Roadmap on how to deinstitutionalise a setting

Technical support on the deinstitutionalisation process in Greece

European Association of Service providers
for Persons with Disabilities

CREDITS & RIGHTS

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List of abbreviations

DG REFORM
Directorate General for Structural Reform Support

DI
Deinstitutionalisation

EASPD
European Association of Service providers for Persons with Disabilities

EU
European Union

MoLSA
Ministry of Labour and Social Affairs

NGO
Non-governmental Organisation

PWD
Persons with Disabilities

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

1. Introduction

The present document is part of the "Technical Support on the Deinstitutionalisation Process in Greece" project and is part of a series of tools produced to support DI reform in Greece. The project followed the Greek government's request for support to the European Commission for a reform on deinstitutionalisation (DI). The project is implemented by the European Association of Service Providers for Persons with Disabilities (EASPD) in cooperation with the Commission's Directorate-General for Structural Reform Support. It has the purpose of supporting the Greek government in developing the DI national Strategy, a Roadmap and an Action Plan, that lay the basis for the implementation of the DI process; defining and implementing processes and methodologies to run and manage DI; developing communication and outreach strategy and materials; and developing and providing training programmes to support the DI process. The DI Strategy and key deliverables of the project were developed in consultation with stakeholders, civil society, and persons with support needs. The roadmap is part of the project deliverables but is intended also to be a standalone text with practical guidance on deinstitutionalisation (DI) for managers and directors of institutions.

The roadmap provides guidance on how to move out from institutional culture and practices and embrace a person-centred approach, providing family-based and community-based alternatives to persons with support needs. The roadmap also provides guidelines to address staff needs in the transition process and to respect the rights, needs, and wishes of all supported persons.

This document can be used as a toolkit that will support the development of a comprehensive action plan for the transition to community-based care for each institutional setting which will address genuine needs and problems and make good use of available resources.

This deliverable is focused on the Greek context and it is addressed primarily at managers of institutional settings who will play the main role of the deinstitutionalisation process, managers of Social Welfare Centers, who will proceed to the necessary actions in order to initiate the DI process, policymakers and staff who work on providing care and support to children, adults with disabilities and elderly persons in Greece. It also provides useful information to those responsible for monitoring and supporting the DI process in Greece in the Ministry of Labour and Social Affairs (MoLSA).

2. Deinstitutionalisation in Greece

As the old paradigm of placing people in need of support into an institutional system of care proved to harm the residents and infringe their human rights, as declared in international human rights frameworks, there is a wide recognition for the need for deinstitutionalisation (DI) reforms.

These reforms include:
• the transition of individuals living in institutions into community- based settings where they can receive support and that facilitate their social inclusion, and
• the development of a range of person-centred support systems and services in the community and at home.

The UN CRPD Committee in its Constructive Dialogue with Greece (2019), advised Greece to "adopt a comprehensive national strategy with clear time-bound measures and the allocation of sufficient funds for effective deinstitutionalisation at all levels".

Greece began two years ago formulating a specific strategy for DI and has already produced legal and policy documents supporting DI. The National Strategic Policy Framework for Social Integration 2014 – 2020 acknowledges that people with disabilities and people in need of long-term care are at an increased risk of poverty and social exclusion. As such, the objectives of the Strategy include expanding the provision of community-based services and promoting DI, e.g. implementation of supported living unit schemes for adults and children with disabilities.

For adults with mental health issues, Greece has implemented a psychiatric reform by replacing psychiatric hospitals with acute wards in general hospitals, and many efforts have been made to improve the quality of the mental health care system. However, community-based services remain underdeveloped in many parts of the country and there is still a lack of comprehensive legislation explicitly supporting independent living in the community.

Regarding children with and without disabilities, the Strategy of the Region of Attica and Western Greece is the only document that mentions DI as a specific policy measure. Unfortunately, in Greece, there is still a general belief that institutions can provide a suitable solution for children in out-of-home care. However, the new Law on Foster Care was adopted in 2018 and is expected to enable the development of family-based forms of care for children and boost DI reform at a national level.

The situation of unaccompanied and separated migrant children in Greece also remains unsatisfactory. In 2018, 3,250 unaccompanied and separated migrant children were reported to be living in shelters for unaccompanied children, police departments, reception centres, safe zones or temporary accommodation sites. These settings do not usually have transition strategies in place.

Although the new homelessness national strategy has been announced in 2018, it does not provide any funding information, except for a short-term Action Plan for the period 2019-2021. At the same time, there has been a poor development of mechanisms of prevention[1].

For elderly persons, long-term care continues to be an underdeveloped policy area. A comprehensive formal long-term care service that guarantees care provision for all simply does not exist. The state's involvement is limited and, therefore, long-term care remains a "family affair". It also needs to be noted that austerity policies have caused further, if not exclusive, reliance on informal support networks and heavily burdened the capacity of families to cope.

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[1]National Strategy for Homeless https://government.gov.gr/vasiki-pilones-tis-ethnikis-stratigikis-gia-tous-astegous/

2.1 DI Strategy in Greece

The development of a DI Strategy in Greece began two years ago with the support of the technical support project. The aim of this strategy is to develop a stable framework of systems of social care that can support children with and without disabilities, persons with disabilities, and elderly persons with support needs. The DI Strategy also seeks to make society more inclusive and more accessible to those in need of support by giving them the potential to enjoy their fundamental rights, empowering them, and promoting their active participation as full citizens with equal rights.

The National Action Plan for the Rights of the Persons with Disabilities (hereafter referred to as "NAP"), presented by the Greek government in 2020, is a roadmap that provides us with a clear, cohesive and systematic framework of action, mainly for the period 2020-23. At the same time, there are actions with a more long-term perspective of implementation. Being the result of a cooperation of all ministries and the political leadership, NAP adopted a specific methodological approach that permitted a comprehensive strategic planning of specific actions of each ministry and other relevant authorities, with specific timetables and indicators for its implementation. NAP will be integrated in the National Monitoring Governmental Program in order to ensure its implementation and its continuous updating in collaboration with Confederations of Persons with Disabilities.

On the 20th of September 2020, the Greek government formed a task force for the implementation of the NAP with more than 100 members, including members from all Ministries and other relevant authorities and organisations with a mandate to conclude their work in June 2021. At the same time, and for the first time since the voting of law 4488/2017, there is an implementation of all the actions regarding the identification of specific reference points in all the Ministries as well as Regional and Local Authorities, and the activation of the Mechanism of Coordination.

3. Overview of institutions in Greece

For many years, persons living in institutions have been the recipients of a medical model of care and this prevented the development of an organised and integrated human-rights based social care. Its realisation needs strategic cooperation of policy makers, experts and professionals, local community, persons with support needs, and their representative organisations.

According to the existing legal framework, institutions are run by Boards of Directors. In institutions that are legal entities under public law, the Board of Directors is appointed by the Prefect or the General Secretary of the District and they are overseen by the regional Social Welfare Centres. In Legal Entities under Private Law, the Boards of Directors are elected by the General Assembly of the Charity Association established by the institution. In the institutions belonging to the Church, the President is the Metropolitan Bishop.

In Greece, several institutions provide care services to children, adults with disabilities and the elderly persons. It is difficult to find comprehensive data covering all institutions and service users. Several problematic areas, however, have been documented:

- **Unsuitable buildings**
  A significant number of institutions are in old, damaged buildings, not originally intended for the care of persons with support needs. This not only creates problems for safety and accessibility, by not meeting all the required standards, but also resulting in the image of abandonment. Moreover, the lack of fully functional buildings has as result the exclusion of people from certain areas. This leads to confinement both physically and mentally. They cannot in any case be called a home.

- **Insufficiency of spaces**
  Most institutions are too small for the number of persons they accommodate. This results in a lack of dormitories, therapy, and recreational activity rooms. On the other hand, rooms of 100 square meters might accommodate 15 to 20 people. This can depend on the unavailability of smaller rooms that can accommodate an adequate number of people.

- **Large numbers of people in the same Institution**
  Several institutions host from 80 to 100 people, others have a significantly larger number of residents that can get to 150, 250 or 350 people.

- **Lack of equipment and insufficient use**
  The quality of social services and its purposes and goals depends on the availability of equipment how it is used. A lack of sufficient equipment both in therapy rooms but also in workshops is evident in most institutions. Moreover, available equipment if often left unused.

- **Understaffing**
  Due to lack of funding, staff is often insufficient in number and in its level of training, understaffing in some institutions is severe, with negative consequences on the quality of support, which can even lead to life risk for service users. Especially in the support of children with disabilities, persons with disabilities and chronic conditions, it is not uncommon to have one social carer assigned to 15 people or more.

3.1 Institutions for Children (with or without disability)

According to a research in 2014,[2] there were approximately 2.825 children with or without disabilities that were accommodated in 85 institutions. Of the 2.825 children, 883 children were with disabilities. Children over 18 years old were the majority of the total population (N = 760), while children 0-3 years old were a minority (N = 182).

Childcare services are fragmented. The state's institutions also include accommodation facilities for unaccompanied migrant minors which get financial support by the state, and the accommodation facilities for minors that belong to the Ministry of Justice. Nevertheless, their viability, along with their capacity, greatly relies on EU funding. In addition to the institutions of the public sector there are non-profit and b) Church-run institutions (under the aegis of the Greek Church). It is estimated that 1.000 children are accommodated in public institutions, and almost 2.000 children in private or Church institutions.

While in Europe the traditional institutions of childcare have been replaced with smaller units of family type, or with units with therapeutic direction, in Greece, children removed from their families in most of the cases have no other options than being placed into an institution. At the same time, due to the lack of foster care or adoption programs, and of any effort that seeks any possibility of them returning home, the time of the children's stay at the institutions is very long. The Greek Government has recently started reviewing the legislative framework and foster care and adoption programmes to promote alternatives to institutional care.

3.2 Institutions for Persons with Disabilities

As collected by 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 Social Welfare Centers and in Evrytania Chronic illness Treatment Center.

Additionally, in ten 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.

[2] Mapping of institutions for sheltered child protection and Protection of children with disabilities in Greece, Roots Research Centre, 2014. Available at: ΧΑΡΤΟΓΡΑΦΗΣΗ-ΤΩΝ-ΙΔΡΥΜΑΤΩΝ-ΤΕΛΙΚΟ-FINAL-28.9.15-2.pdf (roots-research-center.gr)

3.3 Institutions for the elderly persons

Elderly persons in Greece can reside in institutions that are either volunteer or Church initiatives, public/non-profit organisations, private/for-profit organisations or run by informal and family networks.

According to the law, every unit of care can have from 10 to 100 beds. According to the Greek Care Homes Association in Greece there are 120 private entities that accommodate 7.000 – 10.000 elderly, while non-profit organisations (NGOs) are estimated to accommodate 10.000 – 15.000. NGOS are monitored by the Municipality to which they belong. While there are many units without permit, it is estimated that an average unit in Greece works with 50 beds. The great majority of the units of care for elderly persons work without any state funding.

While the institutions for chronic illnesses do not seem to refer just to the older persons, yet a great percentage of the people living at them are indeed elderly persons.

The residential care facilities – either by the Church, or public – can be distinguished in 2 categories:

a) nursing homes for elderly that cannotget self-served,
b) asylums that accept elderly with chronic illnesses.

Compared to other European countries, Greece has a smaller percentage of elderly persons living in institutions (0,6%) - yet, it is estimated that this number will grow in the following years, not only because of the expansion of life expectancy, but more importantly, because of socio-cultural changes. Nowadays the informal care sector is crucial for elderly persons and needs to be further supported by the state, besides the small help now received, either by way of tax relief schemes, or through coverage of certain costs by social security.
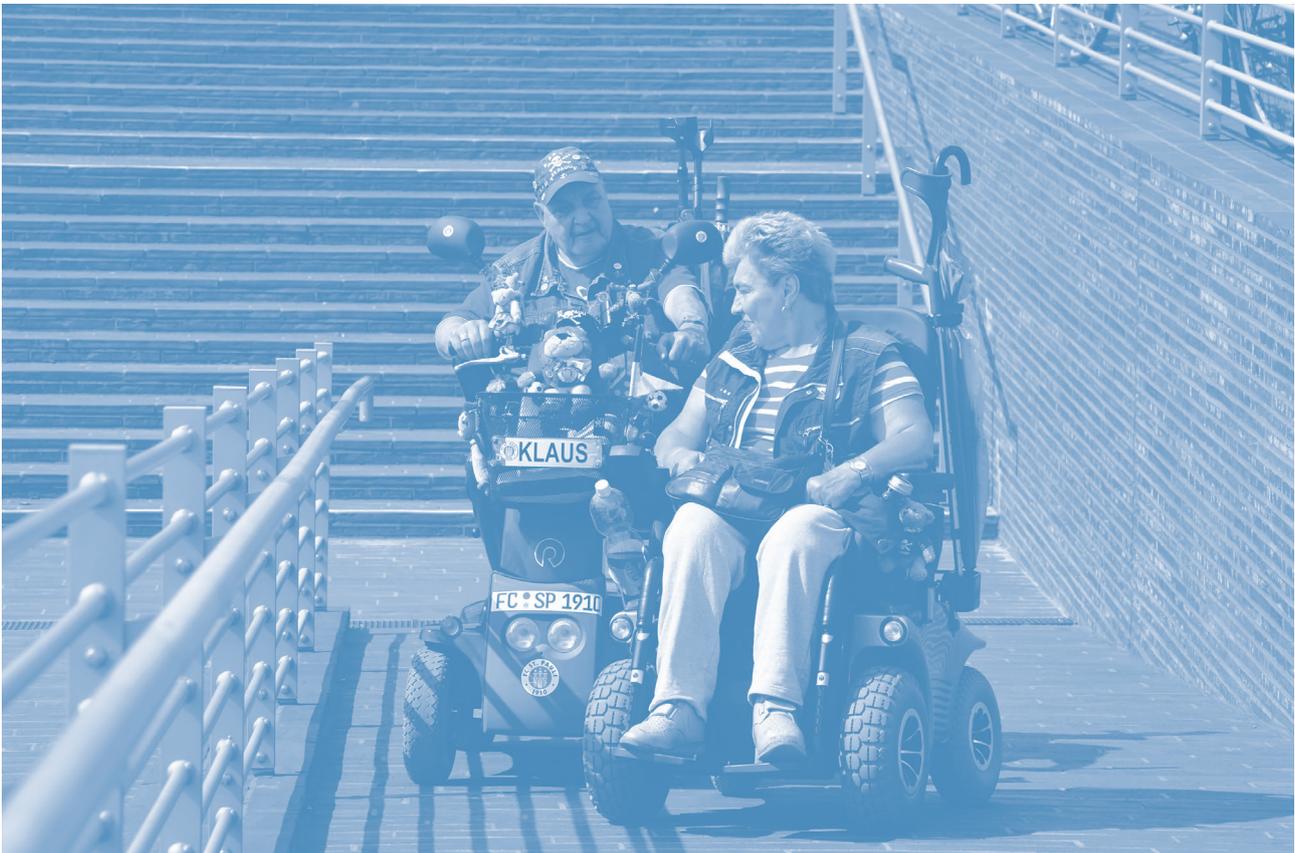
4. Focusing on service users – A Person-centred approach

A cohesive strategy for DI needs to focus on preventing institutionalisation, along with supporting the independent living of persons living in institutions by bringing them back to the community. In terms of prevention, for children this means supporting the family, while for the elderly enabling them to stay at their home. As for the second set of measures that will seek to relocate service users from institutions to community-based settings, in the case of children, there must be an emphasis on the possible return of children to their birth or extended family. Persons with disabilities, including with mental health issues, and older persons should get appropriate support for them to move back into their homes or small residential units in the community, and live independently. This can be implemented through a range of actions including family empowerment, self-directed support, and supported decision-making.

It is crucial to prepare people in the best possible way for a smooth and successful transition process. This includes assisting them in broadening their knowledge of the world, creating opportunities for choice, empowering them to communicate their wishes and helping them gain power over their lives. This will ensure that service users can make decisions and make the most of the transition to the new setting whether it is their family home, a foster or adoptive family, a small group home, supported or independent living arrangements.

Needs assessment is another important step. A multi-disciplinary team composed of staff members who are familiar with the service users and professionals specifically hired for the purposes of the DI process should assess the needs of each service user. Also, a key worker should play a mediating role and ensure that needs and wishes of the supported person are expressed and respected. Once the needs assessment process is completed, a person-centred plan should be formulated. Person-centred planning enables the persons and the ones supporting them to learn what is important to the person, their strengths, fears and dreams and how they wish to live their life now and in the future. It is a respectful process where the voice of the persons is heard and, as such, all information provided must be in a format that is meaningful to them. All staff members should endorse person-centred thinking, no matter their level of involvement in the service user's lives. The active involvement of the service user and his/her family is also important throughout the assessment process as well as the planning, implementation and review of the person-centered plan. The commitment of each participant in the process will constitute a key factor in determining its overall success.

During the assessment meetings, one should ensure that the individual is always the focal point of the planning process. Comments, questions, and statements are to be addressed to the person, whether or not the person communicates verbally. The person's input should be held as primary, and all other participants should act as consultants and advisors rather than decision-makers.

There is a range of person-centred planning methods that can be used independently or combined, based on the age of the person, their abilities and objectives. Commitment to underlying values, preparing properly, and staying true to methodology concerning implementation and revision of plans guarantees the best possible outcomes for those involved. Revision of plans, monitoring and evaluation are fundamental for DI procedures. Plans may need to be reviewed from time-to-time and reflect changes in people and circumstances over time. Service users should be able to request a review of their plan when there is a change in circumstances. Any changes identified should be reflected in an updated care plan. It is particularly important for service users leaving an institutional setting to start living in the community, who may gain confidence, develop new skills and become more independent.

While adequately investigating the needs and desires of the individual, it is also important to thoroughly research all available options of the individual's social inclusion, according to his/her interests and needs. It is essential to always opt for community-based services in the area of origin of the person, or where there is a network of natural social circle.

The next step is to proceed with the transition plan, taking into account the individual's person-centred plan and the community-based services that best match their needs and preferences whilst identifying all necessary actions to be carried out in order for the individual to transition smoothly from the institutional setting to the community.

After the person has moved from the institution to a family or a community-based service a new person-centred plan should be carried out focusing on the context of his/her new home.

There are several principles that underpin an individualised approach.

4.1 Person centred planning

As mentioned above, person centred planning should be an integral part of the DI process. Person centred planning is about support tailored to individual needs, it 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).

Some of the most common approaches on person centred planning (PCP) are: Essential Lifestyle Planning - developed initially for people returning to their home communities from institutions, PATHS (Planning Alternative Tomorrow with Hope), MAPS (Making Action Plans), and Personal Futures Planning. PCP has increasingly been applied in the planning of care and support both for children and the adults, with or without disabilities. One's own person-centred plan can be used in the formal assessment, in the development of an individual care and support plan, for linking individuals and families with public services, and, finally, in the review process. What distinguishes PCP is that it focuses on the person's aspirations. As such, the planning process begins by exploring what is important for the person in the present and goes on to building a vision for the desired future, based on his or her capacities and resources, rather than on deficits and needs. The final step is the development of an action plan, where the vision of the future is translated into clear goals, with specific steps for achievement, and specific responsibilities to be assigned to all people involved in the planning. The family members and the social network of service users are actively involved in the planning process, becoming the person's "circle of support". They participate in the planning, by way of taking specific responsibilities in the implementation of the plan, and usually continue to support the person even after the end of the planning process.

In general, the plan provides information regarding the accommodation and living arrangements of the service user, and the additional help needed for the person and his or her family and carers. It requires the formulation of specific and measurable results and, therefore, the responsibilities of each person involved need to be specific. Overall, it should clearly demonstrate the views of the person and the family involved and the way these are supported by the plan.

For children, the key aspect of all planning should be their best interest and their safety. Therefore, several principles should be followed. The removal from the family must be seen as the last resort, it should be temporary, and short-lived. In case of placement in a care setting, children should be as close as possible to their home, and communication with their families should be encouraged, when it is not against their best interest, while any disruption in education, cultural and social life should be avoided. If the child is separated from its family, reintegration should be the first option, as placement in alternative care should be provided only in cases where the family is unable to provide adequate care, or it is unsafe for the child to return home. For children under 3 years old any care should be provided in family-based settings. Residential care should be limited only to cases where it is considered not only necessary but also constructive. Perhaps more importantly, siblings should not be separated – siblings should be enabled to live together. Finally, changes in care settings can be devastating for children, so one must aim at long-term solutions until they are able to return to the family home.

For adults with support needs, support should be in accordance with their informed decisions; based on how they want to live, that will also define the kind of support they will receive. They have the right to choose their place of residence and with whom they will live with, and their choice should be respected.

The review of the plan is an essential part of the PCP process as it monitors the progress towards the goals that have been set and makes necessary amendments in accordance with new information and circumstances. For example, the review of the plan for children in alternative care should determine whether it is still necessary to be away from the family and which type of living environment would be the best one for his/her development. The frequency of such reviews should be legally defined and be connected to a change in circumstances, while service users should also be able to request a review when they feel that the circumstances have changed.
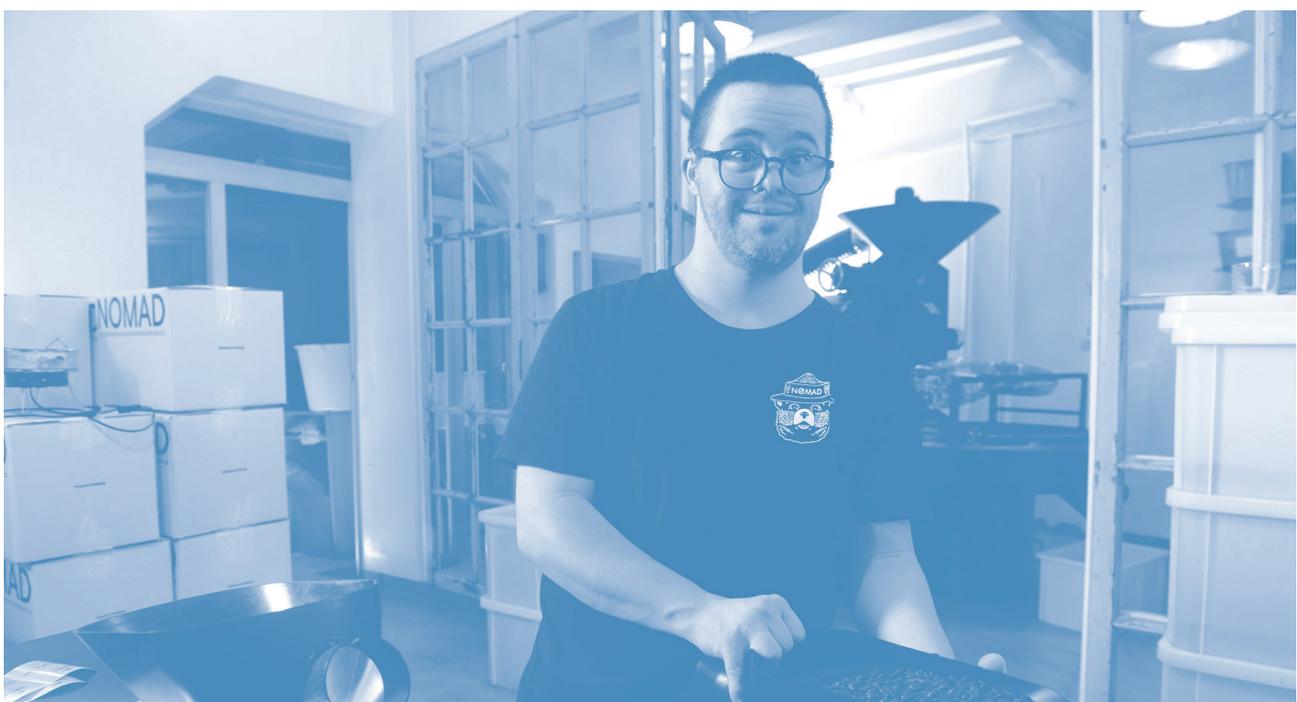
4.2 Supported decision-making

Supported decision-making is a tool for persons with support needs to make choices about their lives. Thus, the social worker needs to explain all necessary information in an accessible way and facilitate understanding of all available options, listen carefully, and adequately communicate the decisions. The persons' views and choices should be respected even when they conflict with the views of the social care worker or family members. Service users should also be active in their individual-needs assessment process.

Since this is a potentially stressful procedure, the person should be made comfortable, if needed inviting a friend or a relative to support. For children, the assessments can take place through play activities. Communication can be achieved even when there is a speech difficulty; through other ways of communicating, such as facial expressions, gestures, symbols, pictures or writing. Therefore, communication can be achieved by choosing the appropriate method for each service user.

4.3 Self-advocacy and self-expression

Self-advocacy is an important part of the transition from institutional care to community-based settings. It seeks to empower service users and enable them to speak up and take control of their lives, and to inform policies and actions. The development of self-advocacy might include supported decision-making. As most service users have never been allowed before to decide for themselves, there is a need for support in decision-making with the help of family members, carers, friends, or other persons with disabilities. Self-advocacy can help develop skills including assertiveness, socialisation, and public speaking.

Developing self-advocacy skills entails four key-steps: knowledge of self, knowledge of rights, communication of knowledge of self and rights, and leadership. Developing self-advocacy skills empowers a person to better organise his or her thoughts and, therefore, his/her self-expression is more efficiently articulated making one's views and wishes clearer and consequently taking control of their lives. Access to all relevant information on law and rights is a very important prerequisite for self-advocacy. Self-advocacy supports service users to accomplish independent living and to exercise their rights.

4.4 Co-production

While there is no single formula for co-production there are some core features: viewing service users as persons with skills, building-up on service users' skills and capacities, removing barriers between users and professionals, inclusion of reciprocity and mutuality, collaboration between peers and professional networks, facilitation of services helping organisations to become agents of change.

There is a big difference between co-production and participation. "To participate" means to be consulted, whereas "to co-produce" means being an equal partner and co-creator, which means that service users are able (with the professionals) to design, create, and deliver the services themselves. Therefore, co-production includes, co-design of the services, co-decision in the allocation of resources, co-delivery and co-evaluation of the services.

There are different levels of co-production which can be descriptive, intermediate, or transformative. When descriptive service users and practitioners work together, but the services delivered are not challenged in any way; here, co-production is not recognised. If intermediate, there is recognition and mutual respect, for example service users are actively involved in the recruitment and training of professionals. In a transformative co-production, there is a new relationship between service users and professionals, as the former is recognised as an expert on its own rights. In transformative co-production, professionals and service users are considered as equal partners moving together towards a shared goal. Persons with support needs have a more meaningful role and are involved in all aspects of the provided service, and the powers and resources are transferred from managers to service users and carers, with the latter also seen as a group that needs to exercise more autonomy and a greater role in planning services.

Co-production needs structural changes in the organisations of support: overcome the lack of infrastructure and of clarity in role descriptions. More specifically, in order for co-production to be successful an organisation needs to set new goals, revise staff roles, develop peer/mutual support networks, create new management structures, revise procedures for commissioning, etc. In a sense, organisations, especially large ones, need to reinvent and transform, as the emphasis on personal relationships present in co-production obliges them to move away from centralised and hierarchical structures.

4.5 Self-directed support

Most systems of support do not offer control to service users, and thus defy their human rights. Self-directed Support seeks to answer to this problem, as it aims to enable people to take control of any support, to claim its ownership, and thus enable their independent living for a better wellbeing. In short, Self-directed Support seeks to help service users to be in control of the support they receive, and therefore, aims at a broader change of the way the support was provided until now.

Self-directed support can help families that risk having or that already have one of their members in an institution in their communication with the authorities, in developing family skills, in their communication with the person in the institution, provide financial support, legal advice and contact other organisations that can help in meeting their needs.

4.6 Preparing service users for the transition

The transition of service users from an institution to a community-based home setting should be carefully planned. It constitutes a major change in the life of service users that can turn into a traumatic experience. Thus, the Person-Centred Plan (PCP) should provide all information about activities, expected results, location of the activity, and a specific timeline. It is also crucial that the PCP is followed with precision and that service users reintegrate gradually into the family and/or community settings. Moreover, the plan should be flexible and under constant review, making any necessary changes as circumstances change, yet always with the full knowledge of all involved parties. The purpose of the transition period is to familiarize with the new settings and develop a trusting relationship with new professionals/carers.

4.6.1 Children

In the first preparatory stages of the transition of children (with or without disabilities), activities should take place in a familiar environment, and if possible, at the presence of a well-trusted person. As soon as the child feels comfortable, there can be visits arranged to their new home. At first these visits should be kept short, with a trusted person from the previous institution present, and then longer, even with overnight stays. The final move to the new setting should also involve the continuance of all necessary support. The preparatory process of the transition should involve all interested parts regarding the new placement, i.e. the parents, being birth, adoptive, or foster parents, other children (in case of a group-home), and the carers, all of which will certainly need all information regarding each particular case.

4.6.2 Adults

The transition of adults, and/or the elderly (with or without disabilities) needs also to be gradual, well prepared, and supported. As the elderly usually move into institutions at a later stage of their lives, changes are much more difficult to manage. Still, the transition process follows the same steps; familiarisation with the new environment and gradual move to the new settings (e.g. gradually moving the residents' personal belongings, increasing visit times etc.). It is also crucial that during the transition process service users have the opportunity for groups of friends to continue staying together, or to stay in contact.

4.7 Independent living and daily living skills

Due to institutionalisation, it is common for persons with support needs (especially people with disabilities) to have lost their daily living skills, or never had the opportunity to develop them. Thus, they need support in developing them, including home management (cooking, cleaning, laundering, ironing, etc.) personal hygiene, money transactions, shopping, the use of transportation and public services, as well as safety and ways to establish social relationships. This should take place both during preparation phase as well as after the transition process has been completed (i.e. within the community-based settings) in order for them to achieve the highest possible level of independence.

5. Training needs of staff – preparing them for the transition

The employees of social care systems are central for any reform and must have adequate support to surpass prejudices and embrace a new model of work. Practitioners must be empowered to become agents of change and this means reversing the current situation with poor working conditions and training.

Providing appropriate support to service users requires well-educated and well-prepared professionals, able to implement the therapeutic programs efficiently, and according to the needs and potential of each service user. It is, therefore, necessary to develop special programs of continuous training, as the knowledge on care constantly develops and changes. Initially, it is important to develop and deliver training and awareness raising programmes aimed at all professionals involved in the DI process. From policymakers and key senior officers in Ministries, Regional Governments and Municipalities to professionals who will be asked to implement this reform and staff members who work directly with people who draw on support. More specifically, all professionals should be familiar with the values and the key elements of the DI reform, such as the UN Convention on the Rights of the Child (CRC), of Persons with Disabilities (CRPD) and of Older Persons. Moreover, all professionals should be made aware of the importance of person-centred approaches, social inclusion, and the active involvement of service users in designing and delivering of services. Finally, it is important to address issues of diversity and equality in order to ensure quality service provision.

In terms of the professionals involved directly in the provision of care, not all staff members have the same level of work experience and knowledge. A needs assessment process should, therefore, be carried out and identify the training needed by each professional in order for them to be well-equipped to support people in community-based services.

Training programmes should ensure that professionals have the required skills and knowledge, such as:

- principles of supported living
- ways to support people through the transition process from institutions to community based settings
- specialised training on working with specific client group (children, persons with disabilities, elderly persons)
- new methods of care and intervention
- person-centred approach
- individual assessment and intervention plans
- communication skills (both verbal and non-verbal) to meet service users' needs
- supported decision-making processes
- importance and implementation of co-production
- involving and helping families stay engaged in decision-making for their vulnerable members
- identifying and addressing professional burnout
- inter-agency work and collaboration with other services

The education of the care workers can be part of university curricula, could be delivered by special educational institutions, or it could be part of on-going professional development training activities. In any case, it is necessary to have an explicit connection between theory and practice, for the professionals to make a significant difference in social care.

For the professionals who do not have immediate access to these training activities due to geographical distance – and, therefore, have fewer opportunities for training, and updates in practice – offering them incentives for their participation should be considered. Another solution for this could be to create Mobile Units of Training who could provide educational activities in various regions across the country. Apart from training, some other important staff needs should be taken into account:

(a) Inform and involve staff members in the DI activities.
(b) Staff members should have a clear understanding of their new role within the community-based settings.
(c) All professionals involved in direct care provision must participate in interdisciplinary teams.

(d) Professionals should be given the opportunity to communicate and create networks with other professionals in community-based services.
(e) Exchange of good practices at a transnational level can introduce staff members into a new landscape of ideas. It can change the approach to disability and the philosophy behind social care.
(f) Professional exhaustion is a common problem that needs to be dealt through adequate programs of psychological support, especially in residential units of care, to ensure the quality of the services. One way to avoid professionals' exhaustion is the role-playing system; a system of rotation of tasks and role exchange where care staff switch between themselves the group of service users of their immediate care. This strategy also seeks to prevent the "institutionalisation" of employees and, again, ensure the quality of the services.
(g) It is important to develop and adopt a standard selection methodology to ensure the suitability of all new staff members who will work with children, people with disabilities and older adults.
(h) Introduce a staff evaluation procedure to regularly assess and identify training needs.

6. Social Inclusion and community-based services

Institutions are defined by the isolation of the service users from the community, their lack of control over their lives, and the fact their individual needs are not met. Transition to community-based settings, therefore, aims at providing a person-centred approach and achieving social inclusion. Community-based settings' principle is that all service users who need support in everyday living should be supported within and by the community itself. In general, Integrated Housing Support (IHS) serves two principles: housing-like settings where service users receive support in communal house settings, and housing-led support, where people receive support at their home.

Although DI has mainly focused on community-based housing, community-based services encompass a spectrum of other services such as healthcare, education, employment, leisure activities, substitute family care, family strengthening programs and specialised services including personal assistants and respite care. It is essential for institutions to map the available services, make the link with the community and not persist in the practice of keeping all services amidst their walls and – limited- capacities.

Persons with support needs must have access to all types of community-based services whilst taking into account their interests and needs and should start accessing community-based services while they are still in institutional care. For example, service users could start supporting their health, education and employment options or generally broadening their knowledge of community life and offering them leisure opportunities outside the institution.

Moreover, some community-based services could also play an important role in supporting service users to develop important independent living skills, such as communication and social skills, daily living skills etc., as well as enhance their self-esteem and active participation in their life-planning.

Finally, community-based services are of high significance as they offer housing-led support to service users enabling them to stay at their home.

6.1 Community-based services

Several community-based services are already in place and could help service users receive support within the community and enable social inclusion. In the next paragraphs you can find some examples for children, persons with disabilities and elderly persons.

6.1.1 Children

A) Housing-led support

When children cannot be raised by their birth parents and are looked after by other family members from the extended family; this is called "kinship care" and is the preferable form of foster care. In case kinship care is not possible then there are options in "foster care"; a family-based placement option that can be long-term when all attempts for the return of the child fall short. As such it would be useful to be able to plan a range of foster care so that it can involve more children in need.

B) Housing (or family)-like settings

When support provided to families is not enough for the latter to keep their child at home, and in order to avoid institutionalisation, there is a need for providing care by means of family-like setting. This can be achieved by way of placing children in small family houses, that is, a small-scale specialist residential care, where they can receive individual care. This is regarded as a good option when foster care is less likely to happen (e.g. due to particular complex needs).

6.1.2 Persons with disabilities

A) Supported housing

Supported housing for people with disabilities in Greece is currently available in the form of supported living houses, SYD. Supported living houses offer 24/7 support whilst taking into consideration service-users' individual needs. They offer services covering all aspects of life such as daily living, medical needs, leisure activities, social life, family involvement etc. In most cases, they offer a long-term solution for service users who have moved out from family home or other residential services. Although there is a growing number of supported houses operating in Greece, more are needed to cover the increasing number of interest/applicants.

B) Day care centers

Day care centers provide services to people with disabilities. More specifically, they help them to develop daily living and social skills through participation in vocational training workshops, recreational and cultural activities, etc. The legislation of the Day Care centers (dated in 1993), tends to be influenced by the medical model of care, but their stable funding from insurance funds and the European Social Fund (ESF) has led to the sustainability of the organisations that run them as well as their strengthening and expansion.

C) Creative Activity Centers for Persons with Disability

The Creative Activity Centers operate for children and adults with disabilities and are licensed by the Local Government. They aim at empowering families and offer them opportunities for participation and leisure time activities (e.g. arts and sports) whilst some also provide speech therapy, occupational therapy, etc. Most Creative Activity Centers are funded by the ESF whilst some of them operate through service-users' financial contribution (families pay for the services). The rapid increase in numbers during the recent years shows their importance. Their increase in number has also shown that a change of their legislation is of high importance, something that is being currently completed.

D) Supported or protected employment

Employment can be particularly beneficial to persons with disabilities. In contrast to other European countries, Greece does not have programs of professional training for persons with disabilities. Most of them are related to traditional works (sewing, ceramics, carpentry, etc.), and more contemporary works are not developed. This makes it hard to integrate them into the labour market. The prevailing form of employment is "protected work". Protected work has many forms, such as group work in various workshops (mainly in day care centers) laboratories, working in normal businesses but under protection, integration to the free market with an escort of support and through the mechanisms of Accompanying Structures of Support. There are also some people with disabilities that enter the open labour market, but in small percentages. It is important to support persons with disabilities so that they can find a jobs that matches with their capacities and wishes, that can provide them with economic independency and that can drive their social inclusion.

E) Other services

The Greek Government and MoLSA have announced two new services that will start operating in the next 2 years which will help to prevent institutionalisation. The institutional framework regarding these new services is almost complete and it is planned to be piloted in 2022. These are:

- early childhood intervention, an action regarding people with disabilities at a preschool level
- the "personal assistant" who will support people with disabilities at a European standards level offering individual support according to their needs enabling them to stay at home (a step towards supported living)

6.1.3 Elderly persons

A) Help-at-Home

This is a program of social protection that aims to provide support to the elderly in need of support, at their home. Priority of the program is the population that lives alone, that cannot be self-served, or their income does not allow them to have the necessary care services. It started in 1996 in the Municipality of Peristeri. After the successful implementation of this pilot program and in collaboration with the Ministry of Health and Care, it expanded to more municipalities. While the program gone through several changes, especially regarding its integration requirements, it is still active, yet in jeopardy due to problems in funding, not yet solved. The programme has supported thousands of elderly and families; indicatively, in 2013 more than 80.000 persons were supported by it.

B) Friendship Clubs

This is an initiative started in 1985 in the Municipality of Athens. The clubs work in neighborhoods and support permanent habitants over sixty years old. Their main goal is to support the elderly with no family and no financial resources to take care of themselves. Their weekly program is comprised of creative activities, occupational therapy, physiotherapy and self-defense, while they also organise trips and cultural visits. Today there are 25 clubs in the Municipality of Athens, serving 50-70 people per day.

C) Centers for the Open Care for the Elderly (KAPI)

These are structures of care for the elderly that work under the aegis of the municipalities they belong to. They began working in 1984 with the initiative and funding by the Ministry of Health and Social Care. Today there are more than 900 KAPI, and their services are available to elderly, over sixty years old (able to walk), regardless of their family and economic status. Their goal is to support the elderly in order to conserve their autonomy and equality as active members of their community, by way of staying with their families in the neighborhood. The basic purpose of KAPI is to defend the elderly's rights through primary and secondary prevention with vaccinations, early screenings, and advice, support in social and psychological problems that the elderly may deal with, and the raising of awareness regarding the needs and problems of the elderly persons.

D) Day care centers for the elderly (KIFI)

There are approximately 55 KIFI which offer short or daily accommodation to the elderly with disabilities, and whose family have social, economic, or health problems, and thus cannot take care of them. Their goal is to support the elderly to keep staying at their home, to maintain the coherence of the family, to avoid institutionalisation, and to support the elderly and their families in their efforts for a decent living.

6.2 Working with the communities

Communities as the final destinations of the DI process also need to be addressed, as service users (mainly people with disabilities) often face prejudice that can lead to discrimination and even violence. Several actions could help prepare the community. Firstly, "community building" needs to be established as the foundation of inclusion, as the latter benefits the community at large. In addition, it is important to plan and implement awareness raising actions, to prevent possible opposition to community-based services, and to ensure the full inclusion of service users.

It is also important to work directly with communities to understand and address their fears, and implement local campaigns that promote independent living and the value of social inclusion. Finally, we should acknowledge the fact that when we refer to communities, we do not just mean strictly the local setting: professional and informal agents and organisations such as schools, universities, institutions, volunteer teams, hospitals, and the Church are part of the community. All of the above should be a target of the awareness-raising activities regarding DI.

7. Financial Framework

The financial aspects of DI are of high importance. In order for DI to take place financial commitments must become policies. All costs including staff, infrastructure, equipment, medications, and services should be considered. However, according to the data collected in different countries community-based services are not more expensive than institutional care. Also, several studies have shown that community-based services result in broader benefits of social inclusion and solidarity for the whole community.

Perhaps the most important part of the planning, along with a good understanding of the structure of service provision, is the current financial arrangements, i.e. how the services are funded. The services can be funded by way of taxation, of payments by "user charges", of private, or social insurance. In order to decide the suitable funding for each of the services, we need to put them in the context of DI, and thus to evaluate them in terms of whether or not a particular form of funding becomes an obstacle for DI. In this manner, different services can be funded, if necessary, in different ways. For example, a social care service financed by service users, could result in an under-utilisation of the services. The ideal would therefore be to find the funding for each service that will help the DI process.

Thus, regulatory mechanisms should be set up so that eligibility criteria and assessment procedures are properly defined. As the WHO report on disability shows,[3] care services that rely only on service user charges are the least equitable; for example, for users with mental health problems it can pose barriers in terms of entitlement and access, and therefore determine inequity in access. Three elements that can ensure fair access are, (1) adequate resources so that services are provided to all that need them, (2) fair assessment processes, and (3) the opportunity to challenge decisions about eligibility.

The funding routes should also be defined in the stage of planning; whether the finances will be raised centrally and allocated directly to service providers (if it is through central allocation, it should pass through commissioners responsible for the particular needs) or by way of consumer-directed care, i.e. give service users the funds and the responsibility to purchase the necessary services. In the latter case, suitable and adequate options should be made available to service users and support them (when needed) to manage their budget. "Self-directed" or "consumer-directed" care seems to be an increasingly popular option in care provision. It offers "independence" and "choice" and its key principle is that the necessary funding needs to be handed to those in need, in order to purchase the suitable care for them. Being cost-effective, consumer-directed care can transcend the barriers between services and sectors, as funding can be used for health and social care sectors, but also culture and education sectors. As it also gives more responsibility to the users and/or their families, it seems to generate the feeling of independent living. Yet, and in order for this type of financing to work, funding should be adequate in order for service users to receive care services of their choice and based on their needs.

For moving on with the DI process, the financial framework should include the funding of both institutional and community-based care until the process is complete. Although these double costs will burden the budget until the last service user leaves institutional care, the process should not be rushed in order to reduce costs, for this would result in inadequate care. On the contrary, there is a need for careful planning and management of institutional closure.

There is also a need for defining the role and framework of volunteers in structures of care and ensuring that the volunteers cannot and should not substitute the professionals.

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[3]World Health Organisation & World Bank, op. cit., p.150.

7.1 Sources of funding for Community-based services

7.1.1 European funding programmes

There are two EU main funding sources that can fund DI actions

- **European Regional Development Fund (ERDF)**. The ERDF was set up in 1975 and provides financial support for the development and structural adjustment of regional economies, economic change, enhanced competitiveness as well as territorial cooperation throughout the EU. Along with the European Social Fund (ESF), the Cohesion Fund, the European Agricultural Fund for Regional Development (EAFRD) and the European Maritime and Fisheries Fund (EMFF), the ERDF is one of the five Structural and Investment Funds (ESIF) of the EU.

- **The European Social Fund (ESF)**. The ESF is Europe's main tool for promoting employment and social inclusion – helping people get a job (or a better job), integrating disadvantaged people into society and ensuring fairer life opportunities for all. It does this by investing in Europe's people and their skills – employed and jobless, young and old.

Through the above-mentioned funding institutions, social care services were able to cover the cost of construction, equipment and operation of social community structures were supported, as well as actions for the prevention of institutionalisation and poverty. Currently, among others, actions such as the operation of Day Centers, Creative Activity Centers are being financially supported, as well as supported living houses for people with disabilities.

7.1.2 Health Insurance Funds

The National Organisation for the Provision of Health Services has also contributed significantly to cover the operating cost of Day Centers, Creative Activity Centers and Supported Living Houses. More specifically, there is a specific amount that these services receive for each service user they provide their services to. This is the case both for service users that have national insurance as well as those without.

Developments in the institutional framework show that Greece, in accordance to the social model, is moving towards models such as those of the personal budget. In fact, in legislation such as the one for the Supported Living Houses (SYD, 2019), they also promote tactics such as the co-financing of services by service users themselves (where possible), or their welfare benefits.

8. Monitoring & Evaluation - Examining the quality of services

8.1 Quality standards

Perhaps the most important issue to be considered in DI is that community-based services improve the quality of services they provide, moving away from institutionalised care. Thus, we will need specific criteria to measure and ensure the quality of the services, such as assessment, planning of treatment, safety, family engagement, cultural competence, effective treatment, competent staff, positive outcomes, and after-care. Here we will outline the need for monitoring, evaluation, and the ways service users can be involved in the evaluation process. Under the UN CRPD, the state should establish a monitoring mechanism as well as a particular and independent body of coordination in order to oversee the implementation of the DI nationally.

8.1.1 Defining quality standards

One of the remnants of institutional care is the importance of technical aspects of the services, i.e. focusing on quantitative data rather than the quality of life of service users. Thus, the standards set for institutions – limited to issues of infrastructure, health and safety, hygiene, food and clothing, employees and their wages, etc. – have been relying completely on a bureaucratic conception of care services and have been excluding any evaluation of the end results. Furthermore, there has been no involvement of service users, no monitoring of the implementation, no regulation of the services or the staff, and no evaluation of the quality of the service. This paradigm-shift towards individual and person-centred support planning needs to develop new standards in order to properly implement DI reforms. Quality principles, linked to the rights and the quality of life of service users, can be the guide to establish an efficient system that regulates the services. Accountability, quality balance, monitoring of the budget and a system of evaluation are all necessary parts of this shift.

In the definition of quality standards, it is now widely accepted that the results should be determined by service users themselves; for an effective system of evaluation, a mere tracking of progress is not enough, but mechanisms of assuring and improving both the quality and the results of the services need to be implemented.

Yet some risks that can jeopardise this paradigm shift and reintroduce several setbacks of institutional care settings, and must therefore be avoided. Standards should not be strictly defined, but rather be flexible to respond to individual needs; and cannot have a "minimum" character, and fund just the minimum needs. By way of other countries' experience, the setting of standards has the tendency to focus on easily quantified data, such as the size of the infrastructure or the amount and quality of the food required. Still, in order for DI to succeed, there is an absolute need for standards that can measure the quality of care and of life provided, and these standards need to have the ability to adjust its powers and resources in order to adapt to each case in particular.

8.1.2 Standards implementation

As these standards need to engage with different levels of administration – central government, regional and local authorities, service providers, etc. - there are several proposals, by UNICEF and the World Bank for a successful DI transition that can provide us with inspiration on the required actions for the implementation of the process, as well as an overview of its complexity.

1. Central government level
It sets the strategic direction of services and establishes systems to develop and monitor quality services within the overall deinstitutionalisation policy.

1.1. Assessing the current situation by reviewing current standards, regulations and monitoring mechanisms and identify good practice.
1.2. Deciding on the type of standards, regulation mechanism and monitoring systems to be implemented.
1.3. Developing an implementation plan covering use of pilots, training and orientation of personnel and develop incentives to implement standards.
1.4. Creating a legislative framework for standards and monitoring.
1.5. Setting up regulatory bodies such as Inspectorates, Accreditation Councils, Professional Councils, Professional Training Councils, Ombudsmen, as required.
1.6. Developing data systems to collect information on the quality of services.
1.7. Developing and updating standards, codes of practice (ethics), practice guidance, performance indicators and regulation through broad consultation gaining commitment and ownership, and involving users and carers.

2. Local and regional level
It provides for, coordinates and plans the provision of services that are responsive to local needs.

2.1. Implementing or improving quality assurance mechanisms for service planning, management and purchasing of services, coordination of local services and directly-provided services.
2.2. Implementing or improving inspection services. If required, set up inspection units and recruit and train inspectors.
2.3. Implementing or improving systems to identify problems or opportunities for improving quality including information systems, complaints systems, problem reporting and identification mechanisms, surveys, statistical monitoring, research and performance measurement using indicators, benchmarking and quality teams.
2.4. Promoting understanding and acceptance of standards and performance improvement mechanisms by personnel, local communities, users and parents.

3. Practice settings

To include a review of the organisation's services.

3.1. Assessing the current situation, identifying areas of exemplary practice and poor practice requiring change.

3.2. Selecting a quality improvement approach. This may focus on monitoring desired or adverse outcomes, or on service delivery and support processes to determine areas for improvement.

3.3. Setting up a team responsible for initial quality assurance activities.

3.4. If the service's mission is unclear, or if it is unresponsive to community needs, strategic planning might be required. To do this: define the organisation's mission; assess the opportunities and constraints in the external environment and the organisation's internal strengths and weaknesses and determine priorities.

3.5. Setting standards, developing guidelines, standard operating procedures and performance standards through a consultative process involving all personnel, carers and users.

3.6. Developing or improving monitoring systems such as information systems; complaints systems and indicators.

3.7. Developing a quality assurance plan covering the objectives and scope, responsibilities, and implementation strategies.

3.8. Reviewing achievements and restarting the process to implement ongoing improvements.

8.1.3 Defining the content of quality standards

In the EU social services, as defined in the European Commission Communication on social services of general interest of April 2006, include services such as social assistance, long-term care, childcare, employment and training services, personal assistants and social housing. The 2007 Communication, also sets the objectives and principles that should guide social services that ought to be comprehensive and personalised, conceived and delivered in an integrated manner.

The European Quality Framework for Social Services

Adopted in 2010 by the Social Protection Committee, the European Quality Framework for Social Services (hereafter called as the "Framework") sought to create a common understanding regarding the quality of social services in the EU. As such, the Framework identifies on the one hand the quality principles, and on the other, proposes suitable methodological guidelines to be used by Member States to develop tools of definition, measurement, and evaluation of the social services' quality. Thus, while establishing the overarching quality principles, the Framework covers all three dimensions of the social services: (1) the relationship between providers and users, (2) the relationship between providers and public authorities, and, (3) the human and physical capital. For each of the above three there are specific operational criteria that can help

Member States to monitor and evaluate social services. A summary follows:

- Overarching quality principles: Available, Accessible, Affordable, Person-centred, Comprehensive, Continuous, Outcome-oriented.
- Relationships between service providers, public authorities, social partners and other stakeholders: Partnership, Good governance.
- Human and physical capital: Good working conditions and working environment, Investment in human capital, Adequate physical infrastructure.
- Relationships between service providers and users: Respect for users' rights, Participation and empowerment.

The European Platform of European Social NGOs sets nine quality principles , each combined with a set of indicators; thus social care aiming at quality services, should (1) respect human dignity and fundamental rights; (2) achieve expected results; (3) be tailored to each individual; (4) ensure the security of all users, including the most vulnerable; (5) be participative and empower users to make decisions on their own; (6) be holistic and continuous; (7) be provided in partnership with communities; (8) be provided by skilled professionals working under good employment and working conditions; and (9) be managed in a transparent way and be accountable.

Schalock's Quality of Life Framework

In order to define and thus evaluate the quality of services, one must see how these services affect the life of service users. Professor R. Schalock[4] defines "quality of life" as a multidimensional phenomenon composed of certain core domains that are influenced both by individual and environmental characteristics (the assessment of the quality of life needs to be based on culturally sensitive indicators).

Domain Indicators	Descriptors
Emotional Well-Being	1. Contentment (satisfaction, moods, enjoyment) 2. Self-concept (identity, self-worth, self-esteem) 3. Lack of stress (predictability and control)
Interpersonal Relations	4. Interactions (social networks, social contacts) 5. Relationships (family, friends, peers) 6. Supports (emotional, physical, financial)
Material Well-Being	7. Financial status (income, benefits) 8. Employment (work status, work environment) 9. Housing (type of residence, ownership)
Personal Development	10. Education (achievements, education status) 11. Personal competence (cognitive, social, practical) 12. Performance (success, achievement, productivity)
Self-Determination	13. Autonomy/personal control (independence) 14. Goals and personal values (desires, expectations) 15. Choices (opportunities, options, preferences)
Physical Well-Being	16. Health (functioning, symptoms, fitness, nutrition) 17. Activities of daily living (self-care, mobility) 18. Health care 19. Leisure (recreation, hobbies)
Rights	20. Human (respect, dignity, equality)
Social Inclusion	21. Legal (citizenship, access, due process) 22. Community integration and participation 23. Community roles (contributor, volunteer) 24. Social supports (support networks, services)

As all eight domains are in accordance with the UN Convention on the Rights of Persons with Disabilities, the Framework can become the tool of measuring the implementation of the Convention, but also for reporting, monitoring, evaluation and improvements; thus it can underline the DI process. In conclusion, measuring the quality of social care services should include the accessibility of the service, accountability, behavior, continuity and skills of the employees, flexibility of the services to adjust on personal needs, privacy, dignity, and reliability. Moreover, measuring the quality of life should include the improvement of service users' health, service users' fulfilment of basic needs with everyday activities, their safety and security, a proper living environment, access to social contacts, maximisation of autonomy, development of service users' skills, and service users' increase in self-esteem and confidence.

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[4]Wang, M., Schalock, R.L., Verdugo, M.A. & Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. American Journal on Intellectual and Developmental Disabilities, 115, 218–233, p.221.

8.1.4 Monitoring and evaluation

Monitoring and evaluation are critical components both of the planning and the implementation of care services, as they seek to ensure transparency, accountability, and control of the process; they should be present at all stages of the DI process, and be the result of cooperation between all parties involved, i.e. service users, their families, professionals, and organisations, in order to ensure the necessary quality. An effective monitoring implicates a range of mechanisms, such as:

- Regulatory mechanisms; licensing, accreditation and certification.
- Inspection; it should result in public reports that highlight good practices, areas for improvement and recommendations.
- Performance measurement and indicators; they are used to assess the performance of services funded by the state and require the existence of measurable indicators that can access the quality of the service.
- Complaints system; it should provide protection to those making the complaints and an independent system for processing complaints.
- Ombudsmen, children's (and other) advocates.

The monitoring process must focus on the personal outcomes and satisfaction of each service user and to the level their issues are addressed.

The evaluation of the services can either be external or internal (self-evaluation). Yet, before starting with the evaluation some terms of reference should be outlined: (1) the objectives and scope of the evaluation, (2) the methodology, (3) the necessary resources, and (4) how the results will be communicated. In general, evaluation should address the structure, the process, and the results of any service; it needs well-trained professionals to implement it; it should include recommendations of improvement; and perhaps more importantly, to have implications in the continuation of the service itself. Moreover, the monitoring and evaluation process should also address the overall implementation of the DI process. This can take the form of monthly evaluation reports based on key indicators which could include certain details regarding the persons affected by the process, the staff members, the development of the new services, and the financial state of the process. Then, every six months, there can be a more detailed report which could include qualitative information about the level of satisfaction regarding the implementation of the new services. A final report should then also address the wider impact of the DI process to all involved.

A key factor in the evaluation process is the active involvement of service users and their families. This should implicate their housing, living and working conditions, that can be addressed within different aspects, such as their satisfaction with specific aspects of their life and the support they get; the value and importance people attach to these aspects; the degree to which their preferences and wishes are met; the degree to which they can aim to personal objectives; the degree to which they feel that improvement is possible. Although the user involvement mechanism should be the same for all, its implementation should be according to each person's state and choice.

9. Overcoming barriers during transition

There are many challenges in the transition from institutional to community-based care, especially during the first part of the transition process. Careful planning is, therefore, necessary to avoid or overcome them. DI involves a complex web of different stakeholders, i.e. public authorities at national, regional, and local level, services ranging from health to disability, education, employment, together with service users and their families, local communities, etc. The transition needs to take into account each and every one of them. Considering the experience of other countries, one should carefully prepare to overcome certain difficulties.

9.1 Financial issues

Apart from securing adequate short and long term funding for the new care services, there is also the issue of dual funding, i.e. adequately supporting both systems of care until the transition is complete. Dual funding is usually the result of the state's stagnation, on the one hand, to reduce the institutions' staff and make the necessary cuts in the facilities' operations as the number of service users decreases, and on the other to relocate this funding completely to the community settings. In other words, dual funding is the result of the state's ambivalence in completing the transition. Moreover, DI requires financial resources for the funding of the infrastructure, the planning, the staff recruitment, and their training. Still, in the long term its implementation is proved to be less expensive than an institution, and able to provide high quality service of care.

9.2 Community

Resistance from the local community against small group homes has also frequently been documented. Under the light of this possibility, the planning should define early on the particular destination communities, so that adequate preparation is ensured, along with the timely resource allocation to the selected communities. Also, after deciding to close an institution, a comprehensive closure plan should be developed together with a strategy for communicating the decision and the process to the public, while background information and factsheets dealing with anticipated questions and concerns about institution closures should be developed and refined to address local issues. Thus, in anticipation of resistance from the community, governments and local/regional authorities must be well prepared, and with clear information about what is planned and why this decision is in everyone's best interest, and especially in favor of the interests and the rights of the citizens who are part of the process.

As DI refers, besides the housing per se, to the actual participation of the community itself, it is important for service users to have access to medical care and services, education, employment, leisure activities, etc. Several of the communities have inadequate medical care, and therefore a lack of professionals with adequate training and experience in these social groups (especially people with disabilities). It is important, therefore, to provide educational activities to professionals in the community.

9.3 Staff

While shifts in societal attitudes can shape and facilitate independent living in the longer term, implementation of DI rests largely with the care workers. Yet, most of the workers have been trained and worked in providing treatment in large institutions that serve uniform standards for large populations; it is not always easy for them to respond to individual and personalised needs of each service user. Changes in their attitudes, both in the designing and the delivering of the services, is therefore inextricably linked to achieving the promise of Article 19 of the UN CRPD. It is most important therefore to properly prepare all staff members who will provide care services in community-based settings, to avoid institutional habits to resurface at the new settings. More specifically, suitable training must be provided aiming to equip all employees with the necessary skills and attitude change towards individualised, user-controlled support in the community.

At the same time, resistance of institutional care personnel to closure is likely to be one of the major barriers in the transition process. However, good communication along with the engagement of personnel at various stages of the transition, could help to minimise this resistance and ensure that personnel performance does not deteriorate during the process of closure. Experience shows that even those facing redundancy are likely to be cooperative, if this process is handled well.

In addition, in several countries there is a severe shortage of qualified professionals to carry out services in the community. The introduction of professions such as personal assistants, occupational therapists, careers coaches, psychologists, foster parents and social workers, definitely require, not just training and certification, but also, legal recognition and budgeting at a national level, as well as a specific regulatory framework.

That being said, it also needs to be noted that new professionals seem to be more acquainted with new practices and work methods, as they have been taught contemporary methods during their studies, shaping their perspectives as against rigid methods, and they have little or no experience in institutional settings.

In conclusion, the persistence of institutional culture, in all of its aspects and agents, seems to constitute the major barrier for the DI process; a culture that regards service users merely as under the power of practitioners, leaving the latter without voice and control; a culture that prevents people to move to the community, and makes institutional practices to persist. Appropriate training and positive attitudes of staff who embrace the concept of independent living, seems to be able to contribute greatly to a successful DI process.

9.4 Government

Although there is a wide consensus on the necessity of a DI transition, there is a need for an explicit commitment by the government to develop community-based alternatives to institutional care; lack of commitment is therefore one of the main barriers for an implementation of DI. Seemingly, this lack of commitment implies a lack of information, both on the current situation and the way out of it; it is in this way that the need for reform remains ambivalent, as governments do not seem to understand its importance. Yet, part of the problem is the lack of information regarding the current situation of service users, as there are problems in obtaining reliable information; available information is usually inconsistent, and not comprehensive, with differences ranging from region to region and year to year.

Still, it is without doubt, that better information and analysis will not only improve our knowledge, and thus government's understanding, but it will also help us develop care services responsive to the actual needs of service users and therefore increase the chances for a successful DI implementation. At the same time, another barrier posed is the lack of effective coordination between the central government's ministries, but also between the different levels of governance. This generates inconsistency and lack of clarity, especially regarding the roles of each level of governance which translates to the local participants as lack of guidance and exclusion from the national decision-making that creates after all, mere frustration. Better top-down information and better collaboration between all levels of governance is therefore of high significance.

9.5 Families

Parents and families might consider public institutions the safest and most secure form of public assistance for their children and/or relatives, and this moves along with the perception, or actual experience, that there is a lack of appropriate community-based alternatives. Thus, given the risk for families to resist DI efforts, it is very important for them to be involved at an early stage in the DI process.

This can help to build their support for the process and overcome their fears, so as to become from a possible barrier to an active agent of change. Therefore, there needs to be sufficient preparation and information about how and when the DI will be implemented; guidance and information about what will happen in particular, is rather important for the families' active participation in the process.

9.6 Service Users

Learned dependence had been noted as a great barrier to DI. Learned dependence is a widely recognised consequence of institutionalisation, as people do not learn – or forget – how to do certain tasks that are provided to them in institutional settings; from basic skills to the ability to reflect on, and make major life decisions. As a result, in many cases, it cultivates a reluctance among service users to leave the institutions they have been living in for many years.

Thus, there is a need for supporting service users through programs that will aim at overcoming this dependence and develop their full capabilities in order to acquire independent living skills.

In conclusion, cooperation is the key for the DI process and it should be achieved between sectors and different levels of governance, with the local settings of the community, with the families of service users, with service users themselves, and with third sector organisations and NGOs.

10. Recommendations

Here a list of recommendations for successful deinstitutionalisation of settings in Greece:

- Implementing the strategic action plan for DI. Greece now has a strategic action plan for DI which has been planned in detail and with clear goals. Its implementation should not be delayed or postponed.
- Implementing the UN CRC, the UN CRPD and the United Nations Principles for Older Persons. These instruments and the good practices from abroad show us the path we need to follow.
- Acceleration but no rush. Past experience in the field of mental health shows that our steps must be steady but not rushed.
- Preparation, support and respect for the people. We must include the end users of the services in the decisions that concern their lives. They must be prepared for and supported throughout the DI process.
- Generalities and over-ambitious plans should be avoided. Experience at a national and international level, shows that over-ambitious plans leading to changing the system overnight are unlikely to be successful. Step by step, focused intervention plans which will concern specific units and areas is a much safer strategy.
- Involvement of the Local Governments. The Primary and Secondary Local Government must be involved in the process and fulfill their responsibilities. At a local level, plans could be developed, funded and promoted through the local community while contributing to the local economy.
- The DI process cannot continue to be considered a separate issue, not linked with other government policies. Policies, interventions, etc. should be included as elements in other strategic development plans and policies. For example, in the strategic plan of the reform of the Public Sector, the DI process should be included and developed as part of this.

- Smaller scale and focused plans of DI. For example, a breakdown of actions focusing on children or the elderly is a positive element which can lead to significant results.
- The implementation of new working or supporting models is essential. For example, as it turns out, supported housing must include other forms of support, not just supported living.
- Termination of funding for the development of institutional structures. Institutional infrastructure still is being funded.
- Funding and implementation of research and data collection on the status of institutions, number of beneficiaries, etc. The picture of institutional care in Greece should stop being vague.
- Invest in education and training. The training of the employees working in institutions and in community-based services is crucial. Modern and up-to-date educational material, based on adult education, professional certification of care and support workers is needed. Universities and other education providers need to incorporate DI relevant topics in their curriculum replacing those that support institutionalisation.
- Establish co-operations and partnerships. It is necessary to develop synergies and joint actions with NGOs, local communities, etc. at local, national, European and international level.
- Update and interconnect the legal framework. In our study we found that although efforts are being made to update the legislation, there are still outdated legal frameworks such as the one concerning Day Care Centers for the Elderly (1993) or the one concerning Charities (1972). The legislative framework must also ensure interconnection with other relevant frameworks. For example, the legal framework for residential care units for people with mental health problems and that of supported living houses for people with disabilities.

- Pay attention to the transition process from old structures (i.e. institutions) to community-based settings. A plan must also be prepared for the use of the building facilities that will be closed down. Any income raised could help fund the new structures.
- All institutions need to close down, this is the main aim of DI and therefore a deadline for leaving the institutional framework behind must be set. This date can be the starting point for all programs, actions, etc. that need to be taken.
- Evaluation process. Development of an evaluation process for each project and each community structure.

11. Conclusions

This roadmap attempted to give an overview of different aspects that policymakers, and directors of social services should take into account when planning the deinstitutionalisation of a setting in the context of its local, legal, and financial framework. Other documents developed in the framework of this process in Greece project should be read if looking for more indications about needs assessment, standard procedures and training[5].

To conclude, a summary of key elements for DI planning and implementation follows:

- Develop a deinstitutionalisation (DI) plan with a concrete timeframe and indicated resources for each residential care facility.
- Hire interdisciplinary teams who have been specifically trained for this process to work alongside existing members of staff.
- Involve and cooperate with all parties mentioned in the DI process (service users, families, staff, local authorities, community etc.).
- Identify staff training needs and develop training programmes.
- Co-operate with community-based services to enhance social inclusion of service users.
- Plan how to redirect existing resources to new services (e.g. financial resources, personnel, equipment etc.).
- Implement a person-centred individual assessment and intervention plan for service users.

- Create a complaints mechanism for service users to safely express their concerns. People in institutional care frequently do not speak out for themselves since their entire lives are dependent on personnel, and they are afraid of the consequences of criticising their job or the services they get.
- Establish quality assurance procedures to reduce risk and caregiver accountability. It takes time and effort to assist people in feeling safe and joyful. One of the drawbacks of the existing planning system is that the focus regards mainly safety while overlooking needs and interests.
- Do actual or virtual study visits to countries that have achieved deinstitutionalisation and networking with managers that have already led the process in their countries.
- Monitor and evaluate the process in order to secure high quality standards of services.

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[5]Needs assessment protocol developed and adapted to Greek context; Factsheets on promising practices on community-based living; Guidelines on standard procedures on Deinstitutionalisation, including recommendations tailored to the Greek context; Guidelines on support procedures in community-based settings, including recommendations tailored to the Greek context; European Association of Service providers for Persons with Disabilities (EASPD), Brussels, 2021. Available at: https://www.easpd.eu/en/content/di-greece   37

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