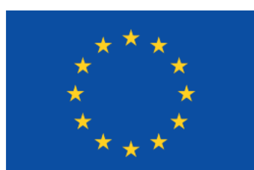
Guidelines on support procedures in community-based settings

Technical support on the deinstitutionalisation process in Greece



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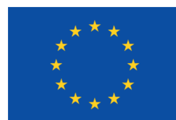

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1. Introduction

Greece has made significant progress in some parts of the social and childcare reform, and good efforts to stop relying upon institutional care for vulnerable children, persons with disabilities and elderly persons. In the framework of the running project providing technical support on the deinstitutionalisation process in Greece, Greek Authorities and key stakeholders joined forced and developed National Deinstitutionalisation Strategy, Action Plan and Roadmap for deinstitutionalisation. While developing this policy documents, work had been done to provide tools to facilitate a correct implementation of the reform, including this manual on support procedures in community-based care.

The way to community-based care has been paved by many countries all over the world. Governments in Anglo-Saxon countries began to call for and plan the closure of institutions and the provision of community-based supports since 1960[1]. Most European countries have made significant progress in closing institutions in the last twenty years, but this has not always been done the right way[2]. The impact of deinstitutionalisation (DI) policies and practice on the lived experience of persons with disabilities and older adults is under scrutiny[3].

Being only at the initial phase of the DI reform in Greece has one positive aspect: we can build on shared experience and lessons learnt and turn delay into an opportunity to implement better care and avoid common mistakes[4] when implementing gate-keeping mechanism and when helping children and adults move to their own homes in Greece. Given what we now know on how to support children, persons with disabilities and elderly people in the community effectively, we should invest all our energy in disseminating good practices to develop even more community capacity and services. We can learn from each other and, most importantly, keep learning from the children and people we support.

Key elements that emerged from the development of community care internationally are presented here as recommendations on how to develop support procedures to amplify and supplement community-based settings in Greece so that they can:

- **protect children** and increase their life chances and prospects of inclusion,
- **enable persons with disabilities to take control** over the support they have and the services they use,
- **ensure people age well** and have a dignified life as older adult.

[1]The paradigm shift in residential services: From the linear continuum to supported housing approaches Ridgway, P. and A. M. Zipple, 1990, Psychosocial Rehabilitation Journal 13, pp. 11-31; Lieberman, M. A.; Institutionalization of the aged: Effects on behaviour, Journal of Gerontology, 1969, 24(3), 330-340; Chronic mental patient: Current status future directions, Paul, G. L., Psychological Bulletin, 1969, 71(2), 81.

[2]Wasted Time, Wasted Money, Wasted Lives ... A Wasted Opportunity? European Coalition for Community Living, Focus Report, 2010. Available at http://community-living.info/wp-content/uploads/2014/02/ECCL-StructuralFundsReport-final-WEB.pdf

[3]Šiška, J. and Beadle-Brown, J., Transition from Institutional Care to Community-Based Services in 27 EU Member States: Final report, 2020, Research report for the European Expert Group on Transition from Institutional to Community-based Care.

[4]Lost in Interpretation: The use of ESI Funds during 2014 – 2020 and the impact on the right of persons with disabilities to independent living, European Network on Independent Living and GUE NGL, 2020. Available at: https://enil.eu/wp-content/uploads/2020/12/Study_EP_EN_09122020.pdf

2. Scope and purpose of the guidelines

For this document, we must limit the concept of community care to the target groups of the DI Strategy namely children (including children with disabilities), persons with disabilities, older adults and all parties involved in supporting them to live well in the community. We will do so even though planning for community-based care extends to so many more. Consideration and development of support procedures will eventually benefit directly and indirectly many more than children and people moving there from institutions. For example, children and people who need support but are rarely identified by the social care system, those already living in community-based settings unsupported, those that suffocate in over-protective environments, or those that suffer from family abuse or neglect.

Careful planning for support in community-based settings will also support planning for preventative and gate-keeping services. For example, developing a foster care system will enable children to stay with their families (i.e. short breaks for parents of children with complex needs through respite foster care). It will reduce significantly unnecessary placement in institutions (drawing support from a pool of assessed, approved, trained and well-monitor of foster carers). Societal benefits from community-based care are also well-acknowledged. We know that institutional care impedes the healthy development of societies as it normalises and maintains discrimination[5]. Therefore, planning for community care helps society as a whole. The DI transition will help build a society of people that will understand vulnerability as part of human nature and difference as part of human diversity. Eventually, it will assist a shift in how people think and feel about social care and reshape decisions, priorities and policymaking[6].Although all these behavioural elements are crucial in the DI process, they will not be elaborated in the context of these guidelines.

Further clarifications need to be made concerning persons with disabilities in institutions. We must keep in mind that we generally use the term disability to describe many different impairments that affect the lives of persons with disabilities differently. The impact disability will have in a person's life is a correlation of the type and level of the impairment and the person's geographical, financial, family and social status[7]. Persons with disabilities in institutions also enter the system (usually as babies or toddlers) with different types and levels of impairments. However, the institution soon becomes the only geographical, financial, family and social status they know. Primary research[8] shows that conditions of 'care' in 'rehabilitation' institutions often exacerbate the impairments that children and persons with disabilities have and sometimes even goes to completely dehumanise them. Children with disabilities are almost invisible for the childcare system. They are rarely placed in regular institutions for non-disabled children; instead, they grow up together with adults with disabilities in special institutions. As a result, children can have a clear and accurate picture of what their life will look like in a few years from a very young age. Many attended only the institution's special school, some of them attend special schools in the community, very few attend mainstream schools with little or no support or supervision, and some have never attended any school at all[9].

[5]Children in institutions: The beginning of the end? 2003, Innocenti Research, Centre Innocenti Insight – UNICEF. Available at: https://www.unicef-irc.org/publications/pdf/insight8e.pdf

[6]Talking about a Brighter Social Care Future. 2019, #socialcarefuture. Available at: https://socialcarefuture.files.wordpress.com/2019/10/ic-scf-report-2019-h-web-final-111119.pdf

[7]Employers' Guide for the employment of people with disabilities. 2019, Observatory on Disability Issues, NCDP. Available at: https://www.paratiritirioanapirias.gr/storage/app/uploads/public/5f8/755/bf3/5f8755bf32777484052933.pdf

[8]The rights of children in institutions: Findings and recommendations of the Independent Authority "the Greek Ombudsman" on the function of the child protection institutions. 2015, Greek Ombudsman. Available at: http://www.synigoros.gr/resources/docs/575568.pdf

[9]Special Report on the Rights of Children who reside in institutions. 2015, Ombudsperson's Office. Available at: https://www.synigoros.gr/?i=childrens-rights.el.idrimata_oxi_anapiries.286537

Most of them have loose, weak, or non-existent ties with their birth families. They rarely have friends or even acquaintances outside the institution, and people around them are mainly paid professionals and carers. The institution is all they known.

The general category 'children' includes children with disabilities and non-disabled children from 0 to 18 years old. We have included here young adults (18-24 years old) who have grown up in institutional care (or in and out institutions and other situations outside of their own families) and are struggling with challenges and obstacles in transitioning to adulthood and independence. Cumulating evidence of relevant research on careleavers show that this period is one of the most vulnerable periods of the child's life[10]. When left unsupported, these young people are more likely to experience poorer education and health outcomes, poverty, unemployment, incarceration, substance abuse, violence and abuse, teenage pregnancy, societal and interpersonal relationship issues and even suicide, compared to their peers who have grown up in stable, family homes.

When referring to elderly people, this document also includes younger people in the aged care system. These people might have a disability-related high level of support needs, younger onset dementia and premature ageing associated with life experiences. These people typically enter residential care for older adults due to the lack of availability of more suitable care services[12].

We will look at some Integrated Housing Support (IHS) forms that help few older children and young adults (including care-leavers) persons with disabilities and older adults move from institutions to the community. In IHS we include family-like small scale domestic living for only a few children (12-17 years old) with complex needs that we don't manage to place in professional foster care, or older children[13] who do not wish to be placed in foster care programs older children and young adults who need more support in transitioning to independent living.

We will also look at some of the features of Housing-led services (home-based care, personal assistance services and/or housing adaptations and remote-living support), including kinship and foster care. Because 'community care for children is care that is as close as possible to family-based care and where the community is involved in the process of a child's recovery. Foster and extended families are examples of community-based care'[14].

We will also look at housing-led support for older children and young adults who are leaving care. Regarding support procedures on community-based settings, again we will focus only on how these help children and adults who transition from institutional care to community-based life.

[10]From care to where? Care leavers' access to accommodation. 2017, Carepoint.
Available at: https://centrepoint.org.uk/media/2035/from-care-to-where-centrepoint-report.pdf
[12]Review of innovative models of aged care. 2020, Royal Commission into Aged Care Quality and Safety.
Available at: https://agedcare.royalcommission.gov.au/sites/default/files/2020-01/research-paper-3-review-innovative-models-of-aged-care.pdf
[13]The United Nations defines youth or older children as those between 15-24 years of age
[14]Better Care Network Toolkit and Glossary of Key Terms,
available at: http://bettercarenetwork.org/BCN/Toolkit/Glossary/index.asp

3. What are community-based settings? And why do they need support procedures?

Community-based settings are settings where people reside. They are not large-scale, anonymous and intrinsically abusive for children, persons with disabilities, and older persons the way institutions are. Nor do they perpetuate discrimination by providing tacit approval for the idea that certain groups of people should live far away, apart from society. On the contrary, community-based settings build on the idea that people who share the same vulnerabilities as everyone else in the society with less power to deal with them should be supported in the community.

Integrated Housing Support (IHS) comes in many forms under two primary axes[15]:

(a) housing-like settings where people are supported in communal housing settings,
(b) housing-led support in where people are supported in their home, a foster home or the home they will choose to rent or buy through various support schemes.

In short, 'community-based settings' is a term to describe the process of creating homes for those who need support. Right? But wait, is it not this the same way institutions brand themselves? 'A loving home for those in need', 'home away home', 'like a big family home'? And is any foster home a good home for children that have already suffered enough?

A foster home can offer so much more to a child than even a well-intentioned institution ever could. But not any foster home and certainly not any unsupported foster home. Community-based settings are usually not large-scale (they can be a one-person accessible apartment) and can be placed in lively neighbourhoods. But numbers related to where people live, and a regular home address 'will only tell a very small part of the story of the of people living there'[16]. One should look at a range of indicators to differentiate community-based from institutional settings.

In fact, the report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care[17] referred clearly to the difficulties in defining what an institution is and focused instead on institutional culture. They use the following definition in the report: "any residential care where: (a) users are isolated from the broader community and/or compelled to live together; (b) these users do not have sufficient control over their lives and over decisions which affect them; (c) the requirements of the organisation itself tend to take precedence over the users' individualised needs."

Under this light, any setting, any well-known or innovative community-based living arrangement or even a person's own family home can and will reproduce institutional culture if support procedures are weak, not accessible, or even lacking. There is nothing magical about the walls of a house alone that can make a child feel loved and protected, or any person feel that she now has a network of trusting, caring relationships, that she is listened, that she has choice over her living situation and control in her life, that she participates in the community she lives in.

[15]See: European Core Learning Outcomes for Integration of Support and Housing (ELOSH). 2015, ELOSH library. Available at: https://www.housingeurope.eu/section-87/resources
[16]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.
Available at: https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf
[17]Ad Hoc Expert Group (2009) Report on Transition from Institutional to Community-based Care.
Available at : https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes

Careful planning for support procedures is what will enable people in community-based settings to do what we all do to live well with meaning, purpose and connection: draw upon a range of support and relationships[18].

Countries that respect international human rights and principles do not (or no longer) promote community-based settings **without parallel planning and budgeting for support procedures**. Lessons learnt and key concerns raised[19] make even more clear that when planning DI for children and people that have suffered enough, countries should first ensure adequate planning and funding, enforce existing regulations, conduct research and policy review, guarantee interagency coordination and collaboration, recruit and develop qualified support staff and raise public awareness[20]. This process is an indispensable condition for ensuring the infrastructure and a culture change that needs to be in place to plan for each child's and each person's individualised supports needs.

Guided by the human rights approach, we will look at how we can enhance and develop support procedures (in the form of services, programs, benefits, formal and informal relationships) in community settings. Supports that are directed and controlled by the person and that are respectful of that person's right to make choices and take risks[21].

A common -and honest- mistake when planning for support procedures is often to focus too much on the process and lose sight of the person. Therefore, all our efforts and decisions should be informed by people's lived experience followed by questions on their life outcomes. Through support procedures we are looking to equip children, persons with disabilities and elderly people who transition to community care with high quality, affordable, mobile, and accessible tools that ultimately help them *live their own* life in *their* home.

[18]Crowther N. and K. Quinton: How to build public support to transform social care. 2021, #socialcarefuture
Available at: https://socialcarefuture.files.wordpress.com/2021/04/scf-building-support-report-final-april-21.pdf
[19]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.
Available at: https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf
[20]'Community for All' Tool Kit Resources for Supporting Community Living. 2004, Human Policy Press.
Available at: http://thechp.syr.edu/HumanPolicyPress/
[21]A Guide to closing institutions and reclaiming a life in the community for people with intellectual disabilities. 2010, People First of Canada/Canadian Association for Community Living
Available at: https://institutionwatch.ca/wp-content/uploads/2019/10/the_right_way.pdf

4. Overarching principles[22]

Person-centered and child-centered planning (and support!)[23]

Person centred plans help people get a good start of how to build a life that makes sense to them. Person-centred planning is about support tailored to individual needs, that offers choices and is developed and provided together with the people we support and those who are close to them (friends/teachers/advocates/family members). Plans should continuously increase the effective control people have over the supports they receive and the choices they make and as a person's interests, needs, health and wellbeing change, person-centred planning is not a one-off task; plans should be reviewed periodically. Person-centred planning is a systematic way to generate an actionable understanding of any person as a contributing community member[24] and it therefore, the core of community care, the mentality and attitude that can shift the system's balance from group provision to individualized supports.

A person-centred care approach should also appropriately enable tailored delivery of care to diverse populations (for example, children with disabilities and chronic health conditions or older LGBT+ people). Planning for diverse groups in the community also requires provisions to increase awareness/understanding of these groups' needs. All plans must be accompanied by implementation and ongoing training to those involved in delivering them.

Attitude shift in supporting children and people

From policy-making officers to support staff, foster carers, friends and families should rethink their roles in community-based care. We need to move away from the idea that child-care is meeting children's physical or educational needs (by usually containing them and controlling their behaviours).

We need to move towards a holistic view of the child's needs to help each of them transition to adulthood and independent living. For example, giving children educational opportunities that lead to higher education will not necessarily help them capitalise on academic titles in the market.

When children grow up with turnovers of interchangeable caregivers, have never experienced emotional stability and have developed little if any soft skills needed to navigate society and workplaces, academic titles can only do so much. Attitude shift shall apply to persons with disabilities and older adults as well. Our work should no longer focus merely on the medical conditions a person might have (or not). We now have to identify and assess -together with the people- their individualised needs, preferences, qualities and support them engage in community life. For example, we should consider how to offer a person with intellectual and developmental delays (IDD) tailor-made employment rather than 'work therapy'.

[22]See: Study on Deinstitutionalisation of Children and Adults with Disabilities in Europe and Eurasia. 2013, The European Network on Independent Living (ENIL).
Available at: https://bettercarenetwork.org/sites/default/files/Study%20on%20Deinstitutionalization%20of%20Children%20and%20Adults%20with%20Disabilities%20in%20Europe%20and%20Eurasia.pdf
[23]See: Smull W. M. and S. Burke Harrison. Person centered planning and perversion prevention. 1993, ASA.
Available at: http://allenshea.com/2021/01/27/person-centered-planning-and-perversion-prevention/
[24]O'Brien L. C. and J. O'Brien. The origins of person centered planning: a community of practice perspective. 1999, Research and Training Center on Community Living. Available at: https://files.eric.ed.gov/fulltext/ED456599.pdf

Choice and control[25]

No one could have expressed the right to choice and control better than the president of the National Confederation of Disabled People of Greece (NCDP) and the European Disability Forum Mr Y. Vardakastanis (2011) who says that: "Freedom of choice is the holiest right. If a person is not able to exercise this right, (s)he is in captivity. It is a form of social slavery"[26]. Access to information, advice, and advocacy should be provided to both children and adults with disabilities, so they can make informed choices about the support they receive. All people should be presumed competent to make choices about their lives. Those individuals who have difficulty in identifying and expressing preferences need to be surrounded by a core group of people who know them well to assist with making choices. Choice can be about how can family members, friends, advocates, service providers, and others best help and support individuals to decide on their likes and dislikes. Persons with disabilities will sometimes make bad choices, as do non-disabled people. They still have the right to learn by doing mistakes. Disability or age is not a reason for depriving any person of making the same choices other people have the right to drive. At the same time, choice should never be used to justify neglect.

Importance of mainstreaming

Instead of developing a parallel system of services for persons with disabilities, mainstream services should be made accessible to people with different support needs wherever possible and specialized services should be developed whenever necessary. Integration of services[27] is also crucial to achieving maximum coordination and effectiveness among different services for the best outcomes for service users.

[25]See: Smull W. M. Revisiting Choice. 1995, AAMR's News and Notes.
Available at: http://allenshea.com/2016/10/23/revisiting-choice/
[26]Y. Vardakastanis' speech at the 19th European Social Services Conference in Warsaw 2011.
See: https://www.esn-eu.org/fr/node/5123
[27]Integrating Social Services for Vulnerable Groups: Bridging sectors for better service delivery. 2015, OECD.
Available at: https://read.oecd-ilibrary.org/social-issues-migration-health/integrating-the-delivery-of-social-services-for-vulnerable-groups_9789264233775-en#page8

5. Community-based settings and Support Procedures

5.1 Children[28]

5.1.1 Housing-led support for Children

Placement in the extended family: Kinship Care

Kinship care is when children who cannot or should not be raised by their birth parents are looked after by relatives or family members of the extended family. This can be either short-term or long-term. Kinship care is recommended as the preferable form of foster care. In most countries that have developed a foster care system, kinship care has the same provisions, criteria and financial remunerations as foster care. However, unofficial kinship is most common in many countries around the world, including Greece.

Placement in substitute Families: Foster Care

Foster care is a family-based care placement option for children who cannot or should not be raised by their birth parents. Their extended or kin network family has been identified and is not willing or was assessed not suitable to look after the child. It can be temporary or short term. Foster care can be a long-term care option when all attempts to return the child to the birth or extended family or place the child to adoption have been exhausted. It can also be long-term foster if this is in the child's best interests (i.e. a child that might be legally 'adoptable', but is already secure and happy in a current foster placement). To provide viable alternatives to institutional care, we should plan for a range of foster care, including emergency foster care, professional foster care, respite foster care.

[28]See: Deinstitutionalising and Transforming Children's Cervices: A Guide to Good Practice. 2007, European Commission Daphne Programme Directorate-General Justice and Home Affairs, WHO Regional Office for Europe, University of Birmingham, UK. Available at: http://www.socialserviceworkforce.org/resources/deinstitutionalizing-and-transforming-childrens-services-guide-good-practice
Csáky, C.Keeping Children Out of Harmful Institutions: Why We Should Be Investing in Family-Based Care. 2009, Save the Children. Available at: http://www.thinkchildsafe.org/thinkbeforevisiting/resources/STC_keeing_children_out_of_insitutions_why_we_should_invest_in_family_based_care.pdf

5.1.2 Support procedures *after* placement in foster (or kinship) care

- Train everyone! Anyone caring for, working with or for children in the care system needs to have an attachment aware and trauma informed education[29]. This is critical to create a child centred approach to care and provide therapeutic relationships for children and young people with trauma.
- Identify children in unofficial kinship care and assess theirs and their families' supports needs.
- Throughout the placement the foster carers should be provided with a package of holistic support services, including trainings, counselling and referral to other services such as health, education, recreational activities, access to specialists for help and/or therapies when needed and legal services for the child followed by financial remunerations for all the child's expenses.
- Additional support through short-brakes and respite care should be provided to foster carers that raise children with complex needs.
- Foster carers should be provided links with foster parents' associations and peer-to-peer support groups.
- A social worker should be allocated for each child (or set of siblings) in foster care. The social worker is responsible for overseeing the foster child's support and assesses the child's well-being through using available unified protocols. The supervising social worker must make frequent contact through regular visits, video calls, consultations. The social worker should be trained on child-friendly methods that ensure the child is able to express herself. Children's voices should be heard before and after the placement.
- Every foster carer must be allocated a supervising social worker. The social worker is responsible for overseeing the support the carer receives, assessing the carers' performance and ensuring they develop the skills needed to help raise another person's child.
- Provided that: (a) social care services have recruited, assessed, accredited and trained foster carers who live in the same geographical area with the child's birth family, (b) foster care is not used a pre-adoption measure, and (c) an interdisciplinary team has decided -after listening carefully to the child's voice (or behaviour)- that contact with the birth family this is to the interest of the child, the foster carer should not only agree but also have the skills to facilitate and encourage the child's contact with her parents and/or siblings or family members and model a healthy relationship and bond with the child to the birth parents.
- Contacts with birth families should be done in an enjoyable -yet not loud- place (i.e. a parc) and not in the institution that the child used to live. Meeting a parent, you cannot or should not go back home with is already stressful enough. Re-entering the gates of the institution to do this can be, and usually is a traumatic experience for the child
- Social workers should be provided with supervision and mentorship throughout the duration of the child's placement.
- In cases of abusive birth parents that have been banned from contacting their children, children should be informed timely, carefully in an age-appropriate manner and should also be offered ongoing counselling. In such cases, social services should also activate mechanisms and procedures to protect foster carers.
- The amount and type of support the child, foster carers will need depends on each child's individualised and regularly revised assessment and care plan. This is a complex task that only an interdisciplinary team can undertake. Social workers alone cannot and should not evaluate care placements or do reintegration and permanency planning.

[29] This guideline shall apply to all forms of IHS for children

- Placing a child with an experienced, knowledgeable foster carer is great, but it does not mean case closure. The amount of support foster carers need also depends on their life conditions. And conditions change, in all families.
- Children in foster care should be informed about formal and accessible complaint mechanisms[30].
- The priority for all children in foster care should be to ensure a permanent care arrangement either through family reunification or adoption.
- Deciding on the child's best interests might include staying in a long-term foster care scheme despite being legally 'adoptable' or asking the foster carer to consider adopting the child in long-term foster care.
- Foster carers and older children in care must be supported to participate in developing an aftercare plan that includes the transition to supported or independent living (skill building, setting future goals, mapping available services and support, social networks and people that will be part of the child's aftercare plan).

5.1.3 Early Childhood Education and Care[31]

We believe that we must make particular reference to one service in which all children under six, including those in foster care, should have access to: Early Childhood Education and Care (ECEC). Experiences in early childhood are often the root cause of the hardest social challenges such as family breakdown, addiction, poor mental health, suicide and homelessness. Cumulating evidence of years of relevant research makes this an indisputable fact. From conception to the age of six, what we experience in the early years shapes the developing brain, which is why positive physical, emotional, and cognitive development during this period is so crucial. It is a time when the building blocks are established. It is therefore essential to lay foundations that help provide greater resilience to deal with future adversity. Therefore, ECEC is the cornerstone of preventative services, and it is the epitome of interdisciplinary, inter-agency work. A team of parents and carers, social services, doctors, psychologists, and early years teachers must work together to identify and address issues at an early stage. ECEC helps children and families thrive when it is high quality, accessible, affordable, and inclusive. Although ECEC is key to the development of children with disabilities, it is not only about disability. ECEC is beneficial to all children regardless of their backgrounds and helps significantly children growing up in institutions[32], poor environments due to poverty/ethnicity/crisis, children that have suffered abuse or neglect. Although they are not considered disabled per se, these young children may develop delays compared to their peers due to their living conditions. ECEC increases the prospects for successful inclusion of children with disabilities and disadvantaged children into a society of people that will have learnt to understand difference as part of the human diversity.

[30]This shall apply to all children, disabled people and older adults in community care
[31]See: Council Recommendation on High-Quality Early Childhood Education and Care Systems, adopted by the Council at its 3693rd meeting held on 22 May 2019.
Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CONSIL:ST_9014_2019_INIT&from=EN
[32]See: The Bucharest Early Intervention Project: www.bucharestearlyinterventionproject.org;
in particular: http://www.bucharestearlyinterventionproject.org/Marshall_et_al___2004_.pdf

5.1.4 Housing (or family)-like settings for only a few children

Placement in small-scale domestic care – specialist residential care

Providing birth families of children with disabilities with a range of support services (including adequate financial support, affordable, accessible and high-quality Early Childhood Education and Care, home-based Early Childhood Intervention programs, respite care, personal assistance and accessible housing services, counselling etc.) will prevent so many family separations. But unfortunately, not all of them. Some parents will continue to choose not to raise their child with disabilities or will continue to fail in doing so. Others will continue to choose residential over home-based care for their child who lives with a mental condition. There are also parents struggling with their own severe mental health problems, which can make caring for their child challenging or risky. In short, there will always be parents who cannot assume their parental role despite support. Concerning children currently in institutions, even if we manage to establish a well-developed foster care system, community-based services will always be unable to reintegrate or ensure family-based care for all of them.

Yet, we need to take children away from mental health hospitals, rehabilitation centres and institutions and offer them the best support and care we can provide in a family-like environment.

It should be in small family homes, in the community where children will have individualised care. Children with complex care needs (severe mental health conditions or severe impairments) are less likely to be placed in foster care. Furthermore, some children have spent a long time in institutions and thus have developed environment-related developmental delays and severe behaviour problems and mental conditions[33], or simply reject the idea of being placed in a foster family overall. Some children may require a period of time in a small family home as a transition to care within another family and some children may never have any other option than longer-term residential placement. In any case, where residential care is used, it should be the last resort.

[33] Yang, M., Ullrich, S., Roberts, A. and Coid, J. Childhood IC and personality disorder traits in adulthood: Findings from the British National Surveys of psychiatric morbidity. 2007, American Journal of Orthopsychiatry, 77, 67–75

5.1.5 Support procedures after placement in small scale domestic care – specialist residential care

- Family-like settings mean that very few children live in a home (and not a working place) with a ratio of well-trained, child-centred caregivers that ensure individualised care and support as well as time outside the house walls.
- Houses (and or apartments) should be fully accessible to all children, and children with disabilities should be offered technical aids to access their environment.
- Houses should look like any other house in an ordinary neighbourhood (homes do not need signs hanging from the walls to remind passers-by that this is 'a smiley home', or 'a lovely home')
- Children should adopt nutritional habits and physical activity that will enhance their opportunities for outdoors time. It is prevalent in institutionalised children with high support needs to have developed unhealthy relationships with food (comfort eating especially but also anorexia).
- Children should be supported by staff members, advocates and self-advocates, peer-to-peer support groups in identifying and assessing their needs and asking for assistance in choosing and using services.
- Some children might require additional assistance in decision making through assisting technology, easy-to-read material, active 'listening' of their behaviours (for all children and especially for non-verbal children). Because children with severe difficulties expressing their preferences have always been excluded from anything that concerns their lives. Having a core group of people that invests time and energy to understand their interests and wishes is the utter reminder of what it is to be human with their own identity.
- All children should be supported in taking risks and developing skills that will enhance their independence. Support staff need to be committed to helping them un-learn institutional dependency and should be inventive when doing so.
- Children who have lived in institutions will often have no sense of self, or even worse, they have been labelled and have learned to live by their labels (i.e. 'troublemaker', 'liar', 'stupid'). Very often, those labels appear under different wording in their formal assessments and care plans as well. Support for children in their new environment includes helping them un-become what they aren't and finding out who they are. This will also widen the opportunities for effective communication between staff members and children.
- Children should be encouraged and supported in accessing the range of mainstream services their communities provide (education, leisure, health and mental health).
- Some children might need to be assisted in building social networks[34]. Professionals should be properly trained in supporting this process.
- They should understand what an institution is and what institutional culture means, e.g. when all services and relationships they have are assembled in the house they live in, their house is an institution.
- A weekly allowance should be budgeted for all children in the family-like setting, including those who will need support from a friend, peer, or paid staff member in managing it.
- Children should be supported in planning for their future by providing them consistent information and advice about every aspect of the young person's life, not just housing.

[34]See: circle of friends: https://inclusive-solutions.com/circles/circle-of-friends/what-is-a-circle-of-friends/

5.1.6 Housing-like and housing-led support for youth and care-leavers

Supported independent living helps teenagers and sometimes young adults that need support, to transition to independence and adulthood through aftercare services and supported independent living interventions[35]. It can be Housing-like (i.e. a Supported Living Home) or Housing-led (in the young person's own home when available or in housing provided by the social services). In the first case, children and young adults live in a small-scale group home in the community with a minimum or high level of support staff according to their needs. In the second case, older children and young adults live alone or with roommates they will choose to have and receive support in the form of benefits, counselling, mentoring and guidance on spending individualised budget, making everyday decisions and setting future goals. It should be noted that when planning for young adults who leave care, we should also include those who are reunited with their birth parents. The child will often be reunited with her birth parents only because she turned 18 and not because the conditions that led to her placement in an institution (i.e. extreme poverty, alcoholism or substances abuse) have changed.

5.1.7 Support procedures after placement in Supported Independent Living Arrangement for youth and care-leavers

- Community settings for young people and care leavers should be accessible and fully inclusive places with structure but not rigid routines and regulations.
- They should aim to provide their tenants with a sense of progress and achievement to build confidence and self-esteem.
- All support staff (regardless of their academic background and job description) should understand their central role is to facilitate young people to develop the skills needed for successful independent living.
- Young peoples' training should include things such as: time management, household chores, nutrition and healthy lifestyle, hygiene, budgeting and control over individualised funding, sexual health, safe use (and being safe on) social media, using public transport, their rights and how to access legal representation.
- Young people should be supported in accessing or returning to education (mainstream or vocational education and training) and remaining engaged in it (this might include the provision of incentives, grants, scholarships and positive measures to widen their opportunities for higher education).
- They should be offered careers advice, support in finding employment (taster days with local employers, apprenticeships and short term work experience through strategic partnerships), mentoring and job coaching.

[35]The service is outlined in the International Guidelines for Alternative Care of Children. Available at: https://resourcecentre.savethechildren.net/library/united-nations-guidelines-alternative-care-children

5.2 Persons with disabilities

Integrated Housing Services include housing-like settings and housing-led support:

5.2.1 Housing-like settings for people with disabilities

Communal supported housing

Communal supported housing comes in many forms, the most common for people transitioning from institutions to community-based care are Small Group Homes. There, support is delivered in shared living settings through visiting services in defined working hours or more intensive on-site services 24/7 according to tenants' individualised supports needs. Living there can be long-term, but settings might also be using a 'staircase' model providing steps, each of which is designed to aid a transition towards housing-led support and independent living.

Intentional life-sharing communities is also a communal supported housing model as long as life-sharing is an informed choice of the disabled members of the community as much as it is for the non-disabled members. Intentional life communities do not believe in staff-client distinction. They usually (but not always) operate on a religious or philosophical basis (i.e. Catholicism, anthroposophy, etc) with obvious lifestyle implications for all their residents. They don't suit everyone but can be a legitimate choice for those who make it fully informed.

5.2.2 Housing-led support

Home-based support

Personalised support goes directly to the people (in forms of accessible housing, benefits -personal budget-, services -such as personal assistance-, social and health care, guidance) in the ordinary houses they choose to live alone, with their partner, friends or flatmates. Support follows them if they move, anywhere they move. There are real choices on how to use support including the choice to not use support[36].

[36]For detailed information on IHS, see ELOSH project

5.2.3 Support procedures for persons with disabilities[37] who use Integrated Housing Services[38]

- Ensure housing in the community and wherever people choose their homes to be. Do not set up housing services in remote areas and ensure support (including remote support) for those who might choose to live in hard-to-reach rural areas (i.e. people with disabilities living in their homes -or with their families- in small islands or mountain villages).
- Instead of thinking of new regulatory frameworks, identify and address the circumstances that might create risk for some people in the community. Create strategies to mitigate the risks together with the person. Always keep in mind that these people have already suffered enough from the idea that institutionalisation was the best safeguard for them. Help people create personal relationships and community networks. Meaningful relationships are the most effective safeguards for us all.
- Ensure that former institutional employees that will be chosen to work in community-based settings will have (or have developed through intensive training) the skills and characteristics needed to work with people in the community as those differ significantly from those necessary in institutional care.
- Make sure that all staff members understand that their job descriptions in community-based settings will be as broad as needed to ensure tenants can live full lives. For example, a qualified psychologist might have to use public transport together with the autistic person (s)he needs to accompany in a mainstream mental health service, help the person eat or drink during waiting in the waiting room, help the person use the bathroom if (s)he needs support in using the bathroom.
- Ensure wider provision of broader generic training (i.e. in person-centered philosophy and support, human rights approach to disability, virtual visits in other countries' community services). Ensure that all staff members understand that the IHS sector can be highly diverse and all people are different and have individualised needs. For example, a setting that cares only for adults with down syndrome is one place to find various unique people; having in common an extra chromosome and a home. All the rest that inform their care plans will have to be explored by day-to-day living and interacting with each person. Ensure continuity of individualised service delivery. Support should be provided for as long as an individual needs it, based on their changing interests, health conditions, needs or preferences. An individualised needs assessments[39] will help identify when and how often the user will get support, the organisations providing the support and the contingency plans to cope with emergencies.
- Separate housing and support. The type and level of support should not be determined by where someone lives, and individuals should be able to change their living arrangements without losing the support they receive.
- Support people to decide on their likes and dislikes (involving friends, family, advocates and self-advocates), help them co-produce their care plans and take active roles in decisions that affect their homes, their lives, their communities.
- Invest in -or at least do not underestimate- the power of people supporting people. The support that a person that receives support can give to another person that needs support can be life-changing for both parties. Promote peoples' active participation in peer-support groups. Create social networks that assist in participation in the community and effective safeguarding. Facilitate support circles[40] to help those who might need more support in bringing their skills, capacities and gifts in give-and-take relationships.

[37]Most of these support procedures shall apply to older adults using IHS. Below we develop some more specialised support procedures
[38]See: Developing Community Care. 2011, European Social Network. Available at: http://www.esn-eu.org/developing-community-care
[39]Needs Assessment Protocol for DI, European Association of Service providers for Persons with Disabilities (EASPD), Brussels, May 2021
[40]Developing and maintaining a support: A source for people with disabilities and their families. 2015, Pave the way. Available at: https://www.family-advocacy.com/assets/Uploads/Downloadables/d425931888/11320-Developing-and-maintaining-a-support-circle.pdf

- Support people to self-direct[41] and become full and equal citizens and members of the communities they live in (i.e. control their individualised funding, identify the level of support they want to use, the services they want to use and the way to use them).
- Support people access to mainstream services (i.e. health, mainstream education, leisure activities, employment) and develop more targeted services (i.e. adult skill programs connected with market needs, tailor-made employment schemes). Instead of thinking about setting up new special services and perpetuating segregation, we first need to start thinking about the support, practical tools, and methodologies. A person might need to access mainstream services and facilities.

- Establish mechanisms for tenants' oversight of the homes they live in; Build internal regulations that are accessible to all tenants, use simplified language and focus on[42]:
  - Relationships between tenants (in shared housing) and support staff (when needed) based on respect, openness, honesty and transparency;
  - Communication that ensures that all tenants receive timely, clear and accessible information on the issues that matter to them, including information about their homes, their local community, the association/organisation that provides their housing; Tenants' lived experience where tenants' views inform decisions. Tenants should feel free to express themselves knowing that their voice will be listened and can influence things that matter to them;
  - Accountability where all tenants can hold the association/organisation that provides them with housing to account for decisions or negligence that affect the quality of their homes;
  - Quality that ensures tenants have well maintained and safe homes; Access, advice, and support to complaint processes when things go wrong, ensuring responsive mechanisms. Ensure mechanisms that gather feedback from tenants on the implementation of internal regulations with the abovementioned focus;
  - Support tenants in setting up Self-Advocacy Groups and a Tenant Advisory Board.

[41]For more information on Self-Directed-Support (SDD) see: Citizen Network (https://citizen-network.org/resources/category/individual-service-funds) and Centre for Welfare Reform (https://www.centreforwelfarereform.org)
[42]Extract from: Together with Tenants – lessons from the early adopter programme.
2020, UK's National Housing Federation. Available at: https://www.housing.org.uk/globalassets/files/together-with-tenants/together-with-tenants---early-adopter-report_final.pdf

5.3 Elderly people[43]

5.3.1 Housing-like settings for older adults

Communal supported housing for older adults can be small-scale domestic living arrangements or shared housing arrangements built on a person-centred approach. These models of care are provided as both dementia-specific and generally aged care homes. In many ways, they share things in common with Small Group Homes for disabled adults. Older people live in homelike environments where staff members (usually providing 24-hour on-site care) help them engage in domestic duties or spend time outdoors and focus on maximising their independence and quality of life.

Intergenerational life-sharing communities are also a model that suits some older people. Although most intentional life-sharing communities subscribe to a religious or philosophical model, there are also communities where the connecting philosophical basis is inclusion, equality of choice and treatment, and mutual enrichment. 'Dementia villages'[44] offer small-scale living, but the houses are included in a village environment, with retail services. Services are staffed by carers trained to support people with dementia engage in 'village life'.

5.3.2 Housing-led support

Housing-led support for elderly people refers to care in their own home. The amount and type of care people receive varies according to peoples' individualised needs in carrying on with their activities of daily living. It can be low-level support (home maintenance, shopping, cooking) or high-level nursing (feeding, bathing, walking or strolling outdoors etc). Help is usually delivered by informal caregivers (partners, family members) paid carers or a combination of both. The person usually draws support from mainstream services (health and social care) and targeted services (such as Day Care Centres, Friendship Clubs for Older Adults etc.)

[43]See: Review of innovative models of aged care. 2020, Royal Commission into Aged Care Quality and Safety. Available at: https://agedcare.royalcommission.gov.au/sites/default/files/2020-01/research-paper-3-review-innovative-models-of-aged-care.pdf
[44]See: De Hogeweyk Dementia Village: https://hogeweyk.dementiavillage.com/

5.3.3 Support procedures for elderly using IHS[45]

- Ensure pensions that allow elderly people to buy the services they need to age in their own place whilst remaining integrated within their community, supported by appropriate services, professionals, family members.
- Ensure elderly people have the technical aids they need to increase their independence (i.e. quality hearing aids, wheelchairs they can use independently etc.).
- Set up housing adaptations programmes. Elderly peoples' homes will often need minor but strategic adaptations and arrangements to enhance their autonomy and offer them a sense of safety.
- Ensure home-based health and social care. Mobile units (usually comprised of community nurses, aids, and social workers) that pay regular visits to elderly people is at the core of community care.
- Ensure training to aged care workers so that they can move away from practices largely used in residential care for older persons, understand and deliver person-centred care.
- Ensure capacity and access to Community Sports Clubs that offer reablement or restorative care for elderly people. The goal setting is to combine interventions, including exercises targeting physical impairments, activities of daily living retraining, behavioural interventions, adjustments to the environment, and accessing adaptive equipment to restore (or maintain) physical function[46]. However, these places also provide networking opportunities with the community, offer socialisation assistance and interpersonal interaction.
- Ensure capacity and access to Day Care Centres and Friendship Clubs. Relationships, in general, promote a sense of belonging and security, keep older persons stimulated.
- Train elderly people in assisted technology (basic skills development programs). Technology solutions can have limited acceptance by older users due to their perceptions and reservations on ease of use and suitability for purpose. However, many elderly people saw the benefits of connection technologies and, although sceptical in the beginning, are now self-trained independent users! Assisted technology programmes can involve training from completing a video call to using intelligent health information systems (such as wearable monitoring devices that collect data and provide measurements and feedback on someone's health circumstances or location).
- Ensure dyadic interventions that support both the older adult and the caregiver, consider care challenges and the strengths and capabilities of both the older person and their carer, and work together on tailored, individualised solutions.
- Provide community-based respite care programs.
- Involve elderly advocates and self-advocates in building age-friendly communities.

[45]See: Integrating Social Services for Vulnerable Groups: Bridging Sectors for Better Service Delivery. 2015, OECD. Available at: https://read.oecd-ilibrary.org/social-issues-migration-health/integrating-the-delivery-of-social-services-for-vulnerable-groups_9789264233775-en#page4
[46]Resnick B, Restorative care nursing for older adults: A guide for all care settings. 2004, Springer Publishing Company

6. Recommendations

The purpose of planning for community-based settings is to ensure that no one needs to be raised and/or end their lives in institutions in the future. This process involves:

- **building inter-agency working** (including the NGO sector and Church services),
- **ensuring adequate funds**,
- **ring-fencing resources**,
- **adopting a broader conception of resources** (to include social networks, strategic partnerships etc.),
- **increasing training to help professionals** identify children, families and people who need support, including those who are not yet encountering social services.

The following set of recommendations draws on primary research and research findings well-documented and reported in reviews, publications and public interventions by committed entities and organisations such as the National Confederation of Disabled People of Greece (NCDP), the Ombudsman's Office[47], the National Centre of Social Solidarity[48], the Institute of Child Health[49], the Association of Greek Social Workers, international NGOs such as UNICEF[50], Lumos[51], EASPD[52] and local NGOs such as Roots NGO[53] and Foster Parents' and Volunteers' Network for Children's community-base Care[54].

Once more, the following recommendations focus on the people who transition from institutions to community-based care.

Recommendations should be considered alongside the National DI Strategy and Action Plan for transforming the system of care for children, disability, and older adults, as well as the National Strategy for Social Inclusion[55], and the National Action Plan for the Rights of Persons with Disabilities that was recently prepared by the Greek Authorities in close cooperation with the NCDP.

The implementation of the recommendations requires mostly implementation of existing legislation with the necessary allocation of specific resources. In some cases, implementation may require regulatory and procedural reform, in other cases skills and capacity building and in all cases a cultural shift. This includes moving from a model of task-orientated 'resident care' to people's engagement in a range of formal and informal support and more reciprocal relationships[57].

[47] From the institution to the community: Alternative care for vulnerable children and family support 2020, Ombudsman's Office, Special Report.
Available at: https://www.synigoros.gr/resources/eidikh-ek8esh-prostasia-eyalwtwn-paidiwn_teliko.pdf
[48] https://www.ekka.org.gr/index.php/el/
[49] ICH & LUMOS (2016). Strategic Review of the system of caring for vulnerable children in Greece.
Athens: Institute of Child Health & LUMOS; ICH/UNICEF, (2018).
MAPPING AND ANALYSIS OF THE CHILD PROTECTION (CP) SYSTEM IN GREECE, RFPS-CEECIS-2017-171090
[50] https://www.unicef.org/greece/
[51] https://www.wearelumos.org/what-we-do/global-training/knowledge-portal/
[52] https://www.easpd.eu/en/content/running-projects
[53] Roots Research Centre & Opening Doors Campaign. (2015). Mapping institutional and residential care for children in Greece; Roots Research Centre & Martin James Foundation. (2021). Spelling book of legal concepts and advice to prospective foster parents. Written by Hara Galanou. Available at: https://www.roots-research-center.gr/
[54] https://www.facebook.com/fosterparentsnetwork.gr/
[55] https://www.eydamth.gr/lib/articles/newsite/ArticleID_615/ESKE.pdf and Amitsis, G., & Marini, F. (2015).
The National Strategy for Social Inclusion – Greece: A Brief Presentation SYGLISIS – Strategy & Research Consultancy.
Available at: http://www.housingeurope.eu/file/255/download
[56] http://www.opengov.gr/ypep/wp-content/uploads/downloads/2020/09/%CE%95%CE%B8%CE%BD%CE%B9%CE%BA%CE%BF%CC%81-%CE%A3%CF%87%CE%B5%CC%81%CE%B4%CE%B9%CE%BF-%CE%94%CF%81%CE%B1%CC%81%CF%83%CE%B7%CF%82-%CE%B3%CE%B9%CE%B1-%CF%84%CE%B1-%CE%94%CE%B9%CE%BA%CE%B1%CE%B9%CF%89%CC%81%CE%BC%CE%B1%CF%84%CE%B1-%CF%84%CF%89%CE%BD-%CE%91%CF%84%CE%BF%CC%81%CE%BC%CF%89%CE%BD-%CE%BC%CE%B5-%CE%91%CE%BD%CE%B1%CF%80%CE%B7%CF%81%CE%B9%CC%81%CE%B1_2020_%CE%A5%CE%A0%CE%95%CE%A0-1.pdf
[57] Trigg L, Improving the quality of residential care for older people: a study of government approaches in England and Australia. 2018, London School of Economics and Political Science: London, UK.

6.1 Children

In regard to the social work system that will have to support families, foster placements and family-like settings that will replace institutions, there is an absence of a comprehensive community system of social services as there are only fragmented, understaffed and unequally distributed social services belonging mainly to Municipalities and public bodies supervised by different Ministries[58]. Therefore:

- Current services need to be mapped and reviewed[59] and the Greek Authorities must identify what is needed to establish a comprehensive, community-based social service system/sector with adequate resources, capacity and staff trained on a national assessment framework, unified protocols and guidelines for handling cases (including interacting with children). This system should support and monitor foster placement and at the same time support vulnerable families and children at risk.
- Ensure that infringements of Law on Foster Care and Adoption (L.4538/2018) by any public or private childcare provider are penalised under conditions, both procedural and substantive.
- Ensure that all institutions of childcare implement systematic and permanent DI programs for all minors they protect. Institutions and all legally competent statutory entities for children in institutions (i.e. Social Services in Regional Governments) should actively search for foster carers to place all. Especially those that, due to their characteristics and needs are unlikely to be matched with prospective foster carers based on the preferences that the latter will submit to the anynet.gr digital platform.
- Legislate for sanctions for the providers that refuse to implement the guidelines on developing care plans (ASOA). Interpretive instructions on the correct completion and documentation of individual family rehabilitation plans with the designation "Not able to be rehabilitated" and "Return to birth family" of minors living in child protection and care units (46293/2035/2020 explaining Art. 7 in L.46O4/2O19) are child-centred and concise, covering flawlessly all main issues when working with children's care plans. However, they lack one main point that eventually can render this document inactive: obligatoriness.
- Make necessary configurations to the digital platform so that children can be matched with potential foster carers who live in the same geographical area with them. With few exceptions, staying in the same geographical area is beneficial to the child and it is necessary when the court has ruled for visitations with the child's birth family.
- Although matching children and foster carers digitally is indeed challenging (if not unorthodox), make sure that personal care plans (ASOA) have detailed information about each child (including the type(s) of foster carers that would be more suitable for them) and that potential foster carers have answered a set of scenarios before submitting their application (i.e. would I be willing to host a trans child, a child whose parents are convicted for criminal offenses or whose parents have learning difficulties or mental health conditions?). This will, hopefully, limit failed e-matches.

[58]Mapping and Analysis of the Childcare System in Greece. 2018, Institute for Child Health.
Notes from G. Nikolaidis' brief presentation at UNICEF's Conference in Athens:
Visioning Child Care Reform in Greece National Conference for Civil Society and Faith-based Organizations
[59]Mapping exercise and analysis/ review of support services and procedures implemented in the community in Greece. 2020, European Association of Service providers for Persons with Disabilities (EASPD)

- Make sure that children's preferences are heard and taken into consideration before the matching process. Children should be treated equally with the potential foster carers who are asked to submit their preferences to the digital platform. Children should be able to state their preferences on their potential carers as well (i.e. would I want my carer: to have other children in the house? Pets? To live in the countryside?).
- Unless for the cases of emergency foster care, allow more time and space for the preparation process. A baby or a toddler might be ready to go home with her foster carers within a few days (if not hours!), but an older child (able-bodied or disabled) will usually need more time to trust a set of new people and move in with them. Adequate bonding time will be beneficial to both the child and foster carers.
- Train prospective foster carers on the needs of different groups of children they will be asked to take under their care (i.e. teenagers, children victims of abuse, children with delinquent behaviour etc). Foster care can indeed become long-term when it is for the benefit of the child and some foster carers might even choose to adopt when given this choice. However, the initial plan when training foster carers is that we are training partners that will be asked to replace paid caregivers in institutions. Training perspective foster carers together with potential adoptive parents creates even more confusion over these two institutions.
- Perspective adoptive parents should submit their application under this status only. Social workers can then decide whether there are children available to be placed under their care using foster care as a pre-adoption measure. Being able to apply as both perspective adoptive parents and perspective foster carers maintains confusion and hinders the development of a foster care registry based on the needs of the children in care. It certainly creates numerical data that are inaccurate.
- Implement the UN Guidelines on Children's Rights and the Council of Europe Recommendations to Member-States regarding children in institutions and ensure that no child under three years old grows up in an institutional environment. Extend foster care programs such as the 'foster first hug' program (initiated by Mitera and followed by Anarotirio Pentelis, CSWA) to all institutions that host babies and toddlers. Address this issue openly and honestly with institutions that claim that some babies and toddlers cannot be placed in foster care as their legal status is still to be clarified. No legal status needs to be defined for a child to be placed in foster care.
- Implement law provisions on professional foster care and introduce funding quotas for foster care support in all authoritative public administration services. Do not limit professional foster care only to children with disabilities and children with severe mental health conditions (L. 4538/2018, Art 16), as emergency foster care should also be a paid alternative care service.
- Ensure that children in need of emergency foster care can be placed (right after their removal from their birth family) in homes of people they already know and have an emotional connection with. These people include primarily family members (for whom the Law already foresees an independent process) but also neighbours, teachers, family friends that fulfil the requirements and are suitable to become foster carers (current Law does not include them in the same process).
- Ensure that children 0-6 in foster care have access to high-quality, affordable, accessible and inclusive early childhood education and care (ECEC) programs and can enrol the children under their care in such programs any time of the school year.

- Ensure that all children placed in foster care have a social security number (AMKA). Law 4636/2019 that denies the right of children to have an AMKA if their legal guardians do not have insurance (usually migrant birth parents), affects their access to healthcare, and regarding children with disabilities it excludes them from Early Childhood Intervention programs, therapies, benefits, and technical aids that are normally reimbursed by the National Provider of Health Services (EOPYY).
- Legislate for children's Small Group Homes to allow the placement of only a few children in such settings in the community. Make those homes inclusive so that children with disabilities can live alongside their non-disabled peers (especially when those are their siblings). Ensure national standards of care, inspection and accreditation for children's Small Group Homes.
- Children in community-based settings (as all children) will use the healthcare system. Ensure all primary health care workers have child protection training and all services have clear child protection policies and procedures which workers are fully supported in using through training, supervision and management accountability.
- Ensure all children with special educational needs (either in foster care or SGHs) have parallel support and special support staff in accessible (buildings, equipment, educational material) mainstream schools and that all school staff is adequately trained to include the student fully and equally in the school life.
- Ensure that all children will have access to mainstream Centres of Creative Activities (KDAP) and not only children without disabilities and children with mild disabilities.
- Inform families, foster carers, staff members that support disabled children on their children's rights[60].
- Inform children on their rights and support them in exercising them in all environments.
- Establish Family Strengthening Centres (ensure inter-agency cooperation and coordination, multi-disciplinary teams, joint-planning for children and families and joint action).
- Develop a mechanism for mandatory cooperation and referral between health, education and social services.
- Invest in awareness-raising campaigns to recruit foster carers, prepare receiving communities and inform donors.
- Invest in foster carers' participation in peer-support groups and association of parents.

[60]See: https://www.esamea.gr/publications/books-studies/5033-odigos-dikaiwmatwn-gia-atoma-me-anapiria-xronies-pathiseis-kai-tis-oikogeneies-tous

6.2 Persons with disabilities

- Simplify setting up Small Group Homes involving the National Provider of Health Services (EOPYY) in the DI process.
- Train service providers, families, advocates and self-advocates on how to fulfil the right of persons with disabilities to SGHs[61].
- Develop protocols on supporting people's independence in SGHs, ensure legal protection for all staff members in SGHs, and reduce personal responsibility (through supervision and interagency cooperation). Establish legal protection (along with the introduction of internal monitoring and control processes) so that staff members can actively support people's independence.
- Set up Independent Living (IL) Centres to facilitate people's access to personal assistance services. Train prospective personal assistants (PAs) on the overarching principles of person-centred care, independent living, and the role of personal assistants in countries that have well-developed IL services. Fully inform PAs on the right of their employers (service users and their families when needed) to further train them on the assistance they need upon their unique, individualised needs.
- Implement employability as stipulated in international and national legal frameworks. More specifically:

    - Take immediate measures to abolish the stigmatising phrase: 'incapable of doing any paid work' that often follows people's disability certifications and excludes them from the right to register in the records of the Manpower Employment Organisation (OAED) and participate in any employability program.
    - Ensure people's legal capacity through the establishment of a supported decision-making mechanism. For people with IDD to participate in paid work, they need to be considered capable of signing their name on a piece of a paper.
- Ensure that all persons with disabilities (regardless of the type of their disability) will continue to have access to their disability benefits regardless of their working status or type of employment. Address current inequalities on that issue.
- Create Social Enterprises' capacity and ensure the active involvement of persons with disabilities and that all Social Enterprises are accessible to employees with disabilities. Train service providers, families, advocates and self-advocates on how to set up Social Enterprises[62].
- Inform and encourage public entities and municipal services on utilising the institutional and legal framework for contracting directly and exclusively Social Enterprises (L. 4412/16).
- Ensure that people are adequately trained in new technologies to make use of all possible telework opportunities.
- Ensure that people have access to mainstream higher education and vocational training programs that increase their opportunities to be included in the job market. Ensure that people do not have to choose only between a few special vocational training programs operated by the Manpower Employment Organisation (OAED), Special Needs Lyceum or Special Vocational Education and Training Schools (EEEEK).
- Upgrade the KEK AmeA[63] of OAED and the Special Vocational Education and Training Workshops (EEEEK) and include them in the National Qualifications Certification System.

[61]See the Guide for Setting up and Operating SGHs. 2019, Panhellenic Association of Parents and Guardians of People with Disabilities. Available at: http://www.posgamea.gr/
[62]See: Guide on Social and Solidarity Economy. 2019, NCDP. Available at: https://www.esamea.gr/publications/books-studies/4994-odigos-koinonikis-kai-allileggyas-oikonomias-gia-atoma-me-anapiria
[63]http://prev2016.oaed.gr/kek-amea

- Use the 3% quota for university entrance wisely. Make sure that students with disabilities will have the support they need (accessibility offices in their university, personal assistance, interpretation, accessible textbooks, transportation and physical environment) to complete their studies.
- Establishment of a “supported employment” legal scheme
- When people choose special vocational training programs, make sure these are high-quality, up to date with market needs which have the necessary tools and resources to build networks of cooperation for apprenticeship schemes.
- Support employers in employing employees with disabilities[64].
- Support employees with disabilities in their workplaces (mentoring, personal assistance and reasonable accommodations).
- Ensure access and capacity to Day Care Centres for Persons with Disabilities (KDIF AmeA), Centres of Creative Activities (KDAP AmeA), special sports programs (i.e. Special Olympics) but also support participation in mainstream activity programs provided by local governments (i.e. cultural and sports activities).
- Ensure care for people with severe ID/DD and Down Syndrome who might enter dementia at a young age. These people have a significantly higher incidence of dementia and similar life expectancy trends to those for the general population[65]. Especially for individuals who live without their families, the transition to dementia is frightful and often life-threatening. Intimate knowledge of their usual personality and habits are essential to diagnose dementia early and to provide a safe, peaceful and familiar environment. Introduce assessment protocols and train support staff in identifying the incidence of dementia early.

[64]See: Employers’ Guide for the employability of people with disabilities. 2019, NCDP.
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6.3 Elderly people

- Develop a comprehensive strategy for elderly people and a single appropriate legislative framework (including implementation of existing 'inactive' legislative framework and relevant modifications).
- Develop IHS services for elderly peole. One cannot work on person-centred plans to help older adults transition to the community when the only choice we offer them other than limited home-based support is merely private, large-scale Care Units for the Elderly (MKF).
- Introduce quality standards for all care providers and train all staff members accordingly.
- Make sure that foreign people working in care for elderly people have access to Greek Language courses.
- Ensure that all responsibilities that have passed from the 'Health and Welfare Inspectors Corps' to the National Transparency Authority (L. 4622/2019) are activated and that all providers are controlled, monitored and penalised when they violate older adults' human rights (or the right to be human rather).
- Implement Law 2345/1995 that introduces social consultants who must visit all welfare institutions every two months and alert the Greek Authorities when needed. Train social consultants in writing effective reports and referrals based on the quality of care provided in such settings and not on building specifications (making sure that social consultants engage and interact with people living there and consider their lived experience to write their report).
- Strengthen preventative services such as Help At Home programs, Day Care Centres (KIFI), and Friendship Clubs (KAPI). Address the issue of unequal distribution of the abovementioned programs, especially between urban and rural areas. Distribute them equally in Greece based on population and demographic criteria and geographical needs for a comprehensive support network's gradual, balanced development.
- Introduce quality standards and unified protocols for all the above-mentioned programs.
- Improve the services provided by KAPI, KIFI, Help At Home programs and ensure better interconnection. Ensure adequate funding also to cover logistics infrastructure, travel expenses for both beneficiaries and support staff.
- Further develop Help at Home programs to ensure that elderly people have access to help when they need it. Elderly people need support all days of the week and any hour of the day.
- Define the criteria for inclusion in each of the abovementioned programs and create regional registries that cooperate with a National Registry of Elderly People
- Introduce cooperation protocols between Help at Home (Ministry of Labour and Social Affairs) and Hospitalisation At Home (Ministry of Health) services.
- Ensure funding for Day Care Centres for elderly peole from the National Budget as for more than 20 years they operate merely with European Cooperation Operational Programs with the implications that this has on the continuity of services, retainment of professionals and the social insecurity for professionals working in such programs.
- Plan for ageing populations in remote areas where access to essential health and social services is difficult (remote support, telehealth services, awareness raising in the communities where elderly people reside).

7. Conclusions

From policymakers to professionals working in community services and support staff in institutions, the great majority of people does not dispute the need to replace institutions with community-based care. Scepticism starts when thinking of the massive reforms needed to improve or set up support services so ensure peoples' safety and wellbeing. We do not want to put children and people at risk and close institutions to substitute peoples' isolation outside the community for isolation within the community. So we might well share the same vision on the future of care, but implementing it in a country when there are outstanding issues to be addressed in the welfare and child protection sector can feel overwhelming. Do we take people out of institutions when 'the system' is not ready for this shift? Yes. If we do not the system will never be ready.

Communities are rich in resources, but by keeping institutions open, we are 'robbing' them of the funds and the opportunities to expand services and develop capacity[66]. Will community-based settings ensure that people lead good lives with meaning and are full and equal citizens? Of course not. A house in an ordinary neighbourhood is not sufficient, especially for those with more severe and complex needs; but it is a necessary condition[67]. It is a step which can in fact be 'a giant leap' for those that have a very distorted picture of what home and essentially of what living is like. We cannot wait for community 'readiness' to magically happen when we put of sight and hide people in institutions. When those who have experienced the harm caused by institutionalisation will be present and visible, so will be their needs, gifts and aspirations.

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