and EU CORD, focusing on humanitarian aid.

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[1] The survey questions can be viewed at:
https://docs.google.com/forms/d/e/1FAIpQLSc9Q3MRRsVFOTUOklse4e5dVEE03S4R1nubQIEXVkvNbGy7sg/viewform

A total of six requests for information were submitted to the European Commission, via the asktheeu.org online platform. Five requests were for information on EU funded projects concerning persons with disabilities, and 1 was for information on about a specific project in North Macedonia. As of the 17 January 2022, only three out of the six requests resulted in some information being provided, even though there is a 15 working day legal limit for responding to requests (which can be prolonged by another 15 working days). Lessons learnt from this process are discussed later in the report, but it is clear that more time would be needed to submit additional requests and to chase answers from the relevant departments.

In addition to information requests, a meeting was held with the disability focal point at DG ECHO and a meeting with DG NEAR was requested, but has not taken place. Other DGs were not approached for a meeting due to the limited time available.

In summary, the main limitation of this report is the difficulty of accessing information about EU funded projects in general, and projects related to deinstitutionalisation in particular. The short time that was available for the writing of the report therefore only allowed for a first insight into how EU funds were being spent, with more research required to obtain a more complete and accurate picture.

1.3. Structure of the report

The report is divided into the following chapters:

Chapter I: Scope of the report - This chapter explains the scope of the report, its methodology and limitations.

Chapter II: The case for deinstitutionalisation - The focus on this chapter is on the current context – the continued institutionalisation of persons with disabilities, and the barriers to the implementation of the right to live independently and being included in the community. The chapter explains the main concepts, key instruments and policies which form a legal basis for supporting deinstitutionalisation reforms and investing in independent living.

Chapter III: Overview of funding instruments in the European Union - This chapter explains the main funding instruments that form the EU external action, and to what extent they include persons with disabilities. It explains the difference between the 2014 – 2020 and the 2021 – 2030 funding periods, and how the EU distributes its humanitarian aid.

Chapter IV: EU funding in practice – This chapter provides an overview of information that is available about EU funded projects focused on deinstitutionalisation or persons with disabilities in general. It presents the information collected from desktop research and the European Commission.

Chapter V: Views of DPOs and CSOs on EU's role in supporting deinstitutionalisation – The main findings on EU investments in deinstitutionalisation, collected from interviews with DPOs and CSOs, are presented and discussed under seven headings.

Chapter VI: Recommendations – This chapter sets out a number of recommendations on how to ensure better support by the European Union for deinstitutionalisation reforms globally, based on the findings of this report.

Chapter II: The case for deinstitutionalisation

The focus on this chapter is on the current context – the continued institutionalisation of persons with disabilities, and the barriers to the implementation of the right to live independently and being included in the community. The chapter explains the main concepts, key instruments and policies which form a legal basis for supporting deinstitutionalisation reforms and investing in independent living.

2.1. Persistent barriers to independent living

The right to live independently and to be included in community is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Article 19 requires States Parties to the Convention to ensure that persons with disabilities "have the opportunity to choose their place of residence of where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement". They must be provided with a range of community-based services "necessary to support living and inclusion in the community, and to prevent isolation or segregation". Mainstream services and facilities must also be made accessible "on an equal basis to persons with disabilities" and "responsive to their needs".

Article 19 is "one of the widest ranging and most intersectional articles" and "integral for the implementation of the Convention across all articles"[2]. Without independent living, persons with disabilities are unable to exercise many other Convention rights, such as education (Article 24), work and employment (Article 27), health (Article 25), adequate standard of living (Article 28), participation in political and public life (Article29), and many other.

Despite the broad ratification of the CRPD globally, there are still wide gaps in the implementation of Article 19, and other rights, in practice. It is estimated that between 5 and 6 million children live in institutions worldwide[3], while no overall figure exists in relation to adults and older

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[2] General Comment No. 5 (2017) on living independently and being included in the community, para 6. Available at:
http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt9 3Y3D%2baa2q6qfzOy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3Z YxFwEgh

[3] This is the overall number for children, there is no disaggregated data for children with disabilities.

people[4]. In the 27 countries of European Union, at least 1,4 million people[5] still live in institutions[6], with 302,979 children living in residential care settings.[7]

Moreover, many persons with disabilities living in the community, around the world, are unable to access the support and services they need to live independently, and face inaccessible environments and stigma. The continued institutionalisation of children and adults with disabilities, in large and small institutions, and the lack of community-based infrastructure, presents a major challenge at the global level. The General Comment 5, on Article 19 CRPD, highlights the remaining barriers to the implementation of this right (see below).

The dangers of institutionalisation were highlighted during the COVID-19 pandemic, with an average of 41% of deaths linked to COVID-19 being among residents in care homes.[8] The COVID-19 Disability Rights Monitor, which collected over 3,000 testimonies by persons with disabilities and their families from around the world, including those in institutions, highlighted wide-ranging abuses in institutional care settings. These included severe and prolonged isolation, denial of care, discrimination in accessing health care, lack of information about the measures being taken and failure to access PPE (personal protective equipment).[9]

The impact of the COVID-19 pandemic on children, adults and older persons in institutions has provided an additional impetus for the closure of institutions and the moratorium on new admissions. Yet, as a result of the pandemic, in many countries, deinstitutionalisation reforms have been delayed or stopped, with other economic or human rights concerns taking a higher place on the Government and donors' agendas. For this reason,

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[4] Knapp M, Cyhlarova E, Comas-Herrera A, Lorenz-Dant K (2021), *Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities*, Care Policy and Evaluation Centre, London School of Economics and Political Science, page 12. Available at: https://www.lse.ac.uk/cpec/assets/documents/CPEC-Covid-Desinstitutionalisation.pdf (further referred to as the "LSE Report")

[5] This includes persons with disabilities, including persons with psychosocial disabilities, persons experiencing homelessness, children and older adults.

[6] Šiška, J. and Beadle-Brown, J. (2020). Transition from Institutional Care to Community-Based Services in 27 EU Member States: Final report. Research report for the European Expert Group on Transition from Institutional to Community-based Care, page 3. Available at: https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf

[7] This figure refers to all children (with and without disabilities) in the EU and the United Kingdom. UNICEF and Eurochild Datacare Project, see: https://eurochild.org/uploads/2021/12/Children-in-alternative-care_Comparable-statistics-to-monitor-progress-on-DI-across-the-EU.pdf (page 9)

[8] LSE report, page 34.

[9] Brennan, Dr Ciara Siobhan (2020), Disability rights during the pandemic, *A global report on findings of the COVID-19 Disability Rights Monitor.* Available at: https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf

the CRPD Committee established a working group on deinstitutionalisation in August 2020, to elaborate new guidelines on deinstitutionalisation, including emergency deinstitutionalisation, until 2022.[10]

Barriers to implementation of Article 19 CRPD set out in the General Comment 5:

a) Denial of legal capacity, either through formal laws and practices or de facto by substitute decision-making about living arrangements;
b) Inadequacy of social support and protection schemes for ensuring living independently within the community;
c) Inadequacy of legal frameworks and budget allocations aimed at providing personal assistance and individualized support;
d) Physical and regulatory institutionalization, including of children and forced treatment in all its forms;
e) Lack of deinstitutionalization strategies and plans and continued investments in institutional care settings;
f) Negative attitudes, stigma and stereotypes preventing persons with disabilities from being included in the community and accessing available assistance;
g) Misconceptions about the right to living independently within the community;
h) Lack of available, acceptable, affordable, accessible and adaptable services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services and public buildings;
i) Lack of adequate monitoring mechanisms for ensuring the appropriate implementation of article 19, including the participation of representative organizations of persons with disabilities;
j) Insufficient mainstreaming of disability in general budget allocations;
k) Inappropriate decentralization, resulting in disparities between local authorities and unequal chances of living independently within the community in a State party.[11]

2.2. Definitions of key terms

As noted in the General Comment 5, one of the barriers to implementing Article 19 are the misconceptions about the right to live independently within the community. Without a common understanding of what is

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[10] See page of the Committee on the Rights of Persons with Disabilities, available at: https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx
[11] General Comment No. 5, para 15.

"independent living", "personal assistance" and "deinstitutionalisation", there is a danger that the newly developed services will contain elements of institutional culture under the guise of community living. For this reason, the General Comment 5 includes definitions of the key terms, while the European Network on Independent Living – ENIL has developed a Myth buster[12], with common misconceptions about what it means to live independently.

Including definitions in the relevant policies, strategies, action plans and guidance for funding may help avoid misuse of the independent living terminology to create new institutions.

2.2.1. What is independent living?

"Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights."[13]

2.2.2. What is an institution?

"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. [...] Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a

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[12] European Network on Independent Living (2014), *Myth Buster on Independent Living.* Available at: http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf
[13] General Comment No. 5, para 16a.

family. "Family-like" institutions are still institutions and are no substitute for care by a family."[14]

2.2.3. What is deinstitutionalisation?

Deinstitutionalisation requires "a systemic transformation, which includes the closure of institutions and the elimination of institutionalising regulations as part of a comprehensive strategy, along with the establishment of a range of individualised support services, including individualised plans for transition with budgets and time frames as well as inclusive support services. Therefore, a coordinated, cross-government approach which ensures reforms, budgets and appropriate changes of attitude at all levels and sectors of government, including local authorities, is required."[15]

2.3. Legal basis for deinstitutionalisation

There is a strong legal basis for the closure of institutions and the development of community-based support systems, stemming from the CRPD and other laws and policies at the international and regional level (see Table 1). Considering that this report deals with funding provided by the EU, the focus is on policies and laws at the EU level in its global work. However, other regional treaties, such as the European Convention on Human Rights and the European Social Charter, the American Convention on Human Rights and the African Charter on Human and People's Rights, are relevant to countries benefiting from the funds.

The European Union is the only regional integration organisation world-wide that ratified the CRPD, in 2010, and is therefore bound by the provisions of the Convention. The General Comment 5, on Article 19, contains specific guidance for State Parties to the CRPD in relation to funding. Thus, the EU and other States Parties must "ensure that public or private funds are not spent on maintaining, renovating, establishing, building or creating any form of institution or institutionalisation"[16] and should use all available funding "to develop inclusive and accessible independent living services"[17]. As part of their obligations under the CRPD, they should take "deliberate and immediate steps to reallocate

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[14] *Ibid,* para 16c.
[15] *Ibid,* para 58.
[16] *Ibid,* para 51.
[17] *Ibid,* para 38(h).

funding into realising the possibility of persons with disabilities to be living independently in the community"[18].

The 2030 Agenda on Sustainable Development, which both the EU and national governments have endorsed, also provides a solid framework to address the social exclusion of persons with disabilities in institutions or through the lack of community-based support systems.

Moreover, the Council of Europe (CoE) Commissioner for Human Rights published an Issue paper[19] on the right to independent living in 2012, which includes indicators and guiding questions that can be used to monitor whether governments are implementing Article 19 CRPD.

Table 1: Legal and policy basis for supporting deinstitutionalisation

UN Convention on the Rights of Persons with Disabilities[20]	The UN Convention on the Rights of Persons with Disabilities (CRPD) has been ratified by the EU and another 181 countries across the globe, while 96 countries ratified the Optional Protocol. The articles most relevant to investments of EU funds that have as their objective "deinstitutionalisation" and/or "development of community-based services" are Article 5 (equality and non-discrimination), Article 12 (equal recognition before the law), Article 13 (access to justice) and Article 19 (living independently and being included in the community).
	With regard to development cooperation and humanitarian aid, Article 32 (international cooperation) requires that States Parties ensure "that international cooperation, including international developmental programmes, is inclusive of and accessible to persons with disabilities". Moreover, according to Article 11 (situations of risk and humanitarian emergencies), States Parties must take "all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk,

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[18] *Ibid*, para 59.

[19] Council of Europe (2012), The right of people with disabilities to live independently and to be included in the community, Issue Paper published by the Council of Europe Commissioner for Human Rights. Available at: https://rm.coe.int/the-right-of-people-with-disabilities-to-live-independently-and-be-inc/16807bef65

[20] United Nations Convention on the Rights of Persons with Disabilities, see: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

	including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters."
	General Comments[21], adopted by the CRPD Committee, act as authoritative guidance and should be used by governments and the EU institutions to interpret their obligations under the CRPD. General Comment 5 on living independently and being included in the community contains a number of recommendations in relation to deinstitutionalisation.
	Concluding Observations (COs)[22] in respect of the State Parties reviewed by the CRPD Committee also in many cases refer to the use of EU funds. In the COs on the European Union[23], the Committee expressed concern "that EU international development funding is used to create or renovate institutional settings for the placement of persons with disabilities, segregated special education schools and sheltered workshops, contrary to the principles and provisions of the Convention."
UN Convention on the Rights of the Child[24]	The UN Convention on the Rights of the Child (CRC), ratified by all European countries, recognises that children should grow up in a family environment.
	The 2019 European Parliament Resolution[25] on the occasion of the 30th anniversary of CRC calls on the European Commission "to use EU funds to support the transition from institutional to community-based services, both inside and outside the EU."

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[21] United Nations Human Rights Office of the High Commissioner, Committee on the Rights of Persons with Disabilities, General Comments, see: https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx

[22] All the Concluding Observations are available here: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5

[23] See: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/226/55/PDF/G1522655.pdf?OpenElement

[24] United Nations Convention on the Rights of the Child, see: https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

[25] European Parliament resolution on children's rights on the occasion of the 30th anniversary of the Convention on the Rights of the Child (2019/2876(RSP)). Available at: http://www.europarl.europa.eu/doceo/document/B-9-2019-0180_EN.html?redirect

EU Charter of Fundamental Rights[26]	EU Charter stipulates in Article 21 the prohibition of discrimination, in Article 26 the right of persons with disabilities to participate in the life of the community and in Article 24 the children's right to protection and care according to their best interests.
Sustainable Development Goals (SDGs)[27]	Targets under Goals (SDGs) 4 (quality education), 8 (decent work and economic growth), 10 (reduced inequalities), 11 (sustainable cities and communities) and 17 (partnership for the goals) explicitly mention disability, among other marginalised groups. The EU has committed to implementing SDGs, and under each of the goals has set out actions it plans to take. For example, under the Goal 10 – Reduced inequalities, the EU supports actions to "empower women and create opportunities for youth and disadvantaged communities" and to "enhance social services and ensure access to social protection"[28].
European Consensus on Development (2018)[29]	The Consensus provides a framework for the implementation of the 2030 Agenda, with a purpose of ensuring "a common approach to development policy" by the EU and its Member States (MS), and guiding the action of EU institutions and MS in the cooperation with developing countries.
	The EU and MS commit to "implement a rights-based approach to development cooperation, encompassing all human rights. They will promote inclusion and participation, non-discrimination, equality and equity, transparency and accountability", including when it comes to persons with disabilities (paragraph 16).
	In line with the principle of leaving no-one behind (LNOB), particular attention is to be given to persons with disabilities, with measures ensuring same opportunities and non-discrimination (paragraph 30).

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[26] Charter of Fundamental Rights of the European Union (2000/C 364/01), see: https://www.europarl.europa.eu/charter/pdf/text_en.pdf
[27] See: https://sdgs.un.org/goals
[28] See: https://ec.europa.eu/international-partnerships/sdg/reducing-inequality_en
[29] European Consensus on Development, see: https://op.europa.eu/en/publication-detail/-/publication/5a95e892-ec76-11e8-b690-01aa75ed71a1

	According the Consensus, the EU and MS "will take into account the specific needs of persons with disabilities in their development cooperation". Referring to the CRPD, they commit to "vigorously promote the rights of persons with disabilities and take stronger measures to ensure their full inclusion in society and their equal participation in the labour market" (paragraph 31).
European Disability Strategy 2010 – 2020[30]	The European Disability Strategy 2010 - 2020, adopted in 2010, had eight priority areas: Accessibility, Participation, Equality, Employment, Education and training; Social protection; Health and External action. Under the priority area Participation, the strategy stated that the European Commission will work 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 …". Under the priority area External action, the strategy set out to promote the rights of persons with disabilities within external action. The Commission was to raise awareness of the CRPD and the needs of persons with disabilities, including accessibility, in the area of emergency and humanitarian aid and "ensure that the financial instruments for pre-accession are used to improve their situation".
European Disability Strategy 2021 – 2030[31]	The right to independent living is one of the key priorities of the new Disability Rights Strategy, launched in March 2021, and replacing the 2010 – 2020 Strategy. It calls on the EU Member States to "implement good practices of deinstitutionalisation in the area of mental health and in respect of all persons with disabilities, including children, to strengthen the transition from institutional care to services providing support in the community".

[30] European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010)636 final, 15 November 2010, see: https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF
[31] Union of Equality – Strategy for the Rights of Persons with Disabilities 2021 – 2030, COM(20221) 101 final, see: https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes

	Under the heading "Promoting the right of persons with disabilities globally", the European Commission commits to updating the Toolbox on the "Rights Based Approach, encompassing all human rights for EU development cooperation" (in 2021), and to systematically using the Organisation for Economic Co-operation and Development (OECD), Development Assistance Committee (DAC) disability marker to track disability inclusive investments and improve monitoring.
EU Action Plan on Human Rights and Democracy 2020 - 2024[32]	The Action Plan is based around five action lines: 1) protecting and empowering individuals; 2) building resilient, inclusive and democratic societies; 3) promoting a global system for human rights and democracy; 4) harnessing opportunities and addressing challenges posed by the use of new technologies; 5) and delivering by working together. A total of 1.5 billion Euros has been allocated for its implementation. The Action Plan includes several objectives relevant to persons with disabilities, including: combating all forms of discrimination, advocating for ratification and implementation of the CRPD, accessibility and ensuring access to inclusive services.[33]
Tool-Box for a rights-based approach encompassing all human rights for EU development cooperation (2014)[34]	This toolkit, published by the European Commission, explains the meaning of a Rights Based Approach (RBA) and how to apply it in EU development cooperation. The toolkit refers to the CRPD and includes persons with disabilities under the principle of 'non-discrimination and equal access' (to the basic public services and goods supported or delivered by development interventions). The Toolkit highlights as the two main objectives "Do No Harm" and "Do Maximum Good". Under "Do No

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[32] EU Action Plan on Human Rights and Democracy 2020 – 2024, see: https://www.consilium.europa.eu/media/46838/st12848-en20.pdf
[33] See: https://www.edf-feph.org/eu-to-promote-disability-rights-globally/
[34] A Rights-based Approach, Encompassing all Human Rights for EU Development Cooperation, Commission staff working document, Tool-box, see: https://ec.europa.eu/international-partnerships/system/files/online-170621-eidhr-rba-toolbox-en-a5-lc_en.pdf

	Harm", development cooperation should not "cause unacceptable harm and human rights violations".

Chapter III: Overview of funding instruments in the European Union

This chapter explains the main funding instruments that form the EU external action, and to what extent they include persons with disabilities. It explains the difference between the 2014 – 2020 and the 2021 – 2027 funding periods, and how the EU distributes its humanitarian aid.

3.1. Introduction to EU external action

The European Union (EU) is the leading development aid donor and the biggest humanitarian aid – also referred to as the Official Development Assistance (ODA) - donor in the world, according to the OECD (Organisation for Economic Co-operation and Development).[35] Thanks to its political and economic power, its involvement in important fora and processes, as well as its worldwide presence with more than 140 EU delegations on all continents, the EU has the opportunity to address global challenges and advance progress of the CRPD implementation, as well as the 2030 Agenda.

The EU External Action is mainly funded from the EU budget, under a dedicated heading in the Multiannual Financial Framework (MFF). In addition to this, there are funding instruments and tools outside the EU budget, the development aid provided by the Member States, funds mobilised through cooperation with external lenders (such as the European Investment Bank) and donors. Understanding the different ways external action is funded is important, to show the complexity of the system and the wide range of opportunities to invest in deinstitutionalisation reforms.

A. The main elements of EU financing for external action in 2014 – 2020 were:

- Funds under the heading "Global Europe", which includes most of the European Funding Instruments (see Table 2);
- The European Development Fund, i.e. the largest development fund outside the EU budget;

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[35] European Parliament (2021), *Understanding EU financing for external action,* In-depth analysis, European Parliamentary Research Service. Available at: https://www.europarl.europa.eu/RegData/etudes/IDAN/2021/679101/EPRS_IDA(2021)679101_EN.pdf (further referred to as "European Parliament report")

- The EU trust funds for external action;
- The Facility for Refugees in Turkey;
- The EU external investment framework under the 2017 External Investment plan, in particular the European Fund for Sustainable Development and the loans and guarantees covered by the Guarantee Fund for External Actions (GFEA);
- Other special instruments, such as the Emergency Aid Reserve and the European Union Solidarity Fund.

These funds were distributed in a variety of delivery modes – through grants, loans, investments, guarantees and other – and through different channels, via implementation partners. A significant proportion of EU funding was implemented through multilateral organisations, particularly UN agencies. This, according to a European Parliament report, is due to "their specific expertise, unique capacities, privileges and access to humanitarian aid, and their ability to ensure the continuation of existing programmes", among other. Thus, during 2018, 25% of the EU humanitarian aid, 22% of the Development Cooperation Instrument and around 10% of the European Neighbourhood Instrument and the Instrument for Pre-accession Assistance (IPA II) were contracted to international organisations.[36]

The same report concludes that this complexity and fragmentation of external action funding "makes the overall external financing structure difficult to grasp, hinders transparency and makes it harder to clearly communicate about matters of external financing". It also "makes democratic oversight and budgetary scrutiny more challenging".[37]

Table 2: Overview of the relevant instruments under the heading 4 (Global Europe) of the 2014 – 2020 budget[38]

Instrument	Aim
Development Cooperation Instrument - DCI	The Development Cooperation Instrument focused on combating poverty in developing countries. It also contributed to the achievement of other objectives of EU external action, in particular fostering sustainable economic, social and environmental development as well as promoting

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[36] *Ibid*, page 4.

[37] *Ibid*, page 5.

[38] See: https://ec.europa.eu/info/strategy/eu-budget/long-term-eu-budget/2014-2020/funding-programmes/heading-4-global-europe_en

	democracy, the rule of law, good governance and respect for human rights
European Instrument for Democracy and Human Rights - EIDHR	The European Instrument for Democracy and Human Rights provided support for the promotion of democracy and human rights in non-EU countries.
European Neighbourhood Instrument – ENI	The European Neighbourhood Instrument promoted enhanced political cooperation and progressive economic integration between the Union and its neighbouring countries.
Instrument for Pre-Accession Assistance	The Instrument for Pre-accession provided financial support to the enlargement countries in their preparations for EU accession.
Instrument contributing to Stability and Peace – IcSP	The Instrument contributing to Stability and Peace (IcSP) was one of the key external assistance instruments enabling the EU to take a lead in helping to prevent and respond to actual or emerging crises around the world.
Partnership Instrument (PI)	The overall objective of the Partnership Instrument was to advance and promote EU interests by supporting the external dimension of internal policies (e.g. competitiveness, research and innovation, migration) and to address major global challenges (e.g. energy security, climate change and environment).

B. Changes in the EU external action funding in 2021 - 2027

In the current financing period (2021- 2027), the European Commission set out to simplify the funding structure, to achieve a better geographic focus – on the European neighbourhood, Africa, the Western Balkans and countries most in need – and to concentrate funds thematically on security, migration, climate change and human rights.[39] It therefore merged ten regulations, one decision and one extra-budgetary fund into a single new regulation – the **Neighbourhood, Development and International Cooperation Instrument (NDICI)**. Through NDICI, the

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[39] European Parliament report, page 22.

EU plans to channel 79,5 billion Euros into "eradicating poverty and promoting sustainable development, peace and prosperity".[40] Another change from the previous financing period is that the European Development Fund, used to provide assistance to African, Caribbean and Pacific countries and to overseas countries and territories (OCT) was integrated into the EU budget.

3.2. References to persons with disabilities in the funds' regulations

As party to the CRPD, the EU is obliged to ensure that the projects and programmes it funds are in line with the CRPD. In fact, the EU Declaration of competence, which formed part of the ratification process, included specific reference to external action funding instruments (though these need to be updated).[41] While the CRPD Committee praised the EU for including the rights of persons with disabilities in its external action financing, it also expressed concern about funds being used for the renovation or building of institutions. It therefore made a number of suggestions for improvement:

> "The Committee recommends that the European Union adopt a harmonized policy on disability-inclusive development and establish a systematic approach to mainstream the rights of persons with disabilities in all European Union international cooperation policies and programmes, appoint disability focal points in related institutions and take the lead in the implementation of disability-inclusive Sustainable Development Goals. The Committee also recommends that the European Union identify and put in place mechanisms to disaggregate data on disability in order to monitor the rights of persons with disabilities in European Union development programmes. It **further recommends that the European Union interrupt any international development funding that is being used to perpetuate the segregation of persons with disabilities, and re-allocate such funding**

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[40] See: https://ec.europa.eu/info/funding-tenders/find-funding/eu-funding-programmes/global-europe-neighbourhood-development-and-international-cooperation-instrument_en
[41] EU Declaration of competence is available here:
https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&clang=_en#EndDec

> **towards projects and initiatives that aim at compliance with the Convention**."[42] [emphasis added]

One way to mainstream the rights of persons with disabilities in external action, and to prevent funds from being used to build institutions or other segregating services, is to include references to persons with disabilities, the CRPD, and the need to support deinstitutionalisation (i.e. transition from institutional care to community living) in all regulations and the accompanying policy and funding guidance. During 2014 – 2020, a number of regulations, such as ENI, PI, ICsP, or the European Fund for Sustainable Development, had <u>no</u> specific reference to persons with disabilities.

Nevertheless, some regulations explicitly mention persons with disabilities, the CRPD or deinstitutionalisation. The two tables below (see tables 3 and 4) aim to provide a brief overview for the previous and current programming period. Humanitarian aid is dealt with separately, in section 3.2.1.

Table 3: References to persons with disabilities, CRPD and DI during 2014 – 2020

Name of the document	Any mention of persons with disabilities?	Any mention of the CRPD?	Any mention of DI?
Common rules for the implementation of external action instruments	YES - the need to ensure accessibility for persons with disabilities in the design and implementation of programmes and projects.	NO	NO
Development Cooperation Instrument	YES – under the General principles. Under investment priorities, the need to support the fight against discrimination and discriminatory practices on the	NO	NO

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[42] Concluding observations on the initial report of the European Union, 2015, CRPD/C/EU/CO/1, see: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%252FC%252FEU%252FCO%252F1

	ground of disability is included, as are actions to improve equal access to and quality of education for persons with disabilities. The need to support non-discrimination initiatives and social inclusion through access to basic services, employment, empowerment and respect of rights of persons with disabilities is also referenced.		
Instrument for Pre-Accession Assistance (IPA II)	YES - promotion of social and economic inclusion of persons with disabilities is mentioned as one of the Specific objective of financial support. Under the Thematic priority "Promoting social inclusion and combating poverty", there is a reference to the need to improve access to affordable, sustainable and high quality services, such as health and social services.	NO	NO
European Instrument for Democracy and Human Rights	YES - promoting equal participation of persons with disabilities, fight against discrimination and the rights of persons with disabilities, as set out in the CRPD, are all listed under the Scope as areas to be supported.	YES	NO

Table 4: References to persons with disabilities, CRPD and DI during 2021 – 2027

Name of the document	Any mention of persons with disabilities?	Any mention of the CRPD?	Any mention of DI?
Instrument for Pre-Accession	YES - the regulation notes that funds should be spent in	YES	YES

Assistance (IPA III)	compliance with agreements concluded by the EU; they must be used to ensure respond for fundamental rights and promote gender equality, tolerance, social inclusion and non-discrimination, including in relation to persons with disabilities; they should not support actions that contribute to any form of segregation of social exclusion.		
Neighbourhood, Development and International Cooperation Instrument (NDICI)	YES - the CRPD is mentioned in the Preamble, as one of the documents that should be taken into account when using the funding; there is also a specific reference to the rights of persons with disabilities and the need to support countries in implementing their human rights obligations under the General principles. Promoting and protecting the rights of persons with disabilities is one of the intervention areas for thematic programmes.	YES	YES (but only for children)

3.2.1. Humanitarian aid

Although there is no reference to persons with disabilities in the Humanitarian Aid Regulation[43], the 2007 Consensus on Humanitarian Aid[44] refers to the need to take into account "particular vulnerabilities", by paying special attention and addressing specific needs of "sick and

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[43] Council Regulation (EC) No 1257/96 of 20 June 1996 concerning humanitarian aid, see: https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:31996R1257
[44] The European Consensus on Humanitarian Aid, see: https://ec.europa.eu/echo/files/media/publications/consensus_en.pdf

disabled people". The 2021 Communication on Humanitarian Aid[45] affirms EU's commitment to "meeting the needs and rights" of persons with disabilities.

The inclusion of persons with disabilities is also recalled in the Thematic Policy annex to the yearly Humanitarian Implementation Plans. For example, the Thematic Policy Annex 2021[46] states that:

> "Partners are expected to demonstrate how they plan to identify, remove, reduce and mitigate barriers preventing meaningful access to and full and effective participation of people with disabilities in EU-funded humanitarian assistance and protection programming. It is recommended to actively use the four aspects of protection mainstreaming (safety, dignity, avoid causing harm; meaningful access; accountability; and participation and empowerment) to address the identified barriers and strengthen the enablers and capacities to overcome these."

In 2019, DG ECHO published the **Operational guidance: the inclusion of persons with disabilities in EU-funded humanitarian aid operations**[47], a tool to foster disability inclusion and ensure mainstreaming of disability in the design, implementation and monitoring of EU-funded humanitarian projects. Recently, DG ECHO has started reporting to the OECD on the DAC (Development Assistance Committee) disability marker (see section 3.4.1.). The reporting is done on a yearly basis.

It is worth noting that, among the steps required to ensure inclusion of persons with disabilities, the guidance includes no mention of preventing segregation or identifying the risks for institutionalisation of persons benefitting from humanitarian aid, or their family members.

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[45] Communication from the Commission to the European Parliament and the Council on the EU's humanitarian action: new challenges, same principles, COM(2021) 110 final, see:
https://ec.europa.eu/echo/files/aid/hacommunication2021.pdf
[46] Thematic Policies Annex, Re. Ares(2020)6038752 – 28/10/2020, see:
https://ec.europa.eu/echo/files/funding/hip2021/Policy.pdf
[47] DG ECHO Operational Guidance, The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations, February 2019. Available at:
https://ec.europa.eu/echo/files/policies/sectoral/doc_echo_og_inclusion_en.pdf

3.3. Partnerships with NGOs

DG ECHO works with about 200 partners organisations[48] to provide humanitarian aid throughout the world. This is due to the nature of humanitarian aid and the need to react fast and in difficult circumstances. In this sense, DG ECHO is different from other DGs, which do not pre-approve organisations eligible for funding.

Humanitarian partners are European non-governmental organisations (NGOs), international organisations (including United Nations agencies, the Red Cross and Red Crescent), as well as specialised agencies from the Member States. There is a noticeable absence of DPOs in the list of humanitarian partners. While not clear why that is the case, possible reasons include the lack of financial and administrative capacity to implement large projects.

The relationship between DG ECHO and its non-governmental partners is based on the EU Humanitarian Partnership 2021 Certificate, which identifies the basic principles and obligations and sets the minimum standards for the preparation and implementation of humanitarian actions[49]. Once an NGO is awarded the Partnership Certificate, it can apply for DG ECHO funding. Applications for funding are done through the so-called E-Single Form, which has recently been updated and includes the Washington Group Short Set of Questions (see section 3.4.2.). Partners can also use the Washington Group Short Set of Questions when reporting on persons with disabilities that have benefited from humanitarian aid, but this is not mandatory.

3.4. Monitoring inclusion of persons with disabilities in EU-funded programmes

The collection of disaggregated data on disability is crucial to being able to monitor the extent to which persons with disabilities are benefiting from EU funding. Among the tools being used by the European Commission are the OECD Disability Marker and the Washington Group Short Set of Questions. While useful for following mainstreaming of disability in external action, neither helps monitor whether funds are

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[48] List of NGO partners for 2021 - 2027 is available here:
https://ec.europa.eu/echo/files/about/weblistpartners.pdf
[49] There is also the Sphere Handbook – Humanitarian Charter and Minimum Standards in Humanitarian Response (last edited in 2018), written by humanitarian organisations themselves, the aim of which is to "improve the quality of their humanitarian responses and be accountable for their actions". It is available at: https://handbook.spherestandards.org/en/sphere/#ch001

being used to build or renovate institutions or other segregating settings for persons with disabilities, or indeed support deinstitutionalisation reforms.

3.4.1. OECD DAC Disability Marker: the objective of this marker, introduced in 2018, is to track development co-operation projects and programmes that promote the inclusion and empowerment of persons with disabilities; it also tracks those in support of the ratification, implementation and/or monitoring the CRPD.

Development co-operation activities are classified as disability inclusive if:

- They have a deliberate objective on ensuring that persons with disabilities are included, and able to share the benefits, on an equal basis to persons without disabilities. Or
- If they contribute to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promote respect for their inherent dignity in line with Article 1 of the CRPD. Or
- If they support the ratification, implementation and/or monitoring of the CRPD.

An activity is marked as principal (score 2) if disability inclusion is the main objective of development cooperation; it is marked as significant (score 1) if disability inclusion is an important and deliberate objective, but not the main reason for carrying out the activity; it is marked as non-targeted (score 0) if it has been screened, but not found to target disability inclusion.[50]

3.4.2. Washington Group Set of Questions: different sets of disability questions (short or extended), developed by the Washington Group on Disability Statistics, can be included in existing data collection instruments to allow for disaggregation by disability.[51] The questions are designed to identify people with functional limitations and are mostly use for censuses and surveys.

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[50] See:
https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DCD/DAC/STAT(2018)39/REV1&docLanguage=En
[51] See: https://www.washingtongroup-disability.com/question-sets/

Chapter IV: EU funding in practice

Chapters IV and V seek to answer two questions: a) To what extent has the EU supported the closure of institutions and the development of community-based support infrastructure, in line with Article 19 of the CRPD?; and b) Is there any evidence that EU external action funding contributed to maintaining the system of institutional care, through renovation or building of institutions? They do so by presenting the information collected from desktop research, the European Commission and disabled people's organisations (DPOs).

4.1. Existing research on EU support for deinstitutionalisation

To date, research on the use of EU external action for deinstitutionalisation has been very limited; likely due to the complexity of the funding and the lack of transparency. The information that is available relates mainly to children.

For example, the EU intervention in Georgia is said to have changed from initially funding institutions for children to "deinstitutionalisation of childcare, gatekeeping and transfer of children to family-based settings" after 2003. Through the project "Support to Child Welfare Reform in Georgia", implemented between 2006 and 2010, the EU (through technical assistance – EU TACIS) "helped develop new legislation, standards of childcare, human resources and public awareness". After 2010, the EU supported deinstitutionalisation "only indirectly – through projects in health care, vocational education, justice, issues of internally displaced peoples and so on".[52]

According to Eurochild, the EU played an important role in the process of deinstitutionalisation in Bosnia and Herzegovina, where 1,5 million Euros of IPA funds were allocated to support the transformation of four institutions during 2014 – 2017.[53] Eurochild has been calling for the EU support to continue post 2018.

A comprehensive review of EU funding was carried out by Lumos, whose report "Transforming care systems through EU external action" found that just over 45 million Euros were spent on deinstitutionalisation of children

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[52] Ulybina, O. (2020). Transnational agency and domestic policies: The case of childcare deinstitutionalization in Georgia. *Global Social Policy*, *20*(3), 333-351. https://doi.org/10.1177/1468018120926888

[53] Eurochild, Opening Doors for Europe's Children, Bosnia and Herzegovina, see: https://www.openingdoors.eu/wp-content/uploads/2018/02/country-fiche-BiH-2017.pdf

from 2013 – 2018. However, the report notes that "this figure does not accurately reflect the actual funding aimed at children in institutions, let alone a figure for deinstitutionalisation. The absence of detail in the figures available makes it difficult to accurately assess the level of funding towards the transition from institutional to family and community-based care".[54] Lumos notes that, while there is substantial investment in the rights of the child, there is no strategy to address the needs of children in institutions. It states that "there are very few examples of programmes which are specifically working towards the transition from institutional care to family and community-based care for children."[55] The report highlights as key barriers the very limited number of deinstitutionalisation projects, funding of institutions and the absence of data on "what is being funded, where, and what it has achieved."

Inclusion International (II) looked into how much of the Official Development Assistance (ODA) benefitted persons with intellectual disabilities in 2018, without focusing on the role of the EU or deinstitutionalisation in particular. The findings are nevertheless relevant, because this group is overrepresented in institutional care settings all over the world. II found that persons with intellectual disabilities were largely excluded, and that over a third of ODA projects (more precisely, 36%) that included persons with intellectual disabilities "violated the CRPD, contributing to segregation and other human rights violations".[56]

The report noted:

> "Donors continue to provide funding for segregated education instead of inclusive education, sheltered employment instead of workplace inclusion, segregated service structures (such as day centres) instead of inclusion of mainstream services, and to fund the segregation of people with intellectual disabilities in refugee settlements instead of ensuring that mainstream refugee support strategies are inclusive."[57]

Inclusion International highlights the problems with the "twin-track approach", whereby disability-specific interventions are funded alongside other actions aimed at mainstreaming disability. In the case of persons

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[54] Lumos (2020), *Transforming Care Systems through EU External Action,* page 8. Available at: https://lumos.contentfiles.net/media/documents/document/2020/03/Transforming_Care_Systems_Through_EU_External_Action.pdf

[55] *Ibid,* page 8.

[56] Inclusion International (2021), *Excluded from the Excluded: People with Intellectual Disabilities in (and out of) Official Development Assistance*, page 3. Available at: https://inclusion-international.org/wp-content/uploads/2021/03/Excluded-from-the-Excluded_new.pdf

[57] *Ibid,* page 16.

with intellectual disabilities, the disability-specific interventions may be used to justify segregation (for example, funding a segregated education programme alongside an inclusive programme).[58]

Although not focused on deinstitutionalisation, research on the involvement of DPOs in EU funded projects in Southern Africa is also of relevance and could inform future planning and practice. Initial findings note that "development programmes perpetuate, rather than challenge, the status quo by not addressing power relations within CSOs and society more broadly", and highlight "the need to move beyond awareness of disability to more concrete actions aiming to support disability inclusion in practice".[59]

4.2. Information provided by the European Commission

In preparation of this report, requests for information about EU funded projects concerning persons with disabilities during the period 2014 – 2020 were sent to DG Neighbourhood and Enlargement Negotiations (DG NEAR), DG Humanitarian Aid and Civil Protection (DG ECHO), DG International Partnerships (DG INTPA) and the European External Action Service. The information obtained is presented below.

4.2.1. DG Neighbourhood and Enlargement Negotiations (DG NEAR)

DG NEAR provided a list of projects in the Western Balkans (5 projects), Southern Neighbourhood (3 projects), Eastern Partnership (3 projects) and Turkey (6 projects).[60] Out of these, 3 projects were directly related to institutions or deinstitutionalisation (see Table 5).

Table 5: The list of relevant projects provided by DG NEAR

Title	Project purpose	Coordinator and EU grant amount
SOCIETIES 2 - Support Of CSOs In Empowering Technical skills, Inclusion of	To increase CSOs' capacities, accountability and effectiveness in managing social inclusion and de-	Caritas Serbia - 999,950.31

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[58] *Ibid,* page 16.

[59] Manhique, Jorge (2021), *'The devil is in the details': Ensuring participation and ownership of development programmes for persons with disabilities in Mozambique*, page 16 (pre-publication copy).

[60] The list of projects provided by DG NEAR is available here:
https://www.asktheeu.org/en/request/eu_funded_projects_concerning_pe#outgoing-19136

people with disabilities and EU Standards in Western Balkans, 2nd phase (2020 – 2024)	institutionalization initiatives. and in promoting and advocating for social inclusion of PWDs, in line with the EU accession standards. To foster a conductive environment for civil society activities by establishing permanent structures and mechanisms for the cooperation and dialogue between CSOs and Public Authorities.	
Ensuring safety and human rights of persons with intellectual and psychosocial disabilities in 6 residential institutions during the COVID-19 pandemic (2020 – 2022)	Ensure the right to health of 1700 persons with intellectual and psychosocial disabilities from 6 residential institutions during COVID-19 through increasing access to information and protective equipment.	Keystone Human Services International Moldova Association - 60,000 EUR
Creating a Perspective of Deinstitutionalization among Disabled People's Organizations and Service Providers (2016 - 2018)	Overall objective is creating awareness about the meaning of Article 19 (the right to independent living and being included in the community) of UN Convention for the Rights of People with Disabilities (UN CRPD) among disabled people's organizations and service providers, and thus opening the way to effective	RUSİHAK - Human Rights in Mental Health Initiative Association - 72,000 EUR

	advocacy for transition into community-based services.	

After contacting individual geographical desks at DG NEAR to verify whether the information provided through the freedom of information (FOI) request was complete, an additional number of relevant projects was received (see Table 6).

Furthermore, more detailed information was requested about the 3-year project in North Macedonia – **"TIMOR - Together for introduction of more opportunities and respect"** - from DG NEAR in September[61]. This project, funded under the IPA II Action Programme of the EU Support for Education, Employment and Social Policy (Support for the Deinstitutionalisation Process in Social Sector, for North Macedonia) involves deinstitutionalisation of a number of residents from the Demir Kapija institution, and is being implemented by CeProSARD (the Centre for the Promotion of Sustainable Agricultural Practices and Rural Development), the Association for Special Education and Rehabilitation and the Loza Foundation from Sweden, in cooperation with the Demir Kapija institution and the municipality. It involves moving people with disabilities from the institution into smaller group homes[62].

On 13 December, DG NEAR responded to our request for information. We received a number of heavily redacted documents (six quarterly progress reports and the grant contract), with all information apart from headings deleted. DG NEAR justified withholding of information about the TIMOR project on the basis of "protection of the commercial interests of a natural or legal person, including intellectual property" and "no overriding public interest in disclosure". On 23 December, ENIL filed a confirmatory application (i.e. an appeal) to the Secretariat-General of the Commission, which has not been processed to date.

Table 6: Additional projects provided by DG NEAR

Serbia

IPA 2020 IMBC service contract (2,5 M EUR) and direct grant to the Standing Conference of Towns and Municipalities (6,5 M EUR) for "Support to sustainable community-based social services (CBSSs) and

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[61] The request for information is available at:
https://www.asktheeu.org/en/request/project_together_for_introductio#incoming-34628
[62] See description of the project on the website of the Loza Foundation:
https://lozafoundation.org/en/projekt/timor-together-for-introduction-of-more-opportuneties-and-respect-2/

inclusion policies at the local level", to strengthen capacities of social protection system for the **deinstitutionalisation** process. The activities will provide overarching support for social inclusion and socio-economic integration of vulnerable groups in the community such as Roma, persons with disabilities, children with disabilities, families at risk of children being separated, young people at risk and those leaving social care, violence victims, older persons, children at risk of drop out, etc. The rights of the child and persons with disabilities will be further enhanced by delivering CBSSs to support transition to non-institutional care improving family and children support services and services for independent living of persons with disabilities in the community and family.

IPA 2011 – 2,35 mil. EUR - Enhancing the position of residents in residential care institutions for persons with mental disability and mental illness and creation of conditions for their social inclusion in the local community.

PA 2018 – 20 mill. EUR - EU for Social Housing, indirect management implemented by the UN Office for Project Services (UNOPS). Partially related to disabilities, focusing on targeting vulnerable and at risk-of-poverty population categories, such as women and men with disabilities, disadvantaged women, in particular women victims of domestic violence, young in/leaving care, Roma women and men, local poor population and others living in in inadequate/insecure housing. Currently 80 families are covered from the people with disabilities target group, and 23 families of youth in residential care (5,5%).

Montenegro

IPA OPERATIONAL PROGRAMME multi-annual programme 2015-2017 (SOPEES) – 15 mil. EUR - Includes actions supporting inclusion for children and Roma, which also touch on aspects linked to deinstitutionalisation such as the projects in SOPEES "Improving Social Inclusion and Social and Child protection System", "Support to the Social Inclusion of Roma and Egyptians".

IPA 2015 – 0.13 mil. EUR - Developing and delivering licensed services of social and child welfare for children, youth and adults with disabilities older than 27 years in Pljevlja.

IPA 2018 – 1 mil. EUR - National disability determination system, focused on reform to provide persons with disabilities proper access to services and cash transfers, as well as improved quality of life.

Armenia

'Family Environment and Services in Communities for Children of Armenia, FESCCA''

Amount: 540,000 Euros, Duration: 36 months, From 01/02/2019 to 31/01/2022, FUNDACION WORLD VISION INTERNATIONAL

The main objective of the project is to support the Government of the Republic of Armenia in transforming the residential care institutions, creating services available to children in communities, and developing alternative care and "gatekeeping" mechanisms. Due to the professional and material resources invested in the project during its two and a half years of implementation, it was possible to transform 6 boarding institutions for child care and protection and 4 special schools. The children of the mentioned institutions returned to their biological families, and/or continued to receive family-based care. The individual development plans of 498 children who have returned to their families have been developed and are currently under the control of our specialists, based on which daily work with the children and their families is carried out. 140 children were included in the World Vision Graduation Approach, due to which the entrance of the children to institutions was prevented and social vulnerability was decreased. As part of the implementation of the policy of inclusive education and for the aim of ensuring the right of education of children returning from special schools to their families, about 2,500 teachers, teacher's assistants, as well as trainers, have been trained, which will further contribute to the process of ensuring inclusive education. Within the framework of the project, 53 potential foster families were trained as an alternative type of care, and 464 specialists in the field of child protection were trained on the issues of child protection and "gatekeeping" mechanisms.

4.2.2. DG International Partnerships (DG INTPA)

A list of 45 projects was received from DG INTPA, providing the title of the project, country, the implementing organisation and the funding amount awarded[63]. It is difficult to establish from the titles of the projects which of them target persons with disabilities in institutions, or have a specific aim of preventing institutionalisation, but the list includes 7 projects aimed at supporting children to grow up in a family environment

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[63] The list of projects provided by DG INTPA is available here:
https://www.asktheeu.org/en/request/eu_funded_projects_concerning_pe_2#outgoing-19419

in Kyrgyzstan, Myanmar, Cambodia, Georgia, Burundi and Armenia. There is also a project specifically mentioning independent living for persons with disabilities in Mongolia. None of the projects mention "transition from institutional to community-based care" or deinstitutionalisation in the title of the project.

4.2.3. DG Humanitarian Aid and Civil Protection Service (DG ECHO)

Based on the policy of mainstreaming of disability, while some projects can have a specific focus on persons with disabilities, mostly their needs (together with those of other "vulnerable groups") are taken into account in the design and delivery of all DG ECHO funded humanitarian aid. For this reason, due to the large number of projects, the list of specific projects and amounts could not be provided. Instead, DG ECHO provided examples of actions targeting persons with disabilities. None of these mention specifically persons with disabilities in institutions or at risk of institutionalisation.

Inclusion of persons with disabilities in humanitarian action. According to the different kind of assistance (Protection, WASH, Disaster preparedness, and other), partners put in place specific actions to ensure access and participation of persons with disabilities, for example:

- Analysis of contextualized risk factors and factors of discrimination for persons with disabilities in the humanitarian response;
- Analysis on the barriers and facilitators to inclusion of persons with disabilities;
- Capacity building through awareness raising sessions and trainings on disability and inclusion for humanitarian actors;
- Providing orientation on available services;
- Setting up of accessible spaces (for example in refugee camps, schools, aid distribution points).

Provision of adapted learning material and/or specific support to children with disabilities:

- Provision of tablets and assistive devices to children with disabilities, including to access remote education during the Covid-19 pandemic;
- Provision of hearing aids to children with hearing impairment;
- Improved infrastructure.

Inclusive activities in emergency settings:

- Education activities that take into account the needs of children with disabilities;

- Inclusive recreational activities (sport, art);
- Psychosocial support for persons with disabilities and their families.

Sensitization, training and capacity building for humanitarian actors, health and education providers, authorities etc. on disability inclusion.

Cash assistance for persons with disabilities; and for families of persons with disabilities.

Medical assistance, such as prosthetics, rehabilitation, mental health and psychosocial support, home care.

4.2.4. European External Action Service (EEAS)

The EEAS, although responsible for the running of EU delegations and offices around the world, does not hold any information in the filing systems and document management databases regarding "projects concerning persons with disabilities (including children with disabilities) in the programming period 2014 – 2020". Therefore, no information could be provided.[64]

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[64] Response from EEAS to our access to information request is available here: https://www.asktheeu.org/en/request/9825/response/33437/attach/html/3/Reply%20to%20request%20for%20access%20to%20documents%202021%20125.pdf.html

Chapter V: Views of DPOs and CSOs on EU's role in supporting deinstitutionalisation

Having received limited information from the European Commission about EU external action support for deinstitutionalisation, consultations with persons with disabilities and their representative organisations (referred to as DPOs), as well as other civil society organisations (CSOs), allowed us to identify additional information about the relevant actions and the main challenges when it comes to their implementation. The findings from the survey and the targeted consultation are presented below, and can be summarised under seven main headings.

Key barriers to independent living in the context of EU external action funding:

1. Lack of projects on deinstitutionalisation funded by the EU
2. Deinstitutionalisation understood as moving residents from large to small institutions
3. Lack of clear criteria for the selection of projects
4. Contracts awarded to beneficiaries with lack of expertise on deinstitutionalisation
5. Lack of sustainability of the newly-developed services
6. Difficulty of accessing comprehensive information about the projects funded
7. Lack of involvement of DPOs in the programming, implementation and monitoring of EU funds

5.1. Lack of projects on deinstitutionalisation funded by the EU

DPOs highlighted that, despite the large numbers of people in institutions and the lack of community-based services, the EU does not consider deinstitutionalisation as a funding priority.[65] Many see this funding as the only opportunity to make progress, provided that there are clear indicators and targets, and that the focus is not on relocating persons with disabilities into smaller institutions. A view that the Central Asian region was left behind by the EU in its efforts to deinstitutionalise children was also shared.

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[65] DPOs which took part in interviews were involved in other EU funded projects, aimed at strengthening civil society, empowerment of persons with disabilities, research, women with disabilities, legal capacity and supported decision making etc.

A civil society organisation (CSO) from the Republic of Moldova involved in monitoring the use of EU funds noted that, even though there was a government strategy on DI, there was no support for the process from the European Union. Instead, CSOs find ways to encourage DI through smaller initiatives. At the national level, the lack of concrete plans, vision and resources means that no substantial progress can be made in deinstitutionalisation, especially as the government is reliant on outside funding (including from the EU) to build community-based services. Additionally, some of the work done so far has resulted in the transfer of people from large into smaller institutions.

DPOs from candidate (Albania, North Macedonia, Montenegro, Serbia and Turkey) and potential candidate countries (Bosnia and Herzegovina and Kosovo)[66] agree there is an opportunity to promote deinstitutionalisation during the process of EU enlargement. However, the assessment and guidance provided by the European Commission is not always in line with the CRPD. For example, one screening report on Serbia called for strengthening "the oversight of living conditions in social care institutions and psychiatric hospitals", without mentioning the need for deinstitutionalisation[67]. In another screening report, on social policy, the European Commission referred to the CRPD and commented on the process of deinstitutionalisation and the reform of the social protection system. In this case, there was a specific suggestion to ensure "quality of foster care and of small group homes" for children.[68] In a similar vein, the latest progress report by the Commission on North Macedonia states:

> "The deinstitutionalisation process is completed, the remaining four children in institutional care are in transitional period and soon to be resettled. The conditions for children settled into community-based care homes are generally satisfactory."[69]

Therefore, the Commission services consider the DI process to be completed despite children living in group homes, not families.

In conclusion, DPOs complained that the rights of persons with disabilities were low on the agenda of the EU delegations, with other human rights issues having priority. They also noted that no disability-based indicators

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[66] See: https://ec.europa.eu/environment/enlarg/candidates.htm

[67] European Commission, Screening Report Serbia Chapter 23 – Judiciary and Fundamental Rights, 2014, MD 45/14, page 34.

[68] European Commission, Screening Report Serbia Chapter 19 – Social Policy and Employment, 2016, MD 11/16, page 13.

[69] European Commission, North Macedonia Report 2021, 19 October 2021, page 34, see: https://ec.europa.eu/neighbourhood-enlargement/north-macedonia-report-2021_en

were being used to track spending (unlike, for example, gender equality indicators which are being used).

5.2. DI understood as moving residents from large to small institutions

There is evidence of at least one project where persons with disabilities are moved from large into smaller institutions (see section 4.2.1.).

Thus, serious concerns were raised by DPOs about the lack of understanding of obligations under the CRPD and the concept of "deinstitutionalisation", by all involved in the process. DPOs were unanimous in stressing that there is no real understanding of independent living, and that "deinstitutionalisation" is mostly understood as a process of relocating residents from institutions to small group homes, with the staff of institutions continuing to work in the new services. In this process, persons with disabilities are perceived exclusively as clients, in line with the medical model of care.

Other examples of the lack of understanding of CPRD obligations are investments into small group homes for children with disabilities, the establishment of day care centres, respite care in institutions and the building of nursing homes for older people. This finding is confirmed by a recent report on deinstitutionalisation, which found that international funding has been "misallocated to institutional care instead of supporting initiatives that enable persons with disabilities to live and participate in the community." The report concluded that "Institutional care may be easier to 'sell' to potential donors than dispersed family-based care."[70]

DPOs believe that this lack of understanding on what should be the outcomes of deinstitutionalisation stems from the lack of agreement at the European Union level, and the absence of clear guidance based on the CRPD and the General Comments. This is compounded by the lack of vision by Governments on the right to independent living, with outdated models of care still developed and presented as good practice.

Some of the DPOs insisted that, at minimum, the "Do No Harm" principle should be observed in projects funded by the EU. There are concerns that some of the projects not only fail to ensure that progress is made, but also lead to regression in the rights of persons with disabilities.

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[70] LSE report, page 6.

Although we have not found evidence of investment in large institutions (i.e. specific projects we could cite as examples), this may be due to the lack of transparency and the difficulty of accessing information about what is being funded. In a previous funding period (2007 – 2013), an IPA-funded renovation of institutions in Serbia was prevented thanks to the advocacy efforts of organisations in Serbia and at the European level[71]. This funding was redirected into supporting deinstitutionalisation, though with poor outcomes (as described in the Case study).

5.3. Lack of clear criteria for the selection of projects

DPOs also expressed concerns about the lack of clear criteria for the selection of projects, as well as the failure to monitor and evaluate projects which received funding. One DPO representative noted that the EU was not interested in "details" of the projects funded. Others noted there was no accountability when projects activities and outcomes were not in line with the CRPD.

A recent call for "EU Support to the De-institutionalisation Reform and Economic Empowerment of Vulnerable Jordanians"[72], published in 2020, confirms DPO concerns about the vague selection criteria. Thus, the call aims to support "projects that focus on home-based family services, and/or alternative community approaches and/or on daily care centres". Failure to reference compliance with CRPD as a criterion in either the call or the practical guide to contract procedures[73] (which refers solely to "accessibility for disabled people"), leaves room for potential projects that perpetuate outdated models of care, based on segregation and special services.

A representative of one NGO involved in humanitarian aid noted the cost of interventions was a major criterion. Given the typically higher costs of projects targeting persons with disabilities (taking into account needs for support and accessibility), it was difficult to compete with less costly interventions.

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[71] European Expert Group on the Transition from Institutional to Community-based Care (2014), *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care,* page 61. Available at: http://enil.eu/wp-content/uploads/2016/09/Toolkit-10-22-2014-update-WEB.pdf

[72] The call for proposals is available at: https://webgate.ec.europa.eu/europeaid/online-services/index.cfm?ADSSChck=1617477525963&do=publi.detPUB&orderbyad=Desc&nbPubliList=15&orderby=upd&aoref=171069&searchtype=QS&page=1&userlanguage=en

[73] European Commission, DG iNTPA, Contract procedures for European Union External Action: A practical guide, 1 August 2020, see: https://intpa-econtent-public.s3.eu-west-1.amazonaws.com/ePrag/2020.0/ePrag-en-2020.0-full.pdf

5.4. Contracts awarded to beneficiaries with lack of expertise on DI

Questions have been raised about the capacity of those awarded grants to implement projects on deinstitutionalisation and their understanding of the requirements under the CRPD. For example, several projects in North Macedonia are being implemented by a consultancy company specialising in everything from water and waste, to transport, to "public policies development". According to DPOs, these projects are focused on research, analyses and development of "individual plans" of residents of institutions, failing to produce any concrete results, with regard to providing opportunities for persons with disabilities to live independently in the community.

Another project, whose objective is to provide 50 residents of a large institution with small group homes and "personal assistance", was awarded to an agricultural organisation and a small and largely unknown foundation based in Sweden, working closely with the leadership of the institution and the local authorities.

With regard to international organisations, such as UN agencies, DPOs noted that there was equally a need to ensure full compliance with the CRPD. Concerns were raised about their support for small group homes for children with disabilities, day care centres or sheltered workshops, and the fact that due to prioritising of international organisations for funding, DPOs were being excluded from DI processes.

5.5. Lack of sustainability of the newly developed services

A major concern when it comes to EU funding is what happens when the projects have ended. Without follow-on funding from the state or the local authorities, the piloted services (such as personal assistance, for example) are being withdrawn from persons with disabilities. In practice, this means that persons with disabilities are living "from one project to another". In some cases, it may mean that people are sent back to institutions if the organisation providing support loses funding.

Inability to guarantee sustainability of services is also one of the reasons why CSOs cannot access funding. For example, in the processes of deinstitutionalisation, supported housing tends to be provided by the institution (which is guaranteed continuous funding by the state), rather than a variety of providers, including CSOs.

5.6. Difficulty of accessing comprehensive information about the projects funded

According to DPOs, information about the projects funded is generally available online, but there is not enough detail to understand whether the projects facilitate access to independent living or are CRPD compliant. In terms of the calls, given the variety of the funding opportunities, these are not available centrally but on a number of different websites.

Some DPOs are involved in the Monitoring Committees, but stressed that these are held infrequently and cover many sectors at the same time, not allowing enough focus on the rights of persons with disabilities. Others mentioned using requests for access to information.

The annual Progress Reports (as part of EU accession process) are used by DPOs to raise issues affecting persons with disabilities, including the need for deinstitutionalisation. One organisation, in Serbia, tried to track the use of international (including EU) funding, but found it difficult, given the diversity of funding and implementing partners. It was highlighted that consistent monitoring would be required, rather than one-off investigations, in order to get a complete picture.

An organisation working in the field of humanitarian aid mentioned that ROM (Results-Oriented Monitoring)[74] missions, the external monitoring system of DG ECHO and DG NEAR, could be used to track progress of DI projects. However, they noted that it was not clear what happens to the data once it is collected.

Accessible information about EU funded projects affecting persons with disabilities, in formats such as Easy Read, braille, large print, sign language, is not being provided.

5.7. Lack of involvement of DPOs in the programming, implementation and monitoring of EU funds

DPOs highlighted as positive those projects where sub-grants are given by the implementing organisation(s) to local organisations run by persons with disabilities. A project in the Western Balkans, coordinated by Caritas Serbia, is an example of such project.

In general, however, deinstitutionalisation projects run by international organisations, consultancies and other groups, do not involve persons with disabilities or representative organisations as equal partners. They

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[74] See: https://europa.eu/capacity4dev/rom

may be consulted or informed at various points in the project, but are not given leadership roles or opportunities to make decisions about the project.

When it comes to consultations organised by the authorities, there is a tendency to involve national umbrella organisations, rather than a wide variety of DPOs. Thus, there is a risk that not all issues will be adequately addressed and a danger of governments priorities the less critical organisations.

With regard to programming, DPOs are of view that the EU consults primarily with the authorities and the international organisations (such as UNICEF and UNDP) in relation how funds aimed at supporting deinstitutionalisation will be used, rather than their organisations. DPOs reported being contacted by consultancy companies running DI projects, but only in an advisory capacity (to attend the occasional meeting), not as coordinators or paid experts.

Even when calls are formally open to DPOs, many do not have capacity to apply and are unable to compete with multi-national consultancies or large charities. The lack of access to education by persons with disabilities was highlighted as an issue, with some countries experiencing high illiteracy among persons with disabilities. Therefore, many organisations are able to apply only when it comes to projects for the support of CSOs.

Whereas in the past, the EU delegations had more control over IPA funds, more responsibility has been transferred to the relevant Ministries. This was raised as a problem with regard to funding for civil society. With the Government being in control of this funding, as opposed to the EU delegation, questions were raised about the effect on organisations critical of the government. For examples, DPOs in Serbia have been advocating for civil society grants to be returned to the control of the EU delegation.

Some DPOs are formally involved in EU funds programming, but highlight a lack of overall understanding of deinstitutionalisation and what the process involves. There is a need for awareness raising and training at all levels, based on Article 19 and the General Comment 5, and the forthcoming CRPD Committee guidelines on deinstitutionalisation.

DPOs also suggested the introduction of standards on the involvement of DPOs in EU external action funding, similar to the Code of Conduct on Partnership in relation to the European Structural and Investment Funds.

Case study – "Open Arms" Project Serbia (IPA)[75]

The "Open Arms Project" was implemented in Serbia from 2012 to 2015, with around 5 million EUR of IPA funding, with a contract given to a foreign consultancy company. The official title of the project was "Enhancing the position of residents in residential care institutions for persons with mental disability and mental illness and creation of conditions for their social inclusion in the local community". A total of 11 social care institutions and 5 psychiatric hospitals took part, in partnership with the Ministry of Labour, Employment and Social Policy and the Ministry of Health.

According to project documentation, the aim was " to enhance the social inclusion of people with intellectual and psychosocial disabilities and to enable their deinstitutionalisation through the transformation of residential institutions, with a goal to improve the quality of services and to support the development of community-based social and health services".

The following activities were supported:

- Development of a deinstitutionalisation plan;
- Development of transformation plans for the residential institutions involved in the project, following an assessment of the residents' needs and institutional capacities, and including a plan of services, a budget and a timeline;
- Elaboration of a feasibility study for the transformation of psychiatric hospitals;
- Development of a legal reform proposal for the development of community-based care;
- Developing and delivering training for the staff of residential institutions.

There was also a sub-granting schemes for the provision of community-based services, with 19 projects supported with 2.3 million EUR.

According to the final report, published after the project ended, 160 people left the institutions and 600 staff members were trained. However, the report highlighted the remaining barriers to deinstitutionalisation:

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[75] Keravica, Rados (2017), *Advancing the right of persons with disabilities to live independently and being included in the community – taking advantage of EU leverage*, MA Human Rights Thesis, Central European University, quoting Monika Gabanyi, 'Final Report of the project "Enhancing the Position of Residents in Residential Institutions for Persons with Mental Disability and Mental Illness and Creation of Conditions for their Inclusion in the Local Community".

- Lack of government leadership of the deinstitutionalisation process;
- Failure to redirect substantial funding from institutions towards individuals, providing an opportunity for each person to pay for the needed support (based on the principle of the money following the 'user');
- Lack of coordination between the national and local authorities, with regard to tasks and responsibilities, and funding.

Furthermore, the report noted a lack of ownership and follow-up action by the Government. Thus, the feasibility study for the transformation of psychiatric hospitals has not led to any action by the Ministry of Health. The national plan for deinstitutionalisation, developed through a process of consultation, was never officially adopted by the Government as an official strategy. Based on the individual plans for the transformation of institutions, it would take between 15 years (9 institutions) and 29 years (the largest institution) to complete the process. During this time "1,961 people would be deinstitutionalized, while 1,566 would get back to their families or [be deinstitutionalised] in some other way". There was a lack of clarity of where people would go after leaving the institution.

Finally, after the project ended, working groups in both Ministries stopped meeting and no progress was made in the process of "transformation" of the 11 institutions.

Chapter VI: Recommendations

As noted at the beginning of this report, there is an urgent need and a clear legal basis for supporting deinstitutionalisation. The European Union, as the world's largest donor and the only regional organisation to have ratified the CRPD, is in strong position to provide leadership on this issue and to facilitate better access to the right to live independently and being included in the community.

The EU is in a particularly strong position to promote deinstitutionalisation reforms during the process of EU enlargement. During the negotiations, it has the opportunity to promote and monitor the alignment of these countries' laws, policies and practices in relation to persons with disabilities (and deinstitutionalisation) with the EU *acquis.*

However, in order to ensure the EU funds support deinstitutionalisation in compliance with the CRPD and the General Comment 5, the following actions must be taken:

- There is a need for **significantly more investment in disability-specific projects, in particular in support of deinstitutionalisation reforms and the development of community-based supports and services** which enable persons with disabilities to enjoy the right to live independently and being included in the community.

- There is a need for **clear guidance and criteria by the European Commission on CRPD-compliant deinstitutionalisation**, which must be a precondition for the use of EU external action funding. This should apply regardless of how the funds are spent, whether through the European Investment Bank, Governments, international organisations or others. In practice, this means that all calls for proposals must have an explicit reference to compliance with the CRPD and preventing institutionalisation. The upcoming guidelines on independent living, one of the flagship initiatives of the Disability Rights Strategy 2021 – 2030, provide an opportunity to cover external action funding and include CRPD-compliant definitions of the key terms, among other.

- An **intersectional approach**, which recognises specific and additional barriers faced by women and girls with disabilities, children with disabilities and older persons with disabilities, among other, is required in all phases of funding, from programming and implementation, to monitoring and evaluation. This can help ensure

that those at most risk are reached first and that all interventions respond to the specific needs of different groups. Intersectionality is also important when involving persons with disabilities and their representative organisations.

- When revising the Toolbox on the "Rights Based Approach, encompassing all human rights for EU development cooperation", the European Commission must include **guidance on how to prevent segregation of persons with disabilities** and to facilitate the closure of institutions in any context, whether development of humanitarian.

- Significantly improved **transparency of EU funding for external action** is needed, in order to enable independent monitoring of the various projects and the extent to which they comply with the CRPD. This includes ability to access not just the names of projects, but also information about implementation, as well as results of monitoring and evaluation reports. Information should be easily available and searchable from the websites of DGs, as well as EU delegations.

- Monitoring of EU funded projects must include **indicators linked to the closure of institutions and prevention of institutionalisation, as well as the right to live independently and being included in the community**. Moreover, the European Commission should collect disaggregated data, in order to establish who is benefitting from EU funding and whether the groups most vulnerable to exclusion and discrimination are being targeted.

- Full **involvement of persons with disabilities and their representative organisations** (as defined in the General Comment 7[76]) in the planning, implementation and evaluation of projects on deinstitutionalisation and independent living is needed, in order to prevent investments into new institutions. This includes persons with disabilities in institutions and survivors of institutionalisation. Capacity building of DPOs, to enable them to take part in the implementation, monitoring and evaluation of

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[76] General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, see:
http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnbHatvuFkZ%2Bt9 3Y3D%2Baa2pjFYzWLBu0vA%2BBr7QovZhbuyqzjDN0plweYI46WXrJJ6aB3Mx4y%2FspT%2BQrY5K2mKse5zjo%2 BfvBDVu%2B42R9iK1p

projects is key to addressing the unequal power balance among DPOs and the rest of civil society.

- The European Commission must ensure that by prioritizing **international organisations** for funding, it does not exclude DPOs from DI and other disability-related projects. Equally, international organisations must be transparent and accountable for how they use EU funds. The UN Disability Inclusion Strategy provides a useful framework to achieve progress in disability inclusion, and ensure that, in practice, all projects fully comply with the CRPD and the General Comments.

- The European Commission and other donors should promote and fund **research into the role of humanitarian and development aid in addressing institutionalisation of children, adults and older persons with disabilities** world-wide. This would help identify good practice and avoid the replication of mistakes, such as through investments in segregating services and facilities for different groups of persons with disabilities.

- There is a need for **improved accountability when it comes to how EU funds are used world-wide**. A complaints system, where individuals and organisations can report projects from the perspective of human rights, should be set up as a matter of priority. The focus must be on preventing the use of EU funds for investments in institutions and other rights violations which may be enabled by access to humanitarian and development aid.

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