Deinstitutionalisation Strategy in Greece

Technical support on the deinstitutionalisation process in Greece

European Association of Service providers
for Persons with Disabilities

CREDITS & RIGHTS

Attribution: Please cite this work as follows:
European Association of Service providers for Persons
with Disabilities (EASPD), Brussels, February 2021.

Technical support on the deinstitutionalisation process
in Greece Grant Agreement: SRSS/S2019/02
Deliverable 2 (as per the Workplan) under Component 1,
Output 1.1 Activity 1.1.1 “Support the completion of the national
DI strategy, roadmap and action plan

This publication was carried out with funding by the European Union
via the Structural Reform Support Programme and in co-operation with the European
Commission’s Directorate-General for Structural Reform Support.

Table of Contents

List of abbreviations

DG REFORM
Directorate General for Structural Reform Support

DI
Deinstitutionalisation

EASPD
European Association of Service providers for Persons with Disabilities

MoLSA
Ministry of Labour and Social Affairs

NCDP
National Confederation of Disabled Persons

NGO
Non-governmental Organisation

PWD
Persons with Disabilities

SWC
Social Welfare Centres

UN
United Nations

UN CRC
United Nations Convention on the Rights of the Child

UN CRPD
United Nations Convention on the Rights of Persons with Disabilities

Executive summary

Shared values of dignity, equality and non-discrimination, included in all major international human rights conventions, have been embraced by European legislation and are guiding current and future policy developments.

In particular, both the United Nations Convention on the Rights of Persons with Disabilities[1] as well as the United Nations Convention on the Rights of the Child[2] are considered positive catalysts for change on how rights should be enjoyed and how services can be provided to facilitate their full access. As a consequence, social welfare structures are increasingly called upon to adapt and set up new and innovative systems to support individuals, families and children.

However, a real positive difference in the quality of life of individuals will only be possible with a holistic framework where policies, funding and attitudes can converge to produce the needed changes.

Greece is in need of revising its support framework and it is the will of the Greek Ministry of Labour and Social Affairs (MoLSA) to establish and bring forward a deinstitutionalisation plan across sectors and stakeholders in Greece, which may have the potential to transform the lives of a significant number of people. With the meaningful involvement of relevant stakeholders, including those representing the users of those services, an ambitious implementation plan can lead to a successful and sustainable framework of support systems meeting human rights standards and individual needs.

This document describes the main priorities of the national deinstitutionalisation strategy for Greece. The social care reforms which are referred to in the document are particularly aimed at promoting and developing sound legal and financial frameworks addressing specifically the needs of the following target groups: children, children with disabilities, adults with disabilities and elderly; however, the outcomes of a more comprehensive, inclusive social protection system will be beneficial to all persons that may have support needs throughout their lives.

This document is organised into the following sections:

- **Chapter 1** introduces the case for deinstitutionalisation and the main international legal frameworks;
- **Chapter 2** describes values and principles of the deinstitutionalisation process, key terms, key procedures and the vision behind the deinstitutionalisation process;
- **Chapter 3** focuses on strategic objectives for children and children with disabilities;
- **Chapter 4** focuses on strategic objectives for adults with disabilities;
- **Chapter 5** focuses on strategic objectives for elderly persons.

---

[1] https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf
[2] https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

1. Introduction

1.1 The case for deinstitutionalisation

Across Europe, children, children with disabilities, adults with disabilities, persons with psychosocial disabilities, elderly, persons living in poverty and exclusion, migrants, refugees and other groups with support needs often suffer the most from the lack of solid legal frameworks, financial resources and proactive, concrete and innovative measures aimed at guaranteeing their rights. The lack of support provision inevitably leads to affect negatively every sphere of life. Yet, there is a growing gap between international norms and the provision of support systems on the ground that can cater for individuals' needs throughout the life span.

The old pattern of bringing people into a predefined system of care was an approach that did not focus on understanding the needs of the individuals. Often, the lack of a tailored made approach to the needs of individuals has led to the development of institutional forms of care for children, adults and elderly with or without disabilities, which are not only against human rights frameworks adopted at international level, but also have detrimental effects on the lives of those affected by the system, both at physical and psychosocial level.

Evidence suggests that early institutional care is typically detrimental to all developmental domains of children. As far as cognitive development is concerned, institutionalised children's overall IQ scores tend to be lower (Agathonos-Georgopoulou, 2003). When a child is fostered by a family before 18 months of age there are great chances his score will improve, whereas after 54 months chances of improvement mark a significant drop (Browne, 2009). Research suggests that children who are moved from residential care before the age of 6 months can still reach optimal development (Poertner et al, 2000; Johnson et al, 2006).
Based on an empirical study by the European Union Agency for Fundamental Rights in 2012[3] focusing on the lived experience of living independently of people with psychosocial and intellectual disabilities – covering also information from Greece - some not very optimistic data were collected and a general desire for more autonomy and control over their lives was expressed. For people with intellectual disabilities, real choice of settings where people can live appear to be limited due to the small number of structures available, the lack of resources and support outside of the family, the lack of accessibility and the stigma associated with disability. Living with parents, relatives or in segregating residential care settings seems very often as a compulsory option.

Ultimately, research-based evidence[4] shows that institutionalisation is a direct consequence of poor quality of life outcomes, segregation from society, social exclusion and is clearly associated with isolation from family/community, lack of consistent individualised attention, deprivation of social, emotional and intellectual stimulation which hampers health brain development and the opportunity to learn social and life-skills, attachment disorders, increased rates of mental health difficulties. Moreover, it is associated with higher risk of violence, abuse, neglect, involvement in criminal behaviour and decreased life expectancy.

---

[3] https://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living

[4] R. Martínez-Leal et al. (2011) The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. Journal of Intellectual Disability Research.
Berens, A.E. & Nelson, C.A. (2015). The science of early adversity: is there a role for large institutions in the care of vulnerable children? The Lancet. 386(9991): 388-398. http://www.thelancet.com/journals/lancet/ article/ PIIS0140-6736(14)61131-4/abstract [accessed 16 Sept 2016]
Mulheir, G. et al. (2012). DI – A Human Rights Priority for Children with Disabilities, op. cit.

[5] https://ec.europa.eu/info/sites/info/files/file_import/2019-european-semester-country-report-greece_en.pdf

Greece is in need of revising its support framework and is among the 12 Member States in which the European Commission identified the need for deinstitutionalisation (DI) reforms. The European Commission`s Country Report of 2019[5] also recognises that while the provision of social services in Greece has improved, major steps remain to be taken to ensure quality of support provision and the deinstitutionalisation process is considered a key challenge in this respect. More recently, as part of the review from the UN CRPD Committee in its Constructive Dialogue with Greece – which was concluded in 2019 – Greece was recommended to "Adopt a comprehensive national strategy with clear time-bound measures and the allocation of sufficient funds for effective deinstitutionalization at all levels". This context leads to the necessity to reinforce the provision of social welfare and introduce the needed changes to profoundly revise the way support systems are delivered through a comprehensive deinstitutionalisation strategy. For the purposes of this document, deinstitutionalisation – as described in section 2.2 – includes the transition of individuals living in institutional settings to settings based in the community where individualization of support and inclusion in society is made possible. This implies the development of a range of person-centred support systems and services in the community, at home and in the form of personal assistance where needed.

1.2 International legal frameworks

This section provides a list of the main international frameworks underpinning the need for transitioning towards community-based care systems of support for children, children with disabilities, adults with disabilities and elderly.

United Nations Guidelines for the Alternative Care of Children

The United Nations (UN) Guidelines for the Alternative Care of Children[6] have a non-binding nature; they were adopted in 2009 and they provide indications regarding quality alternative care for children.

They offer a distinction between formal and informal alternative care and the environment that alternative care can take ranging from informal or formal kinship care, foster care, residential care in the community and supervised independent living[7].

Though not providing a definition of the characteristics of institutional care, the Guidelines do clarify that "where large residential care facilities (institutions) remain, alternatives should be developed in the context of an overall deinstitutionalisation strategy, with precise goals and objectives, which will allow for their progressive elimination". They also specify that in the case that residential care facilities are in place, these should be small and be organised around the needs of the children, in a setting as close as possible to a family or to a small group situation.

The UN Guidelines focus on two principles: the principle of necessity and the principle of suitability. The principle of necessity refers to the prevention of children from entering formal care. It emphasises that a child should only enter into care when it is necessary and in the child's best interest. It reiterates the role of the State in developing policies that support families in meeting their responsibilities and the role of States in preventing family separation. It also focuses on the reintegration of children with their families after their placement in alternative care. The principle of suitability refers to the most appropriate form of care for those cases where alternative care is necessary and in the child's best interest.

The UN Guidelines emphasise that it is the State's responsibility to ensure the development and implementation of coordinated policies regarding formal and informal care for all children who are deprived of parental care. There should be a range of alternative care options in place (informal and formal care), and the care received should suit the individualised needs of the child.

United Nations Convention on the Rights of the Child (UNCRC)

The United Nations Convention on the Rights of the Child (UN CRC)[8] is the most ratified Convention across the world. Greece signed and ratified the UN CRC in 1989. The UN CRC is based on four guiding principles:

1. Non-Discrimination/Equality: All are entitled to the same rights without discrimination of any kind.

2. Best Interests of the Child: All actions should take into account the best interests of the child.

---

[6] https://www.unicef.org/protection/alternative_care_Guidelines-English.pdf

[7] (i) Kinship care: family-based care within the child's extended family or with close friends of the family known to the child, whether formal or informal in nature; (ii) Foster care: situations where children are placed by a competent authority for the purpose of alternative care in the domestic environment of a family other than the children's own family that has been selected, qualified, approved and supervised for providing such care; (iii) Other forms of family-based or family-like care placements; (iv) Residential care: care provided in any non-family-based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other short- and long-term residential care facilities, including group homes; (v) Supervised independent living arrangements for children;

[8] https://downloads.unicef.org.uk/wp-content/uploads/2016/08/unicef-convention-rights-child-uncrc.pdf?_ga=2.243917824.462599487.1576669934-1442198959.1575113048

3. Survival and Development: The State has the responsibility to ensure children's survival and development.

4. Participation/Inclusion: All children have the right to express their views in matters that affect them, and their opinion should be given due wait in keeping with their maturity and evolving capacity.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The United Nations Convention on the Rights of Persons with Disabilities is the guiding framework for the enjoyment of rights of persons with disabilities. Greece has signed and ratified the Convention in 2012, while the European Union ratified it in 2011.

Article 19 of the UNCRPD specifically recognises the right for persons with disabilities to have access to a range of in-home, residential and other community-based support services responsive to their needs. It also provides for the possibility for persons with disabilities to choose where and with whom to live and to have access to services of the general population on an equal basis.
In doing so, Article 19 - and particularly General Comment nr 5 linked to it - demands a shift from institutional and segregating settings to living solutions that are based in the community and are tailored to the needs of the person (person-centred services).

The UN CRPD addresses clearly also the needs of elderly persons with disabilities, as well as those of persons who develop a disability by ageing. Therefore, its principles and its set of obligations for state signatories concern as well the needs of the elderly population.

UN Principles for Older Persons (the Madrid Declaration) and the UN General Recommendation on Older Women and Protection of their Human Rights

These two documents recognise the right for elderly people to be integrated in society and to actively participate to it, while receiving adequate support "to reach their optimum level of functioning".

European Union

Through a series of policy instruments and frameworks the European Union has continuously confirmed the need to promote inclusive living and full enjoyment of human rights.

The European Union recognises the right to protect and ensure rights for individuals through the EU Charter of Fundamental Rights proclaimed in 2000. The EU Charter of Fundamental Rights prohibits discrimination on any grounds, such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, birth, disability, age or sexual orientation. Institutionalisation constitutes a form of discrimination as children, persons with disabilities and older people are often placed into institutions because of factors such as their age, ethnic origin or disability.

In 2011 the EU became the first inter-regional organisation signatory of a United Nations treaty and ratified the UN CRPD. The current European Disability Strategy 2010-2020[9] – addresses the rights of persons with disabilities, fully endorsing the principles of the UN CRPD.
In 2017, the European Parliament, the Council of the European Union and the European Commission proclaimed the European Pillar of Social Rights, which has now become the compass for social policy development at European level and, as such, reinforces the need to strive towards more equal opportunities.
Lastly, EU funding has continuously provided substantial support to deinstitutionalisation. In particular, through the European Structural and Investment Funds (ESIF) the EU has assured the availability of funding to promote the transition to community-based living for individuals living in institutional settings or at risk of institutionalisation.

---

[9] https://ec.europa.eu/social/main.jsp?catId=1484

2. The deinstitutionalisation process

2.1 Values and principles of the deinstitutionalisation process

Deinstitutionalisation is based on the principles of participation, inclusion, non-discrimination, equality, choice and control over life and on the right to receive support adequate to individual needs.

These principles are at the basis of fundamental rights and their enjoyment should be asserted and should by no means be put under question.

Participation and inclusion

Persons with or without support needs are citizens first and foremost. A person's quality of life, social interactions, or basic human rights should not be unnecessarily restricted based on disability, family or other status.
Likewise, everyone should have access to the community, being included in society and receiving adequate support to this purpose.

A sense of belonging, positive relationships and contributing to community life are important to people's health and wellbeing. The community is for everyone. This includes people who have complex support needs or behavioral issues that may require intensive care and support.

Choice and control

All persons with support needs, including minors, should be fully involved in all decisions concerning their lives. For children this requires the design of support systems enhancing communication with them on issues concerning their lives. For adults, regardless of their disabilities, it requires exploring the adequate way of communication and providing all needed support to facilitate communication, understanding and allowing full informed choice.

Personalisation

Support should be tailored to the needs of each individual and not to standardized approached as happens in institutions. Personalisation is rooted in the belief that support should be built up around people's strengths and their own networks of support and resources (assets) that can be mobilised from the local community.

2.2 Key terms

Prevention

"Prevention" is an integral part of the process of transition from institutional to community-based care. In the case of children, it includes a wide range of approaches that support family life and prevent the need for the child to be placed in alternative care, in other words to be separated from his/her immediate or extended family or any other carer. For adults – with or without disabilities – it refers to the provision of adequate, person-centred support that meets individual needs and allows to live in the community. In relation to older people, the focus should be on preventing ill health, the loss of function, and the restoration of independence.

Prevention refers to a wide range of support services for individuals and their families, with the aim of preventing the need for institutionalisation. It should encompass both mainstream and specialised services.

Community-based care and community-based services

Community-based care and community-based services refer to the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of the impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities, respite care and others. In addition, the term includes family-based and family-like care for children, including substitute family care and preventative measures for early intervention and family support.

Co-production

Co-production recognises that every individual with support needs should be fully, structurally, meaningfully and in an ongoing manner involved at all stages in the design, development and delivery of the relevant policy, service or activity.

The application of co-production principles allows acknowledging that everyone is an expert in their own life, everyone has something to contribute, and that enabling people to support each other builds strong, resilient communities, strengthening the relationship between citizens and service providers and improving the outcomes from everyone.

Deinstitutionalisation

Deinstitutionalisation (DI) is a complex and multipurpose process which implies a fundamental reshaping of how society can provide the necessary tools to individuals to participate on an equal basis.

As a process, it is often wrongfully associated to the simple closure of institutional settings, however, deinstitutionalisation embodies the transition away from isolating and segregating institutional care towards community-based care and services and the development of a range of support and other services in the community which enable participation and inclusion, such as prevention, early childhood intervention (ECI), family support, health, education, employment and housing. Indeed, access to person-centred and individualised support is a pre-requirement to the enjoyment of human rights.

When developing community-based options caution should be taken not to re-create smaller versions of the large institutions.

Institution

An institution[10] is defined as any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them;
- the requirements of the organisation itself tend to take precedence over the residents' individual needs.

Although living conditions may vary from one institution to the other, common points concern the life conceived by a "ward system, which homogenises and classifies the residents, some of them spending most of their time in their beds, while others having few choices about about their day to day lives. The setting generally discourages personal development due to the absence of meaningful activities, lack of privacy and personal space. Residents mainly relate with other residents, the staff, sometimes with relatives, and, by far, very little and not often with the community outside the institution.

For children, features of institutional care that contribute to developmental delays include low staff to child ratios/interaction, low levels of staff experience and autonomy, strict routines, poor provision of educational and play equipment, lack of personal possessions and individuality and lack of "everyday" experiences and trips outside the institution (Mulheir and Browne, 2007; Smyke et al., 2002).

Particular attention needs to be paid also to the "institutional culture" which may thrive in any setting, regardless of the size; therefore, definitions based only on quantitative indicators (i.e. numbers) are not sufficient to determine the potential institutional character of a setting.

Gatekeeping

The gatekeeping system ensures blocking the entry of children into the residential care system, through the development of community family support services and through the change of dominant models of decision-making regarding actions of social protection of children.

The gatekeeping mechanism is based on the fundamental premise that no decisions regarding the placement of any child into any form of care will be made without a thorough and professional assessment of the child having been carried out by a trained social worker. This assessment will then inform any further decisions concerning the child's future. Any conclusions from this assessment will be based solely on the best interests of the individual child and not in the interests of any system or provider.

The gatekeeping system represents: a system of decision-making that guides effective and efficient targeting of services aiming to ensure that the most appropriate services are provided to those who need them; policies, procedures and services to restrict the flow of children into institutions and contribute to their onward progression back to families or substitute families; a set of actions taken by competent bodies aimed at preventing child separation from the family and community by all means; a process of assessment and planning of children's needs and circumstances which should precede their admission into residential care, and contribute to their onward progression-back to their families, into a form of substitute family care, or moving to some form of independent living.

---

[10] https://deinstitutionalisation.com/eeg-publications/

2.3 Key procedures

In order to successfully implement a deinstitutionalisation process, including the development of a range of community-based care systems, international norms and standards must be transposed into national and sub-national legislation and initiatives should be adapted to national contexts. Central to this process is the need to reflect the concepts of voice, choice and control of the individuals throughout the process as a direct expression of human rights conventions and standards underlying the process.

Below are a list of commonly agreed requirements supporting a successful deinstitutionalisation process.

Data collection-assessment

Data collection is essential not only to have a clear understanding of the situation, but also to plan the reform, the set up and the development of support services in an evidenced-based way. Any data collection primarily qualitative and then quantitative should allow a broad understanding of the needs of individuals in institutions and support the development of services in the community. The Greek State should make sure that data is collected by professionals who have the capacity and the know-how supported by professionals of the field of childcare, disability, and elderly care. There is a need to set up indicators for monitoring and mainstreaming the deinstitutionalisation programme. Close cooperation should be established with authorities responsible for data collection about this matter.

Measurement of success, monitoring and review of the strategy

It is common practice to measure success based on how quickly and how many individuals have been resettled and not on the quality of the support provided or whether there have been well-being improvements on individuals' lives. In order to establish if the needs of the individuals and families have been met and/or changes and amendments are required, a robust person-centred monitoring mechanism of each individual's needs should be put in place. This should be the benchmark for success of the DI process as it should help to monitor how effectively the DI process is being conducted. The outcomes for each individual should be identified in the individual planning process.

Focus on individual support needs

The vision behind inclusion in society of persons with support needs is that support tailored to the individual needs is accessible and available. Support should be provided ensuring choice and control of the individual over his/her life and should take into account personal preferences.

In order to plan adequate and person-centred support, there needs to be a person-centred needs analysis at the level of support planning, delivery and assessment. These processes should be based on a bottom up approach allowing adequate cooperation, communication and involvement of the persons receiving the support.
The critical stage in developing community-based services is the person/child/family centred planning stage at the beginning of the commissioning process as this provides individualised and needs-based information which will allow to have a clear overview of the types of services required. The planning stage must reflect the principles of "voice", "choice" and "control".

Revision and creation of support systems

The range of services catering for individuals should be revised where services do not comply with international legal standards and should be reinforced with the creation of additional and new services where these are missing. Support and care services shall meet the demands and the quality outcomes deemed necessary by international conventions. Standard procedures shall allow overall coordination, monitoring and implementation of the DI process.

As a first step, it is vital to have a clear mapping of residential-institutional settings existing, their users profile, users/staff ratio as well as staffing (including qualifications) and information on material and financial resources. Based on a long-term plan, any form of residential care which does not resemble typical life in the community, needs to be gradually abandoned. Guiding criteria to take into account are:

- The number of persons in each institutional setting. The smaller and more personalised the models, the more likely they are to provide opportunities for users to express choice, take independent decisions and for the service to be provided on the needs of the individual. Insofar as institutional services are concerned, it would be useful for the number of persons residing in each structure not to exceed the number of persons that typically form a family.
- The availability of a person-centred approach that organises and provides support around personal needs and wishes, empowering the individual.
- Recognition and enshrinement in the law to choose where and with whom to live.
- Shifting of decision-making primarily from professionals to individuals themselves and their families.
- Development of self-advocacy and supported decision-making mechanisms and teams.
- On-going interaction with the local community and the services provided therein.
- Facilitating the growth of informal social networks in the community.

Well trained workforce

The delivery of support to children and adults should be based on training programmes that include an understanding of the human rights approach to care and support and are based on quality standards. Any successful DI process should therefore be accompanied by training courses for all professionals involved in the process to develop new skills and competencies. This applies both to staff within the institutional settings prior to their move to community-based services as well as to new staff that will be hired to work in community-based services. The retraining and the training of staff should be accompanied by the development of new professional profiles, creating curricula, trainings and certifications. In this respect, the working conditions of staff in new services (including adequate salaries) should also be properly addressed to ensure quality outputs for the beneficiaries of the services.

Cooperation and involvement of all relevant actors (co-production) generating co-ownership in civil society

Engaging civil society, in particular children, children with disabilities, adults with disabilities, elderly and their representative organizations, but also staff from institutions, policy makers and community stakeholders in the development and delivery stage of the strategy is a challenging but effective way of gaining ownership and the views of children, adults and families in the delivery of the strategy. A comprehensive consultation process should be designed to this extent.

Accessibility and availability of mainstream and targeted services

One of the main barriers in the allocation of housing options to persons with support needs is the lack of compatibility between the resources available and those that are requested and needed by individuals with support needs. Issues such as accessibility of the built-environment and lack of other adaptations that may make the housing setting accessible to a wider public are to be addressed more consistently. Moreover, the use of assistive technology as a tool to enhance independent living should be promoted more widely.

The provision of personalised housing services needs to change towards universal access, disability-inclusion and person-centred approaches. Consequently, universal design criteria need to be considered at the stages of future architectural planning and real estate development.

Availability of well-functioning public transport and accessibility of public infrastructure are major factors determining the mobility of both individuals in the new community-based settings and social care/support employees. In terms this will influence also the availability, accessibility and frequency of support. Where such public infrastructure is not developed, provision of social care and support services becomes costlier and more time consuming.

Adaptation of existing legislation and adoption of new legislation

It is crucial that legislation is adapted to facilitate and enshrine the transition process to community-based care and services. This implies reforms in the field of legal capacity, self-advocacy, new legislative frameworks for all new community- based services.

Major reforms shall concern the development of an Early Childhood Intervention programme (ECI), access to mainstream education (pre-vocational, vocational), support, health and inclusion in the labour market.

Synergies with other policy areas

The legal framework for deinstitutionalization largely falls within the provisions of social protection. However, the perception that the sole ownership of deinstitutionalization lies with the social protection sector contributes to fractured relations with other policy areas such as financial policies, health care, education, housing, accessibility and others. Successful implementation of the Strategy depends to a large extend on the coordination of the goals of public policies in various sectors and levels. Clear modes of cooperation should be set up between central government and local authorities and also between the different Ministries involved, namely the Ministry of State, Ministry of Health, Ministry of Education & Religious Affairs, Ministry of Justice, Ministry of Development & Investment, Ministry of Internal Affairs, Ministry of Environment & Energy, Ministry of Infrastructure and Transport.

Furthermore two other bodies, the Greek Ombudsperson, representing the Framework for the Promotion of the Implementation of the United Nations Convention on the Rights of Persons with Disabilities and the National Commission for Human Rights (NCHR), acting as the independent advisory body of the Greek State in the field of human rights protection, should be actively involved in the DI process.

Awareness raising & cooperation and involvement of all relevant actors (co-production) generating co-ownership in civil society

Deinstitutionalisation requires the participation of civil society and a strong coalition in favour of DI from all stakeholders.

Engaging civil society, in particular children, children with disabilities, adults with disabilities, elderly and their representative organisations in the development and delivery stage of the strategy is a challenging but effective way of gaining ownership and gather the views of children, adults and families in the delivery of the strategy. Awareness raising programmes are effective ways to inform society about the values of inclusion and participation for all. The application of co-production principles would allow acknowledging that everyone is an expert in their own life, everyone has something to contribute, and that enabling people to support each other builds strong, resilient communities, strengthening the relationship between citizens and service providers and improving the outcomes for everyone.

At the same time, it should be acknowledged that collaboration will occur with individuals and groups that initially may not share the goal of closing institutions and creating community living opportunities for all.

According to international experience, individuals and groups that might not support the closure of institutions could include:

- Unions and Staff: whether they belong to a union or not, staff members generally resist any move that appears to jeopardize their jobs. Institutional closure represents change and uncertainty for their futures. Members of staff should be reassured that they will not lose their jobs.
- Large private residential providers protecting themselves against closure.
- Some parents of children or adults living in institutional settings. For many residents, the institution has been their home for many years, and the possibility of change may be daunting. Some parents might have similar feelings, and also they may have taken comfort in an expectation (common in the past) that state institutional placement was permanent.

Cooperation with the (social) housing sector and investment in accessibility

One of the main barriers in the allocation of housing options to persons with support needs is the lack of compatibility between the resources available and those that are requested and needed by individuals with support needs. Issues such as accessibility of the built-environment and lack of other adaptations that may make the housing setting accessible to a wider public are to be addressed more consistently. The provision of personalised housing services needs to change towards disability-inclusion and person-centred approaches. Consequently, both approaches have to be considered at the stages of future architectural planning and real estate development.

Funding and sustainability

Allocating sufficient earmarked financial and material resources is one of the crucial steps of any DI program and the sustainability of the reform. Existing financing of services is centralised and inadequate for the new services which need to be developed. Important issues that need to be taken into consideration include:

- Preserving the resources that are used in the institutions and reallocating them from institutions to new forms of community care.
- Ensuring adequate funds for the transition process (while the institution will continue running and new services will be developed in parallel). “Double funding” to finance both institutional and community-based services simultaneously may be necessary during the transition process[11].
- Securing adequate resources for an increasing number of users which will occur from the DI process and the development of a wider range of services.
- Restructuring of the funding system in order to respond to the needs of the people and be available for them no matter where in the system the services are provided.

---

[11] United Nations General Assembly (2014), Thematic study on the right of persons with disabilities to live independently and be included in the community: report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/28/37, 12 December 2014.

2.4 Vision

In view of the international standards required and of the current Greek context, the DI strategy has the following vision:

The deinstitutionalisation strategy for Greece is aimed at developing a solid framework of social care support systems, so that children – with special focus on neglected children and children with disabilities – adults and elderly with various support needs can be fully included in society.

The Strategy aims at creating the conditions for all individuals, regardless of their support needs, to participate to society, allowing them to enjoy their fundamental rights, empowering them and promoting their active contribution as full citizens with equal rights.

3. Strategic objectives for children and children with disabilities

Context

According to the adoption and fostering information system (anynet.gr), which was established by the L.3548/2018, 1581 children with or without disabilities are accommodated in 83 child protection structures, of which 595 are in public law institutions.

Children that live in institutional care are often admitted into the system due to the lack of services in the community. Their placement in institutions or alternative care in general may not be needed if access to universal, targeted and specialised support services was provided in the community. This is the case for children whose parents cannot – for a variety of reasons – take care of them and that with relevant support would be in a better position to look after their children. This is also the case for children with disabilities who have been traditionally placed in institutional care due to the misconception that children in institutional care have better access to medical support, whist specialised support can be found also in the community with appropriate measures in place.
Comprehensive care and support for children should encompass a range of social services including access to universal services, targeted services, specialised services and highly specialised services as defined by provisions included in the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child.
Access to universal services covers all services that should be accessible to children, for example, children's access to adequate housing, early childhood intervention, inclusive education, healthcare. These services should be made available regardless of the children and their family's status. Targeted services address very specific issues or (temporary) situations and include for example family allowances for single mothers, access to housing and access to nutrition programmes.

When the level of support requested becomes more specific for children and their families, access to specialised services should be foreseen. For example, children with disabilities should have access to personal assistance budget, teacher's support at school and other support that will allow them to have better access to universal services.

Finally, highly-specialised services may address severe social issues faced by the family, such as community-based crisis intervention, drug and alcohol addictions, violence and abuse prevention programmes. Aligned with the UN Guidelines for the Alternative Care of Children, children shall enter the alternative care system, only when it is absolutely necessary and in their best interest. For those children, there should be a variety of care options in place that would accommodate best the individualised needs of every child.

Priorities

3.1 Ensure a solid base of support services aimed at strengthening and empowering families, children and children with disabilities

This shall take place through:

3.1.1 Reinforcing, further developing and harmonising the range of universal services available to ensure accessibility, availability and affordability to all services across the country – including in rural areas and covering both pre and post-natal care.

3.1.2 Developing across the country a wider range of specialised and highly specialised support services available in the community to support families and children with high support needs, so to prevent family separation separation and facilitate the reintegration of children with their families.

3.1.3 Developing legislation and a program aimed at regulating Early Childhood Intervention (ECI) programmes for children aged 0 to 6 years-old, operating at national level as a support system for families in need and as specific support for children with disabilities.

3.1.4 Strengthening the availability of anti-poverty measures, including access to personal assistance schemes, that act as a cushion against social exclusion and poverty, including social housing, support for basic needs (transport, food, health-care, materials) and psychological support aimed at reinforcing the family, addressing emergency needs and preventing child removal from his/her family.

3.1.5 Reinforcing the network of community centres with both financial and human resources and improving the offer of support services available to meet various demands such as day-care centres, creativity centres, kindergartens, rehabilitation facilities, respite-care services, legal aid, etc. so to allow proper follow up of families requesting consultation and ensure continuous support according to need.

3.1.6 Strengthen the gate-keeping system at regional and local level in order to prevent unnecessary separation of children from their families and placement in residential care.

3.2 Develop a range of alternative care measures aimed at providing children without parental care - including children with disabilities - with family-like environment

This shall take place through:

3.2.1 Development of a programme for foster care including:

- The availability of a range of foster care options including short term, long-term and specialised foster care for children with complex needs.
- Procedures for assessment and training of foster carers developed and applied in a harmonised manner.
- On-going monitoring, supervision, support and performance management developed and applied for foster parents.
- The further development of the national register of foster carers.
- The development of appropriate workforce, including social workers, psychologists, foster carers, and other professionals involved in the delivery of quality foster care services.

3.2.2 Development of a range of family-type residential care options based in the community and that will serve the child's best interest. Residential care in the community should be the last resort option if the family of origin is not available to take care of the child or fostering/adoption are not possible. Small scale residential care should by no means resemble institutional care and, to this extent, quality standards should be developed in line with the UN CRC and the UN CRPD and legally adopted. All residential care settings (private, State and faith-based) should be registered and licensed as well as regularly monitored to ensure that the care provided is of good quality.

3.2.3 Ensuring adequate staff-ratios are provided in community-based care settigs and ensuring adequate on-going training, supervision and support of professionals, as well evaluation of the quality of the social care workforce.

3.2.4 Supporting the development of systems to enhance participation of children on issues concerning their lives.

3.3 Ensure the closure of all institutional care settings, the reintegration of children and children with disabilities in their families or their transition from institutional to family and community-based care settings

This shall take place through:

3.3.1 Collecting disaggregated qualitative and quantitative data on children living in large and small residential care settings, including their support needs and their family situation.

3.3.2 Development of deinstitutionalisation plans, including a timeframe, for every large-scale institutional care setting aimed at a gradual closure of the institutional set ting as such. Alternative use of the buildings – non including residential care options – should be explored.

3.3.3 Development of individual care plan for each child living in institutional care to ensure family reintegration or transition to family and community based care.

3.3.4 Support municipalities to put in place family and community-based care services using the released resources from closing down large-scale and other institutional settings. In doing so, the Government should pilot the transformation process, analyse results and replicate this practice to other institutions.

3.3.5 Introduction of a gradual moratorium mechanism in parallel to the development of community-based services. For children without parental care, alternative care options shall be sought looking first at kinship care and secondly at care in fa mily-based (foster care) or family-like environments, ensuring siblings are kept together.

3.3.5 Ensure reintegration in families in so far as possible, and when in the best interest of the child, by providing families with the needed support (financial, material, psychological and practical support), as well as connecting them to professional, community and wider family support. A family support/family strengthening/ reintegration plan/programme for helping the family of origin should be designed and applied. A strategic action plan for the cooperation of all relevant social services should be made with binding status reflected in relevant legislation.

3.4 Reinforce, promote and further develop educational schemes for children and children with disabilities

This shall take place through:

3.4.1 Data collection to monitor the needs of children, their attendance to schools and their educational career in order to plan interventions, follow up the needs and prevent early abandonment.

3.4.2 Granting children with support needs full rights to have access to mainstream education while receiving specific support. A comprehensive plan to address inclusion of children with disabilities should be developed in order to equip schools with the needed resources, train school profes sionals and raise awareness among the schooling community.

3.4.3 Developing guidelines for staff in the education sector to better identify and respond to the needs of children with support needs.

3.5 Develop support programmes for children and children with disabilities leaving care as well as for their after-care support

This shall take place through:

3.5.1 Development of a national programme to provide support schemes for children leaving care and for their after-care ensuring their inclusion in the community. This should include psychosocial support and guidance by trained professionals, financial and housing allowance and more. Children leaving care should be supported as long as it is needed after their transition to independent living.

3.5.2 Ensuring person-centred plans for each child leaving care are developed. These plans should include provisions for on going support throughout education at both secondary and tertiary level and for the development of life skills.

4. Strategic objectives for adults with disabilities

Context

In recent years, Greece has made major legislative reforms, seeking to put in place a new legislative framework that safeguards the rights and promotes the inclusion of persons with disabilities in the community. The most important of such initiatives was the enactment of Part IV of Law 4488/2017 which, drawing on the requirements of Article 33 of the UN CRPD, to enact guidelines for implementing the UN Convention at national level.

Person with disabilities in Greece have to face a shortage in the variety and availability of services and those with high level support needs face the biggest challenges.
Greece has both institutional care-style residential services and community-based accommodation services for persons with disabilities. Based on current available data of the Ministry of Labour and Social Affairs, as the supervising authority of public law welfare structures, 1773 adults with disabilities or chronic illnesses are accommodated in twelve (12) Social Welfare Centers and in Evrytania Chronic illness Treatment Center. Additionally, in ten (10) Chronic illness Treatment Centers of Private Law, 665 people with chronic illness are accommodated and get support. Most adults living in institutional care (83%) are registered as persons with disabilities or with chronic illnesses.

The only alternative to institutional care are "Supported Living Homes" providing support to persons with physical, psychosocial, intellectual and/or sensorial disabilities with various needs. As of June 2018, there were 28 organisations operating 65 Supported living arrangements where 389 Persons are living.
Supported living homes however, cover only a very small percentage persons with disabilities living in the community, moreover, they currently do not have the capacity to replace institutional care as such.

Priorities

4.1 Gradual closure of all institutions and resettlement of residents in community-based accommodation

This shall take place through:

4.1.1 Clear political commitment and legally binding decisions.
A clearly stated political commitment to close down institutions is a prerequisite. The choice should be defined not in terms of "If" but rather as "When" and "How". The commitment shall include a political decision to adopt the deinstitutionalisation strategy at national level through legally binding decisions prohibiting the construction of new institutions, through a moratorium on refurbishment of institutions, except for interventions aimed at providing security and health for the residents and banning new admissions to institutions based on a specific timetable.

4.1.2 Mapping of existing institutions by Social Welfare Centres, providing specific information regarding numbers and profiles of people living, numbers of staff etc.

4.1.3 Developing a community-transition plan for each institution, providing clear guidance as to how the transformation process will proceed and an action plan with a clear time frame and all the necessary steps forward.

4.2 Develop a range of community-based services

This shall take place through:

4.2.1 Development of a range of specialised support systems catering for a variety of needs in the various spheres of lives of individuals. Support systems should be based on quality assurance mechanisms for services including the involvement of a range of experts including persons with disabilities and/or their advocacy/representative organisations.

4.2.2 Reinforcing and further development of supported living homes resembling the size of a common family-type environment including adequate support for persons with complex needs.

4.2.3 Developing a range of community-based services that support persons with disabilities to live their lives independently such as personal assistance services. This requires the development of a legal framework supporting the development of associated professional profiles, training materials and accreditation process. Moreover services such as respite services, emergency help services, legal counselling, day-care support and other should be made available in the community.

4.2.4 Piloting of new initiatives and methodologies regarding personalised funding options.

4.3 Prevention of institutionalisation

This shall take place through:

4.3.1 Development of support services to address the needs of persons with disabilities living at their home with relatives or informal carers. Such assistance should be freely chosen and reflect the shifting needs of the person and his support circle. These services could be developed in the context of the existing "Help at home" program or by the offices offering support services to vulnerable groups set up by the Ministry of Health in cooperation with the Local Government in the context of the implementation of the "Health and Welfare" Operational Program. These programs should be developed at local level so that the citizens' needs can be met with fo cused and productive interventions.

4.3.2 Moratorium on new admissions in every institution within a specific timeframe, assuring alternative options based in the community are made available.

4.3.3 Improving access to information via reinforcing the role and responsibilities of Community Centres.

4.4 Developing a legal framework unlocking participation in the community

This shall take place through:

4.4.1 Promoting access to employment for persons with disabilities via development of a legislative framework for supported employment and a facilitating framework for the employment of persons with disabilities in social economy enterprises.

4.4.2 Facilitating access to mainstream education systems to persons with disabilities by providing trainings to school staff and raising awareness among students-peers; equipping schools with adequate resources.

4.4.3 Enhancing legal capacity as an important prerequisite of independent living and the need to abolish all forms of substituted decision-making regimes and replace them with supported decision-making.

5. Strategic objectives for elderly persons

Context

Older people with or without disabilities experience a range of age-related needs that are not fully met in the current services spectrum. Key services identified include providing support and care for forward planning, community inclusion and availability of more appropriate choices for accommodation in later life.

Limited choices of living arrangements, lack of appropriate and available support services, lack of staff's specialist knowledge of the needs of older people with or without disabilities and barriers in accessing general community services are the key issues to be addressed to provide adequate support services and structures meeting individual needs.

Priorities

5.1 Develop a framework programme to address the needs of elderly and related services

This shall take place through:

5.1.2 Develop a centralised contact point to identify the needs of elderly persons such as nursing, personal assistance, support at home, logistic support, administrative support, transport.

5.1.2 Make ICT support available to enhance independent living at home.

5.2 Develop training programmes for the workforce to better address the changing needs of elderly

This shall take place through:

5.2.1 Identifying training gaps and deliver appropriate training programmes for staff working with elderly.

European Association of
Service Providers for
Persons with Disabilities

CREDITS & RIGHTS

Attribution: Please cite this work as follows:
European Association of Service providers for Persons with Disabilities (EASPD), Brussels, February 2021.

PHOTO CREDITS

©Tandem NGO

This publication has been produced with the financial support of the European Union via the Structural Reform Support Programme of the European Commission.