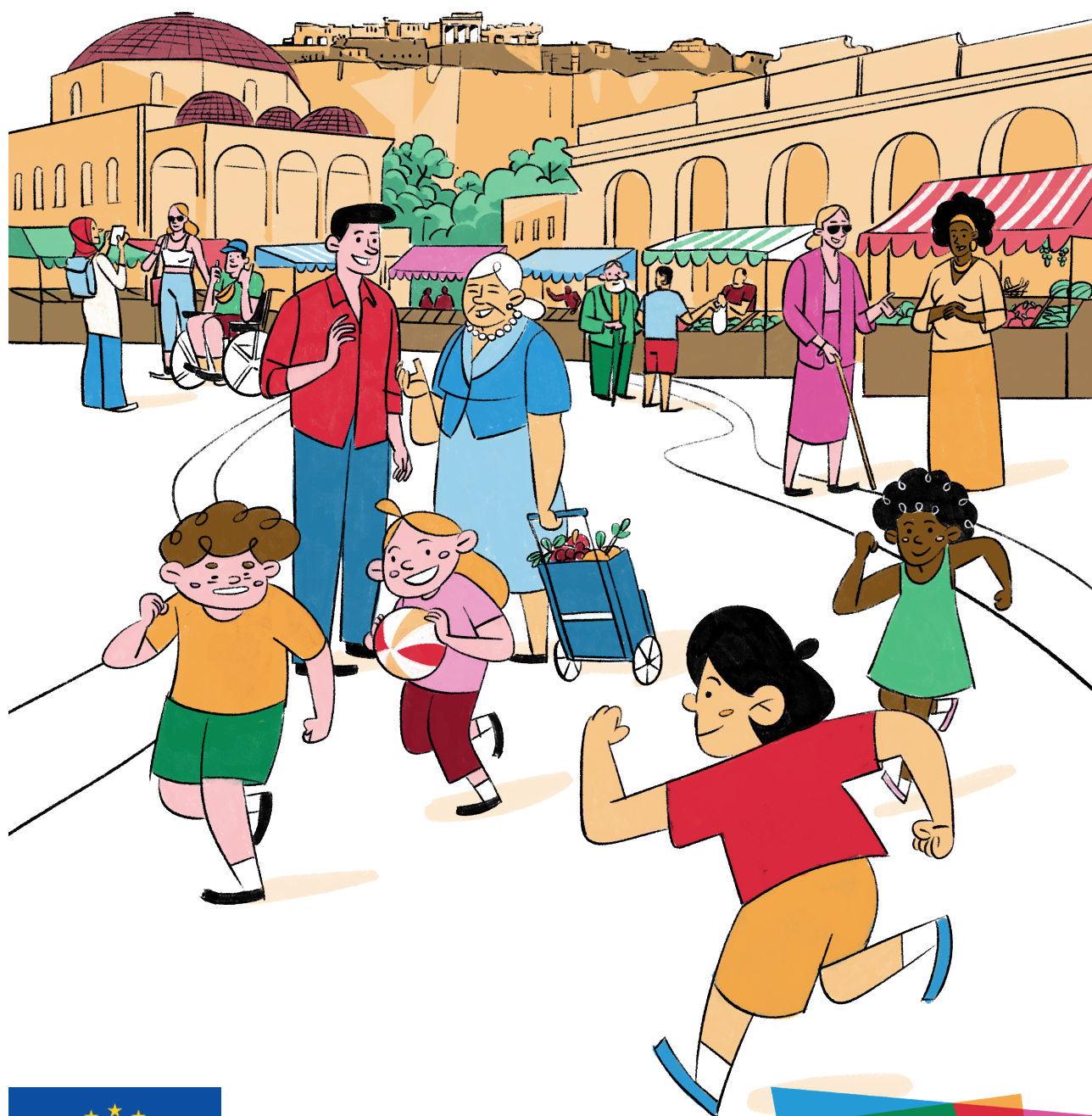


Guidelines on standard procedures on deinstitutionalisation

Technical support on the deinstitutionalisation process in Greece



European Association of Service providers
for Persons with Disabilities



CREDITS & RIGHTS

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

Copyright: Copyright © EASPD 2021. All rights reserved.
No part of this publication may be reproduced, stored
in or introduced into a retrieval system without the prior
permission of the copyright owners.

Technical support on the deinstitutionalisation process
in Greece Grant Agreement: SRSS/S2019/02
Deliverable 10 (as per the Workplan) under Component 2, Output
2.1 Activity 2.1.2 “Development of standard procedures for DI and
community-based care in Greece”

ACKNOWLEDGEMENTS

The European Association of Service providers for Persons
with Disabilities (EASPD) would like to thank Patty Sotiropoulos
for authoring this report and the National Confederation of
Persons with Disabilities (NCPD) for its contribution to it.



This publication was carried out with funding by the European Union
via the Structural Reform Support Programme and in co-operation with the European
Commission’s Directorate-General for Structural Reform Support.
The information contained in this publication does not necessarily reflect
the official position of the European Commission.

Table of Contents

GUIDELINES ON STANDARD DI PROCEDURES ADDRESSED TO PERSONS	5
Introduction: It's kind of difficult to close an institution while there are still people inside! Transition of people residing in institutions	5
Who should read these guidelines?	6
Who will (hopefully) benefit from the guidelines?	6
DOING IT RIGHT: CREATING QUALITY STANDARDS FOR THE TRANSITION	7
Do we really want this to happen?	7
Is everyone on board?	7
Have we got all we need?	7
Are we in this together?	8
Are we keeping people safe and happy?	8
How well did we do?	8
WHAT IS OUT THERE TO SUPPORT THE TRANSITION? MAPPING OF COMMUNITY-BASED AVAILABLE OPTIONS FOR SUPPORTING PEOPLE WHILE IN INSTITUTIONS	9
INDIVIDUALISED TRANSITION TO COMMUNITY PLAN	12
Getting started: What is person centred planning and what is its role in transitioning people to community life?	12
Setting the scene: Prerequisites of making meaningful person-centred plans for the transition from institutional to community settings	10
You cannot create person centred plans if you do not think in a person-centred way!.....	14
Taking a step back: improving communication skills of people and empowering people to speak and supported decision making	14
“How am I supposed to plan anything with her? She doesn't even talk!”	14
“Everything is perfect. Just perfect. The nurses really love us”:	
Empowering vulnerable groups to speak.	16
“Hm...should I get a burger or a salad?”: Supported decision-making	17
Everyone is welcome and needed: Participation of all involved and clarifying roles and responsibilities	18
Tending to practical issues	19
Not a one-off deal: Revision of Individualised plans	19
HOW DO WE GET THIS DONE? METHODOLOGY OF PERSON-CENTERED	20
Essential Lifetime Planning	20
Individual Service Design	21
CIRCLES	22

PATH	23
MAPS	25
Personal Futures Planning	27
Other person-centered approaches	28
RECOMMENDATIONS CONCERNING DI PROCEDURES DURING TRANSITION	
TAILORED TO THE GREEK CONTEXT	29
Legislative reform	29
Policy Makers	30
Managers	31
Staff	31
Advocates	31
CONCLUSIONS	32
FURTHER READINGS	33
Person Centered Planning Readings, Tools and Resources	33
Useful Links.....	35
Further readings on DI and Community Care	35

Guidelines on standard DI procedures addressed to persons with support needs while in institutions

Introduction: It's kind of difficult to close an institution while there are still people inside! Transition of people residing in institutions

Deinstitutionalisation (DI), or, more precisely, the transition from institutional to family and community-based care is not an easy process to plan and implement. However, its benefits have been documented through decades of indisputable scientific evidence of better outcomes for service users and are long overdue from a human's rights viewpoint. Living in a regular home with personal belongings, close to relatives and friends, being able to choose and follow an individual routine and enjoying privacy are the prerequisites for a life in dignity. For these reasons, a paradigm change, away from the predominance of residential care to supported living and person-centered integrated services in the community, is necessary.

The deinstitutionalisation process should entail the following steps:

- Assessing the current situation of services,
- Developing a strategy and action plan and committing to it on all levels,
- Developing a wide range of community-based services,
- Establishing a legal framework,
- Allocating financial, material, and human resources,
- Developing the workforce,
- Making individual plans,
- Supporting individuals and communities during transition,
- Defining, monitoring and evaluating the new services.

To those not familiar with the term, deinstitutionalisation is often believed to be limited to the simple transfer of children or adults from institutions to community settings. This is only a small part of the process. Effectiveness of DI strategies is, however, largely reflected in successful transitions; safe and happy people transitioning are, in the end, the basic indicators of success and reflect all prementioned elements of the deinstitutionalisation process.

The guidelines presented focus on the need to prepare and support children with or without disabilities, adults or older people for the transition based on person-centred plans while they are in institutions. The prerequisites for creating successful person-centred plans, as well as their implementation and revision are discussed. Person centred methodologies are presented through theory and examples. The goal of the transition from institutional to community care should be to improve service users' quality of life (including all emotional, social, and physical aspects of the individual's life¹), and these guidelines aspire to contribute to this goal.

¹ Unless a high quality is assured, community care can also result in a poor quality of life for service users and social exclusion.

Who should read these guidelines?

The guidelines are aimed primarily at people currently working in private, public and church run institutions for children with or without disabilities, for adults with disabilities, and for older people in Greece. The guidelines focus on preparing people for family reunification, foster and adoptive families, community-based settings, supported or independent living. They focus on the need to develop person-centred plans, implement them successfully and monitor their outcomes regularly. Even though the implementation plans will be mainly carried out by the scientific personnel of institutions and carers, the guidelines concern all people involved in the residents' lives as they aspire to emphasise on providing a consensus that people benefit from person centred approaches and that a new culture and practice inside the institutions must be established before the move. Administrative staff and managers play a vital role in the implementation of the process as it will be their role to drive change, coordinate actions, provide administrative support and resources, monitor the process, and manage a possible crisis. Managers also serve as a link between institutions and policy makers. Policy makers can ensure continuity of interventions and make the legislative reforms necessary to facilitate it. The guidelines also target local and regional authorities in the sectors of health, education and welfare responsible for local service provision and management. The guidelines may also be useful for policy makers at a European level to grasp aspects of deinstitutionalisation within a country-specific setting.

Who will (hopefully) benefit from the guidelines?

The Guidelines encompass three user groups that are commonly placed into institutional care in Greece:

- children with and without disabilities;
- people with disabilities;
- older people.

Professionals currently working in institutions are also expected to benefit from the guidelines by valorising their work through new practices and viewpoints closer to the clients' needs.



Doing it right: creating quality standards for the transition

Greece has no binding quality standards for social care services², no regulations for the living conditions of people residing in institutions and no unified data or registration system of service users. Consequently, there is no reporting based on agreed standards, nor meaningful inspections of institutions³, or monitoring and evaluation of the range of services provided.

This chapter does not aspire to propose quality standards for the entirety of services linked to the deinstitutionalisation process. Such a task would be rather pretentious and out of place. It merely hopes to stress the urgent need to ensure quality standards for procedures and services and highlight basic questions that should be addressed when planning and implementing the transition of people from institutional to family or community-based care. Community-based settings and services should be established before making individual plans in order to minimise disruption of people's lives and avoid setting them up for disappointment. Making plans that are not realistic due to lack of resources or community-based services, or that will not be implemented due to lack of commitment and management capacity, or not ensuring they are monitored and evaluated in order to keep people safe will eventually harm the people they were initially set out to support.

Do we really want this to happen?

A strategic vision is one of the most significant factors behind the shift from impersonal medical centered service delivery to supported transition and must be harnessed by the government to animate change⁴. Interdisciplinary and interagency cooperation of the Ministry of Social Welfare, the Ministry of Education, the Ministry of Health, and the Ministry of Interior Affairs along with Municipal and local authorities, must be in place before the transition plans are prepared or executed.

Is everyone on board?

Shared values between all stakeholders, such as a human rights approach and inclusion for ALL should underpin every step of the process.

Have we got all we need?

Adequate material and human resources along with methodologies should be ensured before the transition process begins. Staff should be trained and periodically evaluated. Resources to attain goals in all areas – medical issues, rehabilitation, general wellbeing of residents-useful tools as well as simplified processes for access to needed materials and resources -especially applicable to Public body entities⁵- are prerequisites to initiating the process.

² The European Voluntary Quality Framework sets out four categories of quality principles: general principles for service provision (e.g. availability, affordability, comprehensiveness, person-centred approach), principles for the relationships between service providers and users (e.g. participation, empowerment and respect for users), principles for the relationships between service providers, public authorities, social partners and other stakeholders (e.g. partnership and good governance), principles for human and physical capital (good working conditions, adequate infrastructure)

³ Scarce inspections are carried out by the regional Social Services but the criteria for such inspections have to do with basic safety issues and infrastructure. There have been attempts to legislate standards for institutional settings in the past but to no avail.

⁴ Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J. (2007), Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent

⁵ A ten-year-old in an institution had his birthday and his family- although with strong bonds to the child- could not attend due to financial issues. When asked if the institution can buy the bus tickets (at the cost of 3 euros for each person!) the response was that this category of expenses is not included in the institution's budget provision).

Are we in this together?

At the outset, it is vitally important that support workers really tune into the persons' wishes and goals. This is crucial for finding out their wishes in the beginning but also in managing appropriate supports and finding appropriate workers and volunteers as the process evolves. The relationship between staff members and service users should be based on equality, mutual trust, and respect.

Are we keeping people safe and happy?

The plan should encompass everything the person must have in order to be healthy and safe during the transition process. Safeguarding policies should be shared with those who will be providing support for the person long before the person leaves. It is advisable to develop a transition plan for each person, spelling out how the person will move, who will be responsible at the time of transition for continuity of support, and how problems will be solved.

How well did we do?

No matter how well thought out a plan is, it is impossible to follow its implementation and evaluate its results without specific monitoring and evaluation procedures in place.



What is out there to support the transition?

Mapping of community-based available options for supporting people while in institutions

Community-based services encompass a spectrum of services: mainstream services such as housing, healthcare, education, employment, leisure activities, substitute family care, family strengthening programs and specialised services including personal assistants and respite care. In the scope of the present text the focus will be placed on those services that can contribute to the transition of people from the institution to the community **while they are still in the institutions** either by specifically supporting their health, education and employment options or generally broadening their knowledge of community life and offering them leisure opportunities outside the institution.

In Greece, free access to the **Public Health System** for all citizens (even those who do not have insurance) is established. Beneficiaries are entitled to hospitalisation, medical care in public hospitals and prescribed medication. Unfortunately, due to a recent change of law⁶, migrant children whose legal guardians are not insured (asylum seekers) are denied the right to receive an AMKA (personal registration number) even when they are cared for by a public institution. Apart from making healthcare difficult, this makes the claim of possible disability benefits impossible which in turn makes the chances of finding a foster family for disabled children slimmer. When people in institutions must be hospitalised, there is diffi-

culty to ensure the presence of nurses to be at their side due to lack of existing staff and lack of flexibility to hire and pay private nurses. Consequently, when possible, people coming from institutions remain in hospitals alone or they are sent back to the institution before they have fully recovered. Doctors' appointments for checking hearing and vision or rehabilitation issues can be easily arranged and are free of charge.

The Ministry of Health, through the National Organisation of Health Services (EOPYY), reimburses a percentage of the expenses for wheelchairs and other rehabilitation equipment (that ranges depending on the beneficiary's insurance or lack of it), although expensive tools such as electric wheelchairs or prosthetics are not fully reimbursed. Unfortunately, it is not uncommon to find disabled or older people in institutions that do not own an appropriate wheelchair or even one at all. Disability Assessment Centers⁷ (KEPA) are responsible for ensuring uniform health assessment in terms of determining the degree of disability. When preparing children or adults with disabilities for transition it is very helpful to get the official diagnosis from KEPA in a timely manner, as this opens the way to many disability benefits that will be useful when living in the community either in supported living arrangements or independently.

⁶ Law 4636/2019 - ΦΕΚ 169/Α/1-11-2019

⁷ <https://ec.europa.eu/social/main.jsp?catId=1112&intPageId=4565&langId=en&>

Early intervention programs are mostly private and get reimbursed by EOPPY through the parents' insurances but, when it comes to children living in institutions, most programs are undertaken by the permanent staff. Consequently, not all service users benefit from such interventions and the ones who do have little to no control or choice regarding their therapy sessions and do not profit from the contacts they could make through similar services in the community.

As far as **education** is concerned, public schools in Greece are free and attending them is mandatory from kindergarten to lower secondary school. Preschool settings⁸ do not cover the demand and children in institutions usually do not attend preschool, except when the staff organises such settings inside the institution. **Children with disabilities** often fall through the cracks of the system and do not attend school at all⁹. When they do, they often stop after primary school. Disabled children in institutions are not given the chance to attend mainstream schools because the support to make this possible is missing. The Greek education system has a system of assistant teachers appointed to children with disabilities and school nurses or carers, but in order to be entitled to such accommodations, the child must be diagnosed by KESY¹⁰. The staff of KESY is not trained to evaluate children from institutions and tend to easily send them to special schools without taking into account the deprivation of stimulation these children have had or the benefits of including them in mainstream schools. Even when such services are approved, only an estimated 30%-50% of the needs are covered by the Minister of Education. This, along with knowing that the support of a disabled child in a mainstream

school is more demanding than in a segregated special school, discourages social workers in institutions from going through the process. Thus, the convenient solution of special schools is chosen predominately even if this is not in the best interest of the child. In the case of special schools, the Ministry of Education provides the free transfer of children with buses and taxis to and from school (although not always from the beginning of the year). In exceptional cases, when the children are enrolled in mainstream schools, the absence of drivers, vehicles, or personnel to accompany them also poses barriers to them attending school regularly. Many schools are located inside institutional settings with detrimental consequences to the children's social skills and education. When disabled children in institutions get as far as Secondary school, they have the following choices: Special Needs Gymnasium in the Lower Secondary cycle, and Special Needs Lyceum or Special Vocational Education and Training Schools in the Upper Secondary Cycle (EEEEK).

Children and youngsters without disabilities usually attend schools in the neighborhood but often struggle with prejudices and do not make the most of them. No matter the setting, schools and the connections a child can make through them to break the isolation of institutions is invaluable and should be used to the maximum extent. Youngsters typically move out of institutions between 18 and 25 years old. Having the right education and making correct choices concerning studies or vocational training to maximise job opportunities and help them enter the job market is a crucial part of a successful transition to independent living and a matter that should not be taken lightly during their time in the institution.

⁸ (i) Municipal Infant Care as from 2 months old up to 2,5 years, (ii) Municipal Infant /Child Care as from 2 months old up to 4 years and (iii) Childcare Centers as from 2.5 years up to the age of 4

⁹ According to a research conducted by Action Aid, during the 2010-2011 school year, only 24,105 children with disabilities attended ordinary Greek schools, while 7,656 children attended special schools. This means that out of the 200,000 children with disabilities who are estimated to live in Greece, only 31,761 were able to attend school, the equivalent of 15%. Although official data is not available, and one should be critical towards the specifics of the research, a tendency to exclude disabled children from the school system is clearly demonstrated.

<https://www.actionaid.gr/media/452700/ekthesi-ereunas-actionaid-teliko.pdf>

¹⁰ Centers for Educational and Counselling Support (KEZY-public services) offer educational and psychosocial needs assessment, planning and implementing educational and psychosocial interventions as well as vocational goals, support for the overall work of schools, carrying out trainings and awareness raising actions in the community.

https://www.minedu.gov.gr/publications/docs2018/EPAL_N_4547_FEK_102A_12-06-2018.pdf

Day Care Centers provide care and psychosocial support services for children with disabilities, enhancing their rehabilitation and independence. **Creative activity centers** (KDAP, KDAP-meA¹¹) and **camps** provided for children with¹² or without disabilities can be an important ally to people that are about to move out of institutions for their personal development but also as a support service to foster or adoptive families. In order to maximise leisure opportunities, residents of institutions could also benefit from **Social tourism programs**¹³. **Municipality athletic or leisure activities** are also very useful, but many activities are not accessible to disabled children and adults and lack of personnel prevents even those accepted from participating in them.

Foster care and adoption mainly concerns life outside the institution; however, it is important to note that attracting prospective foster carers or adoptive parents is an ongoing process. Especially in the case of disabled children interest to offer them a home usually comes as a natural step in a pre-established relationship¹⁴. This is another reason why giving disabled children the opportunity to safely encounter people outside the institution is vital.

Employment rates for disabled people in Greece are extremely low¹⁵. Vocational training schools for disabled youngsters and adults have become a never-ending training program (many are placed time and time again in different training programs) that do not lead to real job opportunities in most cases. Taking advantage of specialised employment programs and

making the link with local stores and services could result in job placements and be a valuable learning experience while reinforcing people's autonomy and sense of worth. Once again, lack of staff and stereotypes regarding peoples' impairment prevent this from happening.

Benefits for **older people** (such as housing allowance, social solidarity allowance, disability benefits, old-age pension) or services (such as domestic assistance to older people living alone) or programs (such as home modification program for physical adjustments to their place of residence) could be a game-changer for older people to live independently or with some degree of support in the community and should be examined thoroughly in order to ensure sustainable transitions for each person. Services older people can use while in institutions in order to create connections with their community and improve their quality of life are Municipal Open Protection Centers for the Elderly (K.A.Π.H), Day Care Centers for the Elderly (K.H.Φ.H.) and Summer camps or Bath and Clay Therapy vacations for the Elderly. Participation in such programs and services should be encouraged.

In conclusion, although community-based services in Greece are limited and scarce, actively reaching out to them could be proven beneficial for all parties involved. When preparing one's transition, it is essential for institutions to map the available services, make the link with the community and not persist the practice of keeping all services amidst their walls and limited-capacities.

¹¹ A good practice initiated in 2018 in Greece was applying an ex-ante condition to have a percentage of 10% of beneficiaries originating from institutions in order to be eligible for funding through European Social Funds.

¹² National Confederation of Association of Parents and Guardians of Disabled People <http://www.posgamea.gr/> <https://www.actionaid.gr/media/452700/ekthesi-ereunas-actionaid-teliko.pdf>

¹³ Coupons by the Hellenic Tourism Organization: seven-day subsidized holidays provided for people with at least 67% disability

¹⁴ 100% of the children currently in foster homes from an institution in Athens derived from connections with volunteers.

¹⁵ According to the report of the National Confederation of Disabled People (NCDP) in 2018, only 24% of disabled people between the ages 20-64 were employed (<https://www.esamea.gr/publications/others/3732-2o-deltio-paratiritiroy-thematon-anapirias-tis-e-s-a>)

Individualised transition to community plan

Getting started: What is person centred planning and what is its role in transitioning people to community life?

When making the bridge between living in an institution and living in a family or the community, it is of vital importance to prepare people in the best possible way. Positive changes in their lives, as indicated by thorough needs assessments, should not be postponed until they move into community settings but should be encouraged – to the extent possible- while the people are still in the institution. This will ensure that children with or without disabilities, adults with disabilities and older people are at their best to make decisions and profit the maximum from the move allowing them to further flourish when in more suitable settings like their biological family, a foster or adoptive family, a small group home, supported or independent living arrangements.

Practically this means that before setting out to create individualised person-centred plans, each individual should be empowered to communicate his/her wishes and all necessary medical and rehabilitation actions should be taken before hand. We cannot expect a disabled youngster to make an informed decision about his future when he does not own a wheelchair and his sense of autonomy is undermined by this fact, or when his understanding of community life is restricted by his limited experiences.

Due to years of abandonment, malpractice and understaffing of institutions, the best way to achieve this in the Greek context would be hiring a multidisciplinary group of highly trained professionals to work alongside the people already working in institutional settings. This group of professionals can help shift the current paradigm of care and promote a person-centred culture by setting the example. This group, depending on the settings and the needs of residents, may consist of social workers, psychologists and therapists on a steady basis, and other professionals periodically.

Low self-esteem and lack of experience or meaningful relationships may be the biggest challenges for people living in institutions. Assisting them in broadening their knowledge of the world, creating opportunities for choice and helping them gain power over their lives and relationships is very important and these issues should be tended to before the actual planning sessions take place. We cannot expect someone who has little to no experience of community life or has never even decided upon what they want to eat to suddenly express an opinion about how, where and with whom they want to live. A group of professionals, possibly assisted by volunteers¹⁶, should undertake this task and then proceed to plan, implement and review person-centred plans. Peers and self-advocates can also take on an essential role at this stage.

¹⁶ Volunteers can play an essential role in the process provided they are subject to a clear framework and safeguarding policies are in place. Greece has no relevant law concerning volunteers in institutional settings. The Ombudsman for Children in Greece has made recommendations on the subject (in Greek) <https://www.synigoros.gr/resources/ethelontismos.pdf>

A person-centred planning process 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. Person-centred planning requires the support available to be responsive to the persons and is very results-oriented. The effectiveness of person-centered planning is tested by real changes for the better in the person's day to day life as a result.

In the following chapters, we will not only discuss the prerequisites of a successful person-centred planning process, but also present the most common person-centred planning methodologies step by step: planning, implementing, revising, and keeping them up to date.

We will also discuss possible challenges and how to overcome them. Especially in an environment that has been putting the systems' needs above those of its users for decades, there will be celebrations and setbacks and recognising this fact can reduce possible frustration and reinforce the will to succeed¹⁷.

In a nutshell, person-centred planning consists of a person ready to talk, people eager to listen to him or her, a clear vision of steps to be followed towards achieving the common goal, and the capacity to do so. Currently, in the Greek residential care system none of the above can be taken for granted and they even may seem unrealistic.

However, sharing a common vision of transforming residential care to community-based care amongst stakeholders along with the guidelines and the commitment to follow them makes it a dream within reach.

Key differences between traditional and person-centered planning approaches

Key Question	Traditional Planning	Person-Centered Planning
Who is the person of concern?	The client	The citizen
What is the typical setting?	A group home, adult training centre, special school.	A person's home, workplace or local school.
What is the model?	Development/Behavioural	Ordinary living
What are the services?	Programs/interventions.	Individualized supports.
How are services planned?	Individual program plan based upon professional assessments.	Through a person centred plan.
What is given the highest priority?	Independence/skill Development/behaviour Management	Self determination, relationships and valued social roles.
What is the objective?	To develop independence and change undesirable behaviours	To support the person to have the lifestyle that they chose in their local community.

Adapted from Bradley 1994

(Source: PERSON-CENTERED PLANNING APPROACHES: A LITERATURE REVIEW, prepared for Persons with Developmental Disabilities Central Alberta Community Board, Christine Becker, Robert Pallin, May, 2001)

¹⁷ <http://nda.ie/Good-practice/Guidelines/Guidelines-on-Person-Centered-Planning/Guidelines-on-Person-Centred-Planning-format-versions/5-How-to-get-started-on-Person-Centred-Planning/>

Setting the scene: Prerequisites of making meaningful person-centred plans for the transition from institutional to community settings.

You cannot create person centred plans if you do not think in a person-centred way!

If people who use services are to have positive control over their lives, if they are to have self-directed lives within their own communities then those who are around them, especially those who do the day-to-day work, need to have person-centered thinking skills. In person-centred environments, we must have a deep commitment to understand the individuals being served, respect them, recognise their inherent dignity and be open to be guided by the person without limiting preconceptions. We must be ready to struggle for achieving goals that may initially seem out of reach and flexible enough to be creative when searching for solutions to problems. Integrity and loyalty to our values and the person for which we are developing the plan (the focus person) must lead our thoughts and actions. Person centred thinking goes way beyond a list of tools or techniques. It is a way of being and regarding our position in the world and our relationship with others.

Person centred thinking cannot be acquired overnight. Resistance is to be expected. The fear of the unknown may lead people to doubt new ways of working. According to J. O'Brien and C.L. O'Brien, "Those who want to, can find many ways to avoid engaging the tension between current standardised reality and a desirable individualised personal future. They can compare the best (or even worst) present to worse past conditions instead of comparing it

to desirable future capacities. They can dismiss the image of a desirable future as unrealistic. They can say that they would like to help but that powerful political, socio-economic, or other outside forces forbid them. They can stay busy with activities that allow no time to listen and learn from focus people"¹⁸. The goal is to convince even the most sceptical people of the necessity and efficiency of person-centred approaches and help them adopt them. Unfortunately, people who persist in outdated practices and stereotypes have no place in person centred planning.

Taking a step back: improving communication skills of people and empowering people to speak and supported decision making.

"How am I supposed to plan anything with her? She doesn't even talk!"

Person-centred planning is based on communication. A great part of succeeding is giving the person the tools to communicate effectively, especially if he/she has no verbal communication or limited understanding and/or social skills. Adequately preparing and facilitating staff to support people to think about their life, how they feel about it, how they might like to have it progress and to communicate it effectively is essential for the process.

Children with or without disabilities, adults with disabilities and older people residing in institutions are exceptionally vulnerable and will most definitely need assistance with expressing their thoughts and comprehending their wishes.

¹⁸ O'Brien, J and O'Brien, CL, eds., (2000) A little book about person centered planning, Canada: Inclusion Press, 2000

People with learning disabilities often have unidentified health needs that affect communication, such as hearing or vision impairments, epilepsy, pain, and physical difficulties that make communication effortful. They may also take medication which affects their attention span. These issues should be revisited and taken into consideration as not only do they make communication difficult, but they often lead to challenging behaviours. They may also pretend to understand or respond affirmatively to questions they have partially understood or not at all because they tend to be compliant. Often, when given a choice, they automatically answer with the last option presented to them. Simply rephrasing the questions in a different order will help us rule out this possibility.

Some people take longer to process what you are saying or may not be able to concentrate for long. Others may find physical movement or speech difficult so that it will take longer to respond. It is crucial to make sure to have the person's undivided attention before engaging in conversation and speak in a clear and simple way while using visual aids such as pictures or videos or alternative communication methods such as signs or communication boards when this is helpful. For example, "Memory Boxes" (collections of meaningful artefacts and photos associated with events) or Life Story books can be used as the basis for conversation. A speech and language therapist is very helpful at this stage. Support staff must be observant and attentive to body language, check if they have understood correctly, avoid guessing and don't be afraid to ask the person to repeat if they have not understood his/her response. Not being able to get his/her point through easily may be tiring or frustrating, but genuine interest to understand them will be appreciated in the end. Children or older people might need similar accommodations according to their age and mental state.

The staff shouldn't only aim for what they perceive as tremendous changes in communication skills but have an open eye for small wonders that affect a person's life and the control they have over it. Sustaining eye contact or longing for touch of a person that was shying from human contact is nothing less than a miracle and staff should appreciate such changes and get motivated by them.

An autistic 20 year old boy spent all day in his room in an institution for disabled people doing nothing. He refused to go out except for scarce baths. He was fed and dressed by the nurses and spent all day in bed. When someone entered the room, he ran to the furthest corner and when approached he became anxious and sometimes aggressive. After gradually approaching him day by day he started trusting the staff member and interacting with him. He started choosing what to wear and dressing himself. Over a period of six months, he felt more and more comfortable with the presence of people, exited his room, and started eating his lunch in the common area unassisted. At the dining table he was introduced to activities like puzzles and listening to music which he seemed to enjoy as well as a communication board. He gradually started making choices of what to eat, which activity to do and which song to listen to. During this time, he was also introduced to different people. He even started using some words after years of silence and developed clear signs for saying yes and no. After two months he stepped outside the door into the garden. After getting acquainted with a car and driving around in the institution's driveway for another month he felt ready to visit a local cafeteria where he chose to have a chocolate ice cream. The difficulty was, then, convincing him to return to the institution! This process was long and slow, but the end result compared to the prior state of this young man was well worth the time and effort.

Genuine interest for what the person has to say, attentive observation and listening skills will set the base for successful communication.

“Everything is perfect. Just perfect. The nurses really love us”: Empowering vulnerable groups to speak.

Often children with or without disabilities, adults with disabilities and older people living in institutions have lost all control of their life for so long that standing up for themselves or simply expressing their preferences, likes and dislikes is not an obvious task. In many cases, it isn't even an option. So many aspects of their everyday life rely entirely on the workers and contradicting them or questioning the care and support they offer can be intimidating. In order to empower people to speak, a safe environment must be created, where they are constantly supported and given the opportunity to speak up through nurturing a culture of understanding and openness as well as putting standard procedures in place.

Kendrick made the distinction between trivial and substantive decision making for service users and proposed the following practical scaling of the levels of authoritative personal decision-making into a spectrum from low to high¹⁹:

Level One: The person does not make any substantive decisions about their service.

Level Two: The person does not make any substantive decisions about their service, but the person is routinely informed about the decisions others make on their behalf.

Level Three: The person is routinely consulted, by the actual decision-makers, about his/her personal service decisions.

Level Four: The person routinely begins to personally make a significant minority (25%-45%) of the substantive decisions that constitute their personal service.

Level Five: The person routinely begins to personally make a significant majority (55%-90%) of the substantive decisions.

Level Six: The person is so routinely making the vast majority of key decisions that there is simply no meaningful empowerment issue.

In the Greek context, it is rare to see a service user exceed level one of empowerment even when decision making has to do with trivial aspects of everyday life. Teenagers, high functioning disabled people or older people without dementia may be lucky enough to experience level two or even level three of the scale. Apparently, there is much work to be done concerning empowerment.



¹⁹ Kendrick, M. Levels of Empowerment, Planet Advocacy, Issue Number 7, March 2004, pp 6-7

“Hm...should I get a burger or a salad?": Supported decision-making

Children have the right to participate in decision-making according to their age and maturity, even though legally they will not be the ones making the final decision²⁰. The UN Guidelines for the Alternative Care of Children stipulate children's right to express their opinion on decisions about their life as long as they are respected and supported in doing so. Children should be adequately informed and encouraged to express themselves in ways that are meaningful to them – pictures, poems, drama, photographs, as well as conventional discussions, interviews, and group work. A child is never too young to have a say in matters that regard him/her. Babies as young as three months old have been documented to rejecting prospective adoptive parents by seeming fussy or at unease, while the same babies did not object to connecting with other couples.

Older children and care-leavers can gradually have a more significant say in matters that concern them. They should also be supported and participate actively in decisions about their transition. The process should begin well before the actual transition.

Older people and adults with disabilities are often regarded as incapable of making decisions in their best interest because of their age or the nature of their impairment. However, supported decision making is based on the principle that all people are capable of making decisions regarding their life. The people supporting the decision-making process can either be the legal guardians of the person or anyone who cares about them and has their best interest at heart like teachers, staff members, extended family members, friends or volunteers. They should know the person well and ideally be available for a long period of time. All of us turn to people we trust to make decisions. Supported decision making is basically a more formal way of recognising this need, making sure everyone has a chance to fulfil this right in a way that is suitable for them and regulating the process through specific agreements and the use of existing tools.

²⁰ United Nations Convention on the Rights of the Child, (CRC) (Article 12) states; “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child“.

A. is a 25-year-old tetraplegic young man who has been living in the same institution since he was abandoned by his family at the age of two. After attending primary school inside the institution no action was taken for him to continue his education. When volunteers pressured the institution to enroll him in Secondary School their answer was that they see no point in him going to school. The exact words of staff members were “Why should he go to school? To change the ceiling he stares at all day?”. A. is nonverbal, however he clearly has a very good understanding level and a deep desire to communicate even though, as with wanting to continue school, his voice is rarely heard. Recently, it was decided he would not be vaccinated for COVID-19 without asking him or providing explanation for this decision. In February 2020, an NGO working in the institution provided him with an eye tracking device and he started lessons with volunteers to use GRID in order to communicate. Through this he has openly and repeatedly expressed his will to get vaccinated and shared his feeling of fear and loneliness during the pandemic. The volunteers are currently trying to get this wish heard by staff members, who still doubt his capacity to make decisions.

A useful tool to establish the degree and areas a person needs help with can be found at the following links:

www.supporteddecisionmaking.org/sites/default/files/when_do_i_want_support.pdf

Quality Trust for Individuals with Disabilities (www.DCQualityTrust.Org) and The National Resource Center for Supported Decision-Making (<http://www.supporteddecisionmaking.org>).

**Everyone is welcome and needed:
Participation of all involved and clarifying
roles and responsibilities.**

A clear mandate from the management is important for creating the plans and even more so for implementing them. All staff workers should endorse person-centred thinking, no matter their level of involvement in the service user's lives. From administrative employees to cleaning personnel or therapists and carers, an environment of 'personcentredness' should be cultivated.

The task of identifying key people in the life of people living in institutions - besides the institution's employees- may be challenging, especially when those concerned are particularly isolated or not able to identify them themselves. A good idea would be to start with the caregivers who have an overview of the person's daily life and ask what activities the person participates in or consult with the social worker who handles the person's case in order to find out if he /she is in contact with any family members or if he/she receives visits from other people. The children's parents should also be encour-

aged to participate when possible. Professionals shouldn't assume they have no interest in reconnecting with their children²¹.

Clarifying roles and responsibilities (especially about leading the person-centred planning process both at a general and individual level) and identifying any training and support required is a crucial stage of the process. Whoever is driving the process will need to develop a very clear understanding of the key principles and processes of person-centred planning - and at least some methodologies for developing plans and strategies and putting them into action.

Identification of plan-facilitators who are adequately trained, experienced, and supported should also be done attentively. Plan facilitators should have the necessary organisational, observational and communication skills, knowledge of the local community, experience of gathering and recording evidence as well as the ability to self-reflect on their practice²².

The commitment of each participant in the process will constitute a key factor in determining its overall success.

²¹ In Bulgaria, as part of the major deinstitutionalization program, the government organized a comprehensive assessment of 1,800 children with disabilities living in institutions and of their families. The assessment found that 53% of families wished to re-establish contact with their children, with a view to eventual reunification. European Expert Group on the Transition from Institutional to Community-based Care (2012), Common European Guidelines on the Transition from Institutional to Community-based Care

²² A good facilitator understands and implements the logistical techniques of Person-Centered Planning, including: · Supporting the focus person · Inviting appropriate group members · Fostering a welcoming environment that supports creativity · Graphics skills · Group facilitation skills 6. Fosters commitment and support from members of the support circle to the Person-Centered Planning process and the action plan. A good facilitator is Non-Judgmental, A Good Listener, Self-Confident, Flexible, Genuine and Hospitable (Amado, A. N. and Mc Bride, M. (2001), Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning: A Manual for Person-Centered Planning Facilitators. Minneapolis, Minnesota: University of Minnesota, Institute on Community Integration)

Tending to practical issues

Creating a comfortable, accessible and inviting environment where the meeting will take place may be more of a challenge than imagined in institutions that are often space deprived. However, preparing a clean and cosy space is important. The room should be decorated nicely, labelled and signposted to help people become more independent – putting pictures or symbols on cupboards to show what’s inside; using tactile and visual lines to help people find their way. Well maintained spaces predispose us positively to talk and be heard.

The materials needed for carrying out the planning sessions should be purchased and in place for the meetings. Most materials needed are inexpensive like sheets of paper or markers. A board may be useful for brainstorming. More expensive equipment such as a computer, tablets, speakers and a projector are also useful.

Other aspects of the planning process that should be arranged beforehand include:

- Data collection and protection, confidentiality, storage, and access to plans,
- Establishing communication between group members (progression of plans, problems encountered in implementing plans or changes to plans),
- Maintaining and updating plans over time and changes in circumstances.

Not a one-off deal: Revision of Individualised plans

Revision of plans, monitoring and evaluation is an invaluable part of the DI procedures. It is important to understand that plans may need to be reviewed and adjusted from time to time to reflect changes in people and circumstances over time. Users should be able to request a review of their plan when there is a change in circumstances²³. Any changes identified

should be reflected in an updated care plan. This is particularly important for users leaving an institutional setting to start living in the community, who may gain confidence, develop new skills and see their health improve. The review of the plan for children in alternative care will help determine the adequacy and necessity of the placement in the light of the child’s personal development and the development in their family environment²⁴. Regular feedback opportunities should be in place with the person, their family (if the person chooses so) and/or a circle of support to find out if they are satisfied with the person-centred plan and its implementation in areas such as goals achieved, levels of satisfaction, quality of life improvements, transitions, independence, employment supports, community involvement, barriers, and complaints. The feedback can be gathered through formal and informal measures, such as dialogue with individuals using services, families and staff, face to face meetings, focus groups and surveys. The way in which person-centered planning is to be monitored and evaluated should be decided before person centred planning begins²⁵.

There are two key aspects of person-centred planning which require monitoring and evaluation:

1. Plans (which represent the goals set):
How well does the plan reflect the individual’s needs and desires? How clear is the plan?
2. Programs, processes and supporting structures (which represent the way of achieving the goals set):
Are all participants satisfied with the plans generated? Are the plans realistic and do they lead to action? Are the support mechanisms to realise the plans in place? Are people trying to put the plans into action? Is there a tangible link between plans and the delivery of services?

The **key question** for the monitoring and evaluation process is whether the person is experiencing real and positive changes in his/her life.

²³ European Expert Group on the Transition from Institutional to Community-based Care (2012), Common European Guidelines on the Transition from Institutional to Community-based Care

²⁴ Ibid.

²⁵ A useful starting point for looking at the whole area of monitoring and evaluation in relation to person centred planning might be the UK’s NWTDT’s ‘Framework for reviewing planning’, self-assessment of person centred policies and procedures using ‘The Agency Self-Assessment of Person-Centred Policies and Procedures Instrument’, the UK’s Valuing People Support Team’s ‘How good is our person centred planning framework?’ and, of course, seeking to obtain the views of individuals who have been through the person centred planning process, using, for example: the NDA’s ‘Ask Me Guidelines for effective consultation with people with disabilities’.

How do we get this done?

Methodology of person-centered planning step by step

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 the goals set.

It is important to acknowledge that the practice of person-centred planning is tempered by the fallibility of human judgement, the potential impingement of factors outside the control of the process on its success and the possibility that there will be setbacks along the way, and the fact that it will be necessary to allow some time for learning and adjustment. 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.

Essential Lifetime Planning

Essential lifestyle planning (ELP) was developed by Michael Smull and Susan Burke Harrison for the transition of people from institutions that were closing to their families or other community settings²⁶. ELP is a great tool to get to know someone and to begin building a team around him or her. ELP concentrates on the focus person's life in the present and how it can be improved. It can be especially helpful when very little is known about a person or when he/she does not

have close family or friendship connections. It can be a very effective way to start person-centred planning. It can help in learn who and what is important to the focus person, what support he or she needs in order to have a good quality of life, and the manner in which support should be provided on a day-to-day basis. It also can help identify what is not working for the focus person in his or her life at present.

What we have seen over the years is that nearly everyone in need of long-term services, who is in circumstances where others exercise control, has what is 'important for' them addressed while what is important to them is often overlooked. Essential Lifestyle Planning aimed to discover and gain service provider agreement to address the simple but important issues for each person which, if ignored, lead to unhappiness. A growing community of practice around Essential Lifestyle Planning has generated an array of tools²⁷ for discovering what matters to people, building a deep understanding of the rituals and routines that allow them to express their uniqueness, reviewing the quality of plans, incorporating the perspective of skilled service providers, dealing with conflicts, supporting necessary organisational changes, and bridging to other person-centred approaches as a person's dreams grow bigger and stronger and a person's relationships with potential allies grow wider and deeper.

²⁶ All the people who we were asked to help return to their communities had been labelled as 'not ready' for life in the community and their records supported this impression.

²⁷ See proposed further readings for ELP and other person-centered methodologies

Individual Service Design

Individual Service Design (ISD) works as an add-on to ELP, when ELP uncovers that the person wants a major part of his or her life to change (for example a new place to live or a very different support than what they are presently receiving).

The procedures are as follows:

- Reviewing the ELP.
- Creating a picture of life for the person.
- Exploring whom the person may want to live with.
- Exploring where the person may want to live.
- Exploring how the person may want to spend the day.
- Exploring what type of skills/characteristics the person may need/want in terms of who will provide the support.
- Exploring what the support person may need.
- Exploring options for housing and support.
- Evaluating the options.

ISD applies some of the ideas of social role valorisation to the planning process. Service workers are encouraged to develop a deep sense of understanding and empathy for the focus person. The group examines the person's history, and then looks for connections between the person's experience and the social devaluation that coincides with institutional life. A clever way the group develops an understanding of the individual is through socially valued analogues. Groups contemplate how a life experience of the focus person compares with the same experience for a more valued citizen in society²⁸.



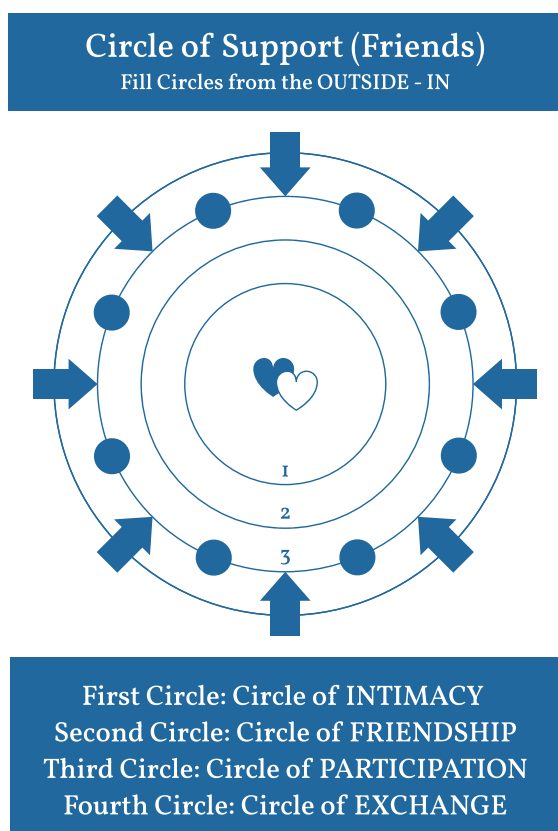
²⁸ O'Brien, C.L. & O'Brien, J. (2000) The Origins of Person-Centered Planning A Community of Practice Perspective, Responsive Systems Associates

CIRCLES

CIRCLES will give a quick picture of who is in your life and the role they play. It is useful to know who you can count on to become involved in certain activities in your life, or to notice when CIRCLES need to be filled especially during big changes in one's life and crisis periods.

CIRCLES goes beyond a simple mapping exercise. It has to do with our way of being and the underlying concept of interdependency. Everyone counts on many kinds of support from other people to get through the day²⁹. In the case of people living in institutions CIRCLES becomes of great importance. The focus of the group is to find and create ways for the vulnerable person to participate in her/his community.

CIRCLES can be a great base for other person-centred approaches since it revolves around the questions of who loves the focus person and which relationships should be sustained and thus can contribute to inviting the right people to participate in other person-centred approaches³⁰.



A CIRCLES session lasts from 15-60 minutes, depending on the depth of the exploration.

Materials needed: Blank sheets for everyone present, pens.

STEP ONE

Introduction on Circles.

STEP TWO

The group draws four concentric circles and writes the focus person's name in the middle of the diagram.

STEP THREE

Explain the 'definitions' of the four circles and demonstrate with examples - preferably from your own life. It is important to note that circles are most easily filled from the outside in.

Definitions:

First Circle: Circle of Intimacy

Think about the people most intimate in your life - those you cannot imagine living without.

Second Circle: Circle of Friendship

Think about good friends - those who almost made the first circle.

Third Circle: Circle of Participation

Recall people, organisations, and networks you are involved with. People or groups where you participate and encounter other people.

Fourth Circle: Circle of Exchange

List people you pay to provide services in your life (medical professionals, tax accountants, mechanics, hairdressers, barbers, teachers, etc.) Note: People can be in more than one circle.

STEP FOUR

Lead the group to fill in the names of people as they fit in each of the four circles.

Soft, gentle music provides a nice background for this exercise. Take time. Allow a minute or more for each circle. When the rustling starts, move quietly to the next circle.

STEP FIVE

Discuss the completed circles and brainstorm on ways to build relationships.

²⁹ Charting Our Circles of Support, Inclusion Press, 2015 https://inclusion.com/site/wp-content/uploads/2020/03/charting-circles.PATH-MAPS-Wkbk-2015.Sept_.pdf#:~:text=Charting%20Our%20Circles%20of%20Support%20Every-one%20counts%20on,Each%20of%20our%20relationships%20offers%20us%20the%20pos-

³⁰ Pearpoint, J. (2020), Circles of Support: How to... 2020, Inclusion Press.

Available at: inclusion.com/site/wp-content/uploads/2020/04/Circles-of-Support.How-to.cd_.pdf

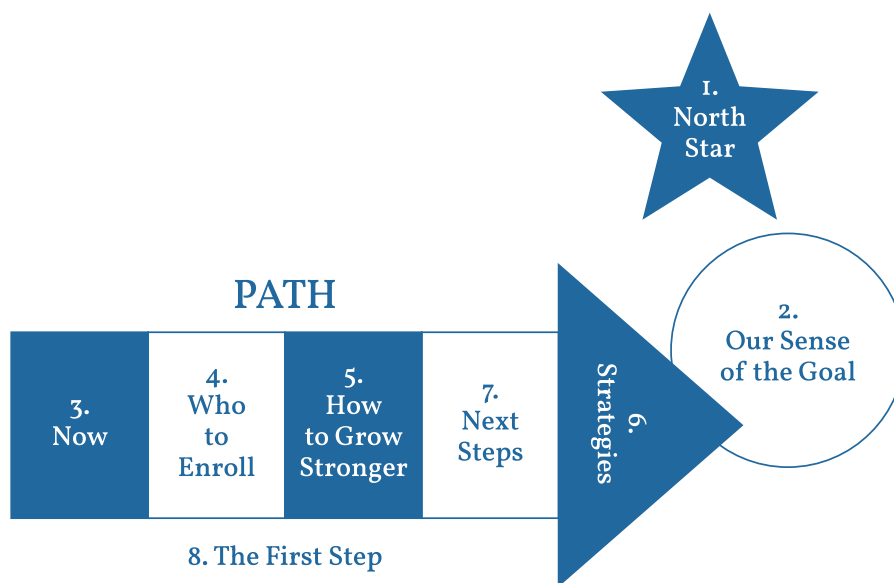
PATH

PATH was developed by Jack Pearpoint, John O'Brien and Marsha Forest. It is a creative conversational planning process which draws on people's capacities and wishes to imagine different futures and think backwards on how the envisaged futures can become reality. It presents an opportunity for the person at the centre, and, at his or her invitation, a number of people who s/he trusts, to give voice to the deepest and most heartfelt vision that they have for their own life and their life with others.

PATH emphasises on deep listening, creativity, collaboration, commitment-building and community-building and is very results-oriented³¹. The process involves the person himself, family, friends, community allies, service managers and service workers and it is clear all must collaborate to bring the future plans to fruition³².

There are two facilitators³³: the 'process' facilitator, who is responsible for leading and pacing the inquiry and tends to be more active, and the 'graphic' facilitator, who is responsible for capturing the ideas, discoveries, challenges and solutions in words and images and tends to be more receptive. It is the facilitators' role to identify, disclose and avoid conflicts of interest, respect confidentiality and keep the person's interests, as expressed by the person.

There are 7 steps in the PATH process. Each step in the PATH process is concluded in an independent session. A typical PATH usually involves a group of 5-10 individuals made up of the focus person and their family, friends and other professionals and support workers who know the focus person well. Each session lasts for 90 minutes to 2 hours (possibly longer with larger groups). Materials needed are very simple: a large sheet of paper and some markers will do.



Source: <https://inclusive-solutions.com/training/person-centered-planning/>

³¹ The PATH Method: Person-Centered Ways to Build Community by John O'Brien, Jack Pearpoint & Lynda Kahn Available at: inclusion.com/path-maps-and-person-centered-planning/path/

³² David Wetherow (2013), Managing Potential Facilitator Conflicts of Interest in PATH and Other Forms of Person-Centered Planning

³³ The facilitator 1. Knows how to facilitate a person-centered plan. 2. Uses pacing to move the Person-Centered Planning process along at a rate that works for the focus person and the circle of support. 3. Uses good listening skills. 4. Uses team work to enhance the effectiveness of the Person-Centered Planning process. 5. Resolves any conflict constructively. 6. Uses consensus building. 7. Fosters the self-determination of the focus person so the person-centered plan is created by and with them and not for them. 8. Builds relationships with the members of the circle of support so they will participate in the work of the action plan on an ongoing basis. 9. Helps the group CELEBRATE successes and accomplishments and grieve over upsets and breakdowns. For more see: Protocol Minnesota Department of Human Services January (2017), Person-Centered, Informed Choice and Transition edocs.dhs.state.mn.us/lfsrver/Public/DHS-3825-ENG

The 7 Steps are as follows:

STEP ONE: INTRODUCTION and SETTING THE GROUND RULES³⁴.

STEP TWO: CREATING the DREAM

The PATH begins by asking the person to imagine what a good life for them would look like and what is dearest to them in terms of goals for the future. At this stage, no limitations are imposed on the person's dreams. The other participants in the group build on the vision. When the person involved has poor communication skills the other people's role in setting the dream becomes more challenging but also more crucial. Even for a person labelled as severely mentally impaired with little or no obvious communication skills, we would be surprised with the things people who care for him/her can put together and get a better idea of their dream. This is the longest step and sets the direction for the rest of the PATH.

STEP THREE: ONE YEAR FROM NOW

'Positive and Possible'. During this session, the people in the group are invited to imagine that a year has passed since the vision was created. Then they are encouraged to look back on the past year and remember which steps have been taken towards realising the focus person's dream. This session isn't about dreaming but identifying steps that are possible (they could have happened) and positive (we are only remembering the good times). This step helps the group envisage what it would be like if they were actually in the process of realising the person's dream.

STEP FOUR: GROUNDING IT IN THE NOW

This step aims to connect the vision to reality at present in relation to the desired future. It is a conversation about where the group is starting from. The next steps are focused on the actions that need to be taken in the future in order to get to the desired outcomes.

STEP FIVE: WHO DO WE NEED TO ENROLL

During this session, people discuss their role in the focus person's future and commit to it. At this stage, names of other people that do not currently belong to the group but would enhance it are given for future invitation.

STEP SIX: WHAT WILL IT TAKE?

This session helps the group talk about what they must do to take steps toward the desirable path ahead. The session also includes naming what skills and capacities they already have and can put to work as well as the relationships, knowledge and skills they will need to develop.

STEP SEVEN: ACTIONS

This final step gets the group to identify the next steps. The focus will move between things that can be done tomorrow and things that can be achieved in a week or a month's time. The facilitators will document who will act, what they will do, and when. Agreement will also be made on when progress will be reviewed.

The PATH process ends with a round of words and reflections from the group on the work they have just done together, and the completed PATH is photographed, taken down from the wall, rolled up and presented to the pathfinder. (inclusive-solutions.com/product/path-process-step-by-step-guide/)

³⁴ Example of ground rules: 1. The right people are here 2. It begins when it begins and ends when it ends 3. Do what you need to do to be here 4. Whatever happens is the only thing that could have happened 5. Be nice or get out. 24

MAPS

MAPS is a creative planning tool³⁵ (developed by Judith Snow, Jack Pearpoint, John O'Brien and Marsha Forest) that uses graphic facilitation. Although MAPS originated in the 'disability' sector, its applications cover the full spectrum of life situations. MAPS work well at times of transition. MAPS uses a person's story to be able to discover a dream, direction and steps to a desirable future. It requires skilled facilitation by two facilitators – in order to make it safe for the MAP finder.

There are 8 steps in a MAPS session that lasts for 90' to 2 hours (possibly longer with larger groups). A typical MAPS session usually involves a group of 5-10 individuals made up of the MAP maker and their family, friends and other professionals and support workers who know the focus person well.

The 8 Steps and the questions associated with them are as follows:

WHAT IS A MAP?

This question sets the context for the session. Its goal is to make the people involved think about what a good MAP entails in order to create one together.

What is THE STORY SO FAR?

The person is asked to talk about his/her personal history so far. If needed, the facilitator uses questions to prompt the group for answers. Visual prompts such as videos or pictures can be very useful for sharing relevant information. When this is completed, the facilitator reviews with the group what has been recorded. The group also reflects on what has not been done correctly in the past and what can be done differently in the future.

What is THE DREAM?

This step is all about dreaming about the future. The facilitator asks the young person first, then the rest of the group and encourages the group to think about short- and long-term dreams and possibilities for the future. This could be kept open ended or can be focused on the 5 pathways to an independent future: · Lifelong Learning · Relationships · Leisure Opportunities · Employment · Independent Living³⁶. Not all dreams are realistic, but in MAPs dreams are not judged. Some dreams may not play out the way they are expected, but pieces of them may be acted on³⁷.

What is THE NIGHTMARE?

This step gives everyone the opportunity to vocalise fears for the person, especially those

³⁵ "MAPs are tools held in the hand of a creative facilitator who can truly listen and hear the dream and cry of pain of people or groups who have been rejected overtly or covertly" Forest M, O'Brien J and Pearpoint J, 'PATH: A workbook for planning positive, possible futures' (Toronto Inclusion Press)

³⁶ Person Centred Planning Regional SEN Transition to Employment Initiative, S. Beyer et al., September 2014

³⁷ For example, a person without previous education may dream of becoming a surgeon. When digging deeper into this dream we may discover that what the person really wants is to be respected the way he sees the doctors being respected in the environment he lives in.

that may make his dream difficult to realise. Fears can be specific, like ‘getting hit by a car’, or more general like ‘being alone’. It is important to know what we want to avoid but we shouldn’t dwell on this step (5 minutes approximately).

NAMING GIFTS

Participants are expected to describe the person through questions about favorite activities, hobbies, foods, their skills and abilities, strengths and weaknesses. The group also focuses on an essential gift and how to support it.

WHAT WILL IT TAKE?

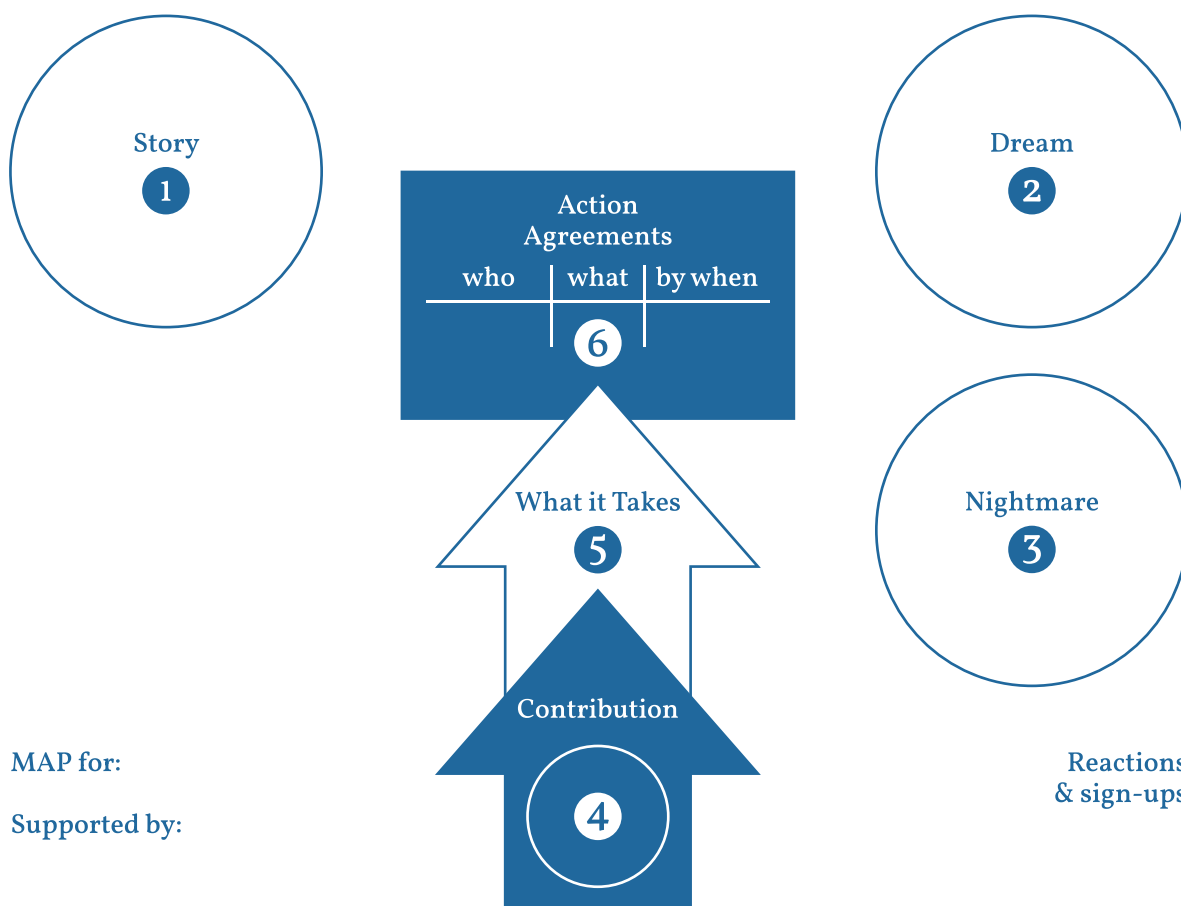
During this step, people identify actions to be taken in order to begin to move away from the nightmare and towards the Dream. This step asks the group to identify the needs of the

person. Needs could include courses that need to be attended, adaptive equipment, help finding a job or activity to develop self-confidence.

What ACTION AGREEMENTS can we make now?

This step asks for specifics: What will our next steps be? Who will do it? By when will it be done? How will we check progress?

The MAP process ends with a round of feelings, appreciations or reflections from the group on the work they have just done together. The completed MAP is photographed, taken down from the wall, rolled up and presented to the focus person and their family (<https://inclusive-solutions.com/product/maps-process-step-by-step-guide/>).



Source: https://inclusion.com/path-maps-and-person-centered-planning/maps_planning/

Personal Futures Planning

Personal Futures Planning, developed by Beth Mount and John O'Brien, contains a series of six tasks designed to help find capacities in individuals, identify options in their communities, and develop supports and services that will meet each individual's strengths and needs.

Personal Futures Planning is a very thorough planning system: it not only seeks to learn more about the person's life (which PATH does not do), but also works at achieving the person's vision (unlike Essential Lifestyle Planning which focuses on achieving a lifestyle that will work for the individual now). It is effective for looking at what aspects of a person's life are working well at the present, and then building on them towards a desirable future. Although it does not provide details about what a person requires on a day-to-day basis, it does provide an excellent overview of the individual from which areas of concern can be considered. A unique way that PFP defines the vision is by insisting that organisational and system change is necessary for any vision to be achieved.

It is based on '6 Windows of Change', which reflect six of the maps or tools of Personal Futures Planning³⁸. Each 'Window' provides tasks to complete and boxes to record the information in. There are some graphics and quotes. This is written in a format that requires someone to read the material with a person and support them to complete it:

The 1st Window

'This is my Question, Listening to Hope', helps the person identify what they want to change and invite a friend or supporter to help them to explore this.

The 2nd Window

'These are my friends and supporters - expanding and deepening relationships', and clarifies the person's support systems and identifies how to build on this and strengthen friendships.

The 3rd Window

'These are my gifts, recognising and developing preferences'. This window presents some thinking tools for exploring and clarifying individual gifts.

The 4th Window

'This is my community: finding opportunities in community life' and suggests ways of exploring and learning about the local community by examining the routines of local community life.

The 5th Window

'This is my vision for a positive future, - developing a future vision' and presents ideals for helping a person to clarify their personal vision.

The 6th Window

'This is what I need to learn - understanding my struggle'. This window identifies what people need to learn to overcome obstacles. Rather than learning new skills, the focus is on learning more about the community, about systems and about oneself.

Other person-centered approaches

John Butterworth and his colleagues in Connecticut developed **Whole Life Planning** (1993), a way to match planning procedures to the individual preferences of people with developmental disabilities seeking employment.

Ann and Rud Turnbull created **Group Action Planning**, adopting ideas from Personal Futures Planning and MAPS to empower families to plan, especially families who are concerned to realise great expectations for family members with behavioral challenges.

Living Well is a person-centered approach to support people to live well with a long-term condition. It also provides a structure to help people think about and plan for the end of life.

The Living Well workbook³⁹ supports a conversation to happen around a range of themes, including:

- Relationships;
- What makes a good and bad day;
- What is important to a person and how to best support them;
- What is working and not working in their life, and what they'd like to change;
- Wishes and desires for the future;
- End-of-life preferences;
- How the person would like to be remembered;
- What decisions will need to be made, and how the person must be involved.

Lifestyle Development Process is unique in that it adds interventions and outcome measures for evaluative purposes to the planning process.



³⁹ Example of Living Well workbook available at: <http://www.helensandersonassociates.co.uk/wp-content/uploads/2015/02/livingwell-hull.pdf>

Recommendations concerning DI procedures during transition tailored to the Greek context

Legislative reform

- Abolish of institutionalisation by provision of law. Pass a law that explicitly states that the already existing institutions must be closed within a certain timeframe and new admissions should be gradually banned.
- Combat discrimination in all areas of the life of persons with disabilities and not only in the field of employment and occupation as it currently applies (law 4443/2016), to be in line with law 4488/2017 (article 74, par. 4)
- Abolish segregation of the education system for children with disabilities and promote inclusive education, starting from early childhood education and care according to the UN Convention on the Rights of Persons with Disabilities. Children with disabilities must not be placed in special education environments (in which institutional culture also prevails), instead, they must be included in mainstream schools with adequate support.
- Prohibit special schools to be built and run inside the institution's premises.
- Establish a single, accessible and inclusive system of vocational education, training, and lifelong learning, where persons with disabilities will not be excluded and discriminated.
- Establish personal assistance legal schemes as a key element of independent living and participation in society for persons with disabilities and older people.
- Establish the "supported employment" legal scheme to enable persons with disabilities to access the labour market.
- Establish a legislative framework for the following services, programs, and structures: family counseling and support centers, early intervention programs, independent living centers, host family programs for all persons with disabilities.
- Legally recognize and support informal carers and provide them with information and training, income support, work-life balance measures and respite services.
- Support the implementation of the law 4538/2018 which includes the provision Professional Foster Care in Greece. Professional Foster Care has been included in the latest law for Adoption and Foster care (law4538/2018), but the Joint Ministerial Decisions concerning its implementation is still pending.
- Revisit the legal capacity legislation. There is no supported legal capacity status in Greece or criteria for deciding upon one's legal capacity, and this results in people put under guardianship very easily and for all issues that concern their life.
- Arrange the legal status of children in order to know if foster care or adoption is in the best interest of the child. Often children are admitted to institutions and their parents maintain custody even if they have no contact with them or this is not in their best interest⁴⁰. As a result, they are not free for adoption and age out of care having spent all their childhood in institutions.
- Ensure a decent income through disability pensions and disability benefits for each individual in transition.
- Revisit legislation concerning the tasks of employees in institutions. Tasks are so narrowly defined that often therapists do not work with residents because it is not in their tasks to go search for the person who is in the schedule and no one available to bring them to therapy (which may be in the next building) or nurses claim it is not their job to keep the children occupied for example but just feed them, bathe them and give them their medication. This results in poor quality of service and bad human resources management.

⁴⁰ There are many cases where parents object to their children being placed in foster care or being adopted and no actions are taken towards the best interest of the child. This is particularly common when parents abandon their disabled child and keep custody (since there is no abuse involved) even when they have no contact with them at all. The devastating results of this malpractice are undeniable.

Policy Makers

- Start transition process only when strong commitment and the end goal are secured in order to avoid the creation of false expectations amongst the residents.
- Develop Local Action Plans for the social inclusion and independent living of persons with disabilities both by the Municipalities and the Regions, in collaboration with the National Confederation of Disabled People (NCDP), based on the National Action Plan for the Rights of Persons with Disabilities.
- Create a fully integrated network of structures and services at a municipality level. This should include the following structures and/or services: a) Family Counseling and Support Centers, b) Early Intervention Programs, c) Integrated Early Childhood Centers, d) Integrated Nursery Centers, e) “Help at Home” service program, f) Independent Living Centers, g) Supported Living Homes (SYD), h) Temporary Hosting Structures, i) Day Care Centers for Older people (KIFI), j) Day Care Centers for Persons with Disabilities (KDIF AmeA), k) Centres of Creative Activities for Children where children with mild disabilities can fully participate, l) Centers of Creative Activities targeted to Children with Disabilities, m) Implementation of supported employment programs, n) Social Cooperative Enterprises for vulnerable groups (see law 4430/2016).
- Coordinate and establish horizontal networks (together with the co-responsible Ministries) and vertical collaborations among the public sector, local governmental bodies, organisations of persons with disabilities, and other bodies of civil society.
- Establish an evaluation system responsible to measure the quality-of-services. The evaluation should rely on the use of indicators and procedures in which the representatives of persons with disabilities must actively participate. The quality standards of the services provided must take into consideration the rights of persons with disabilities (according to the UNCRPD) as well as the degree of choice and control of beneficiaries.
- Address availability issues and lack of services including supported living arrangements, personal assistants for independent living, services for teenagers with mental health issues or challenging behavior.
- Prioritise fostering children with disabilities. Fostering children with disabilities is a result of a relationship built between the child and the prospective foster parent. The platform currently used for linking candidate parents and children in need does not recognise relationships already established and the matching is done automatically for reasons of transparency. However, in the case of children with disabilities there should be a way to link children with disabilities with prospective families directly when they express such an interest (provided they are suitable). A separate database of candidates open to children with disabilities or health issues may also be helpful. Before the use of the platform the social workers working with candidates also had an overview of the children they were hosting and were able to identify people open to fostering or adopting children with disabilities and to link them with specific children. This, sadly, is no longer an option. As a result, social workers in institutions are noticing that more children with disabilities and health issues are being left behind and not chosen by prospective parents.
- Secure and use European and National funding for the transitioning phase of the DI process.
- Hire adequately trained personnel, with proper academic background, create academic and career paths for care workers to redress that in public institutions most staff is underqualified, with Secondary School or even only Primary School diploma.
- Prohibit the placement of children with or without disabilities, adults with disabilities or older persons far from their place of origin and their network of people. Currently, when a child is removed from their family, he/she is placed in any institution in Greece with a vacancy. Also, young adults with disabilities are forced to change institutions when they become adults and often find themselves estranged from all their networks in another part of Greece.

Managers

- Develop a deinstitutionalisation (DI) program for each residential care unit with concrete timetable and identified resources.
 - Hire interdisciplinary groups trained specifically for this process to work alongside existing staff members (due to understaffed institutions in Greece).
 - Identify training needs of personnel.
 - Develop of a complaints' procedures for service users as a safe space to speak. Often persons in institutional care do not speak up for themselves since their whole life relies on staff and they fear vindictiveness when criticising their way of working and the services they receive.
 - Adopt standard procedures to mitigate risk and responsibility of carers. Helping people be safe and happy requires thought and effort. One of the traps of the current system of planning is that we determine how people can be safe before we explore/examine what they require to be happy. We forget that there is no such thing as a risk-free life!
 - Actual or virtual study visits to countries that have achieved deinstitutionalisation and networking with managers that have already led the process in their countries.
- Work with local communities to create positive engagement and avoid that the local population make it difficult for former residents of institutions, shying away from them, ignoring them, or even resorting to verbal and physical violence⁴².
 - Start with or at least don't exclude children and adults with complex support needs. DI plans often focus on the more functional children and adults excluding people labelled as difficult or severely disabled. This poses a direct risk of maintaining two parallel systems and never closing institutions⁴³.
 - Arrange Disability Assessment (KEPA) for all children to be entitled to benefits when placed in alternative settings.
 - Organise visits to Community settings to ensure that residents make an informed decision.
 - Prepare residents for being able to communicate and empowered to make choices.
 - Maximise opportunities for inclusion in Community settings through leisure and educational activities (Volunteers' crucial role in this)
 - Provide all residents with IDs

Staff

- Organise study visits for staff workers to learn from best practice in other countries.
- Reconnect residents with families and friends – Institutions in Greece do not foster resident- parent relationships, which is beneficial for the quality of life of the service users and create allies in the change⁴¹.

Advocates

- Document peoples' stories in Greece. Advocates can often make their point most powerfully through the personal stories of people who have lived in institutions, in the words of the person if at all possible, and/or of family members who are pleased with life in the community for their loved one. In Greek community, the myth of needed and even appreciated institutions still prevails.
- Focus on community commitment building.

⁴¹ One mother with mental health issues had abandoned her two daughters in an institution for babies. She was under the impression that both would be put up for adoption. She was timely informed that one daughter was later placed in a private institution and collaborated with them and kept contact with her. She only learnt the whereabouts of her other daughter 9 years after she had been admitted in a public institution for children with disabilities. At that point the social workers of the institution decided it would not be in the child's best interest to meet her mother and to this day ignores her existence.

⁴² The first time the residents of the institution in Lechaina went to the town square and sat at a local cafeteria accompanied by volunteers inhabitants of the village demanded the cafeteria to throw away the glasses they had drunk out of!

⁴³ A great argument to convince people that everyone can be included in society is the 'functional twin' argument. For every person in an institution that we can not imagine living in the community there are many 'functional twins' already living full lives in the community!

Conclusions

Adopting person-centered methodologies when preparing people for the move from institutional to community-based settings is a key element for the transition as it challenges the basic wrongdoings of institutions that have left people unheard and isolated for decades.

Accepting segregated settings hidden from society behind walls and gates as a suitable environment for entire groups of people equals to dehumanizing them and ignoring basic human needs and rights.

If policy makers, managers and society at large make this realisation and if staff in institutional settings genuinely tune in to each person's desires, hopes and fears and strongly believe in their inherent dignity and right to make choices, moving people to community settings will be the only true and acceptable option. Deinstitutionalisation will then come as a natural consequence of actually seeing all people equal and worthy of living full lives in society.



Further readings

Person Centered Planning Readings, Tools and Resources

Becker, Ch. (2001) Person Centered Planning Approaches – A Literature review prepared for Persons with Developmental Disabilities Central Alberta Community Board

Booth, T. & Ainscow, M. (2002) Index for Inclusion: developing learning and participation in schools, London: Centre for Studies on Inclusive Education

Bowers, H., Bailey, G. Sanderson, H. et al. (2007), Person Centered Thinking with Older People Practicalities and Possibilities, CSIP and in Control

Butterworth, J. (1993) Whole Life Planning: A guide for organisers and facilitators. Cambridge, MA: Institute for Community Integration

Commissioner for Human Rights /Issue Paper (2012) Original version WHO GETS TO DECIDE? Right to legal capacity for persons with intellectual and psychosocial disabilities

European Coalition for Community Living (2008) Creating successful campaigns for community living – Advocacy manual for disability organisations and service providers

Falvey MA, Forest M, Pearpoint J & Rosenberg RL (1997), All My Life's a Circle. Using the Tools: Circles, MAPS and PATHS, Inclusion Press

Gadd T. & Cronin S. (2018), A National Framework for Person Centred Planning in Services for Persons with a Disability, this report was commissioned by the HSE on behalf of the National New Directions Implementation Group, and produced by ACE Communication Ireland

Grove N. (2005), Communication for Person Centred Planning, Department of Language & Communication Science, City University Barbara McIntosh Foundation for People with Learning Disabilities, London

Infusing a Person-Centered Approach Into Transition Planning For Students with Developmental Disabilities (2000), New York State Developmental Disabilities Planning Council

Kendrick, M. (2000), Some Initial Thoughts On Establishing “Right Relationship” Between Staff, Professionals, Service Organisations and the People They Assist, Queensland Advocacy Incorporated Newsletter

Kendrick, M. J. (2001) “Integrity and Advocacy” Gray, Advocacy for People with Learning Disabilities, London: Jessica Kingsley Publishers 2001

Kendrick, Michael J. (2001) The Empowering Value Of “Life Giving” Assumptions About People Opening Keynote Presentation for the Congress “Crossing Boundaries” (“Over Grenzen”), Hosted by Stitchling Perspectief, Wageningen, Netherlands, September 12-15, 2001

Key Elements of a System for Supported Decision-Making, Position Paper of Inclusion International - to be adopted at the General Assembly 2008, Inclusion International

Lansdown, G. (2001) Promoting children's participation in democratic decision-making, Florence, Italy: UNICEF, Innocent research centre

- Minnesota Department of Human Services (2017), Person-Centered, Informed Choice and Transition Protocol
- Mount, B. (1992) Person-centered planning: A sourcebook of values, ideas, and methods to encourage person-centered development (1992 edition). New York: Graphic Futures.
- O'Brien, C.L. & O'Brien, J. (2000) The Origins of Person-Centered Planning A Community of Practice Perspective, Responsive Systems Associates
- O'Brien, J. & O'Brien, C.L., eds. (1998). A little book about Person Centered Planning. Toronto: Inclusion Press.
- O'Brien, J., Pearpoint, J. & Forest, M. (1993), PATH: A Workbook for Planning Positive Possible Futures Author, Inclusion Press
- Pearpoint, J. (2020), Circles of Support: How to... 2020, Inclusion Press
- Pearpoint, J. & Forest M. (circa 1991), Circle of Support (Friends)
- Pearpoint, J., O'Brien, J., and Forest, M. (1992). PATH. Toronto: Inclusion Press
- Pearpoint, J., O'Brien, J., and Forest, M. (1992). PATH. Toronto: Inclusion Press
- Rooney, A-M., Koornneef, E., & Lieshout, M.V., Guidelines on Person Centred Planning in the Provision of Services for People with Disabilities in Ireland, National Disability Authority
- Sanderson, H. (2000) Person centred planning: Key features and approaches. London: JRF
- Sanderson, H., Jones, E. & Brown, K. Essential Lifestyle Planning and Active Support
- Sanderson, H., Kennedy, J., and Ritchie, P. (1997). People, plans, and possibilities: Exploring person-centered planning. Edinburgh: SHS, Ltd
- Save the Children UK (2005), Practice standards in children's participation. London, UK: Save the Children UK
- Smull, M & Burke-Harrison, S. (1992), Essential Lifestyle Planning: Supporting People with Severe Reputations in the Community, National Association of State Directors of Developmental Disabilities Services Inc, Virginia
- Smull, M.W, Bourne, M.L, Sanderson H., (2010) Best Practice, Expected Practice, and the Challenge of Scale, U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services
- Smull, M.W, Sanderson, H. et al. (2005), Essential Lifestyle Planning for Everyone, The Learning Community - Essential Lifestyle Planning
- Snow, J. (1992). What's really worth doing and how to do it: A book for people who love someone labeled disabled (Possibly yourself). Toronto: Inclusion Press
- Snow, J. (2015), Participation Through Support Circles, Inclusion Press

The price of freedom of choice, self-determination and integrity: A report from the Knowledge Project: A cost analysis of different forms of support and service to people with extensive functional impairments (2006), JAG

Useful links

- Advice for using person-centred thinking, planning and reviews in schools and transition (2010), Department of Health, UK https://dera.ioe.ac.uk/15671/1/dh_person_centred_planning.pdf
- Allen, W., (2002), It's My Choice, Minnesota Governor's Council on Developmental Disabilities, Resource guide <https://mn.gov/mnddc/extra/publications/Its-My-Choice.pdf>
- "Community for All" Tool Kit Resources for Supporting Community Living (2004), Human Policy Press <https://files.eric.ed.gov/fulltext/ED503911.pdf>
- Free customised strategic plans available at: <http://www.learningcommunity.us/documents/PCTCurriculumDescriptionJuly2006.doc>
- <http://allenshea.com>
- <http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/>
- <https://inclusive-solutions.com/>
- <https://www.kirklees.gov.uk/beta/special-education/pdf/path.pdf>
- Person centered tools and guidance <https://www.tameside.gov.uk/ChildrenSocialCare/Person-Centered-Tools-and-Guidance>
- Sanderson, H. & Kilbane, J. (1999), Person Centred Planning – a resource guide, NWTDT <http://www.nwtdt.com/Archive/pdfs/pcp.pdf>

Further readings on DI and Community Care

Better Care Network and UNICEF (2009) Manual for the measurement of Indicators for children in formal care

Better health, better lives: children and young people with intellectual disabilities and their families Bucharest, WHO, Romania, 26–27 November 2010

Beyer S, Kaehne J, Sheppard K, Meak A. (2008), What works? Transition to Employment for Young People with Learning Disabilities, Shaw Trust.

Bilson, A. & Harwin, J. (2003) Changing minds, policies and lives: Improving Protection of Children in Eastern Europe and Central Asia. Gatekeeping Services for Vulnerable Children and Families. UNICEF & World Bank

Bogdan, R. and Taylor, S. (1976). The judged, not the judges: An insider's view of mental retardation. *American Psychologist* 31(1)

Child Participation and Children's Ombudsman Institutions within the European Union Preliminary Report BY RACHEL HODGKIN AND PETER NEWELL 2008

Children's commissioner (2019), 'Children's Voices: Children's experiences of instability in the care system'

Choice and control: the right to independent living Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States FRA , 2013

Costa, M. (2012) Deinstitutionalisation and quality alternative care for children in Europe Lessons learned and the way forward, Working paper

Csáky, C. (2009), *Keeping Children Out of Harmful Institutions Why we should be investing in family-based care*, Save the Children Child Protection Initiative Task Group on Appropriate Care

Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent

EASPD (2011), *The challenge is ours! sDeinstitutionalisation of services for people with disabilities in Western European Countries* Brussels, 3-4 October 2011

ECCL European Coalition for Community Living (2011), *Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers*

EUROCHILD (2012), *DI Myth Buster*

EUROCHILD, 'Children's Rights for All' *Monitoring the implementation of the UN Convention on the Rights of the Child for Children with Intellectual Disabilities*' (GR)

European Expert Group on the Transition from Institutional to Community-based Care (2012), *Common European Guidelines on the Transition from Institutional to Community-based Care*

European Social Network (2011) *Developing Community Care, Part III.1 'Strategic area needs assessment and planning'*. Brighton

European Social Network (2011), *Developing Community Care A ESN report that makes the case for community care, outlines the first steps in deinstitutionalisation and identifies key elements for good community care*

European Union Agency for Fundamental Rights (2012), *Choice and control: The right to independent living, Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*, FRA

Evans, P. (2013), *Implementation of the national strategy and action plan for the reform of the residential childcare system in Moldova 2007-2012: Evaluation report*, UNICEF, Terres des Hommes

Freyhoff, G., Parker, C., Coué, M. & Greig, N. (2004) *Included in Society: Results and recommendations of the European research initiative on community-based residential alternatives for disabled people*. Brussels: Inclusion Europe

Gale CH., (2016) *Alternative Child Care and Deinstitutionalisation: A case study of Chile*, CELCIS

Gilbertson, N., Hiles, A., Howard, B & Goldman Ph. (2020), *Rapid return of children in residential care to family as a result of COVID-19: Scope, challenges, and recommendations*, Child Abuse and Neglect

Glasby, J., Robinson, S. & Allen, K. (2011) *Achieving closure: good practice in supporting older people during residential care home closures*. Birmingham: Health Services Management Centre (on behalf of the Association of Directors of Adult Social Services and in association with the Social Care Institute for Excellence)

Goldbart, J. & Caton, S. (2010), *Communication and people with the most complex needs: What works and why this is essential*, Research Institute for Health and Social Change Manchester Metropolitan University (MMU)

Goldman P.S. et al. (2020), *Institutionalisation and deinstitutionalisation of children 2: policy and practice recommendations for global, national, and local actors*

Good Practice Collection (2014), The COMBALL Learning Partnership (N°2013-1-AT1-GRU06-09773) has been funded with support from the European Commission, represented by the Program of Life Long Learning.

Grunewald, K. (2003) Close the Institutions for the Intellectually Disabled. Everyone can live in the open society

Hope and Homes for Children (HHC) and Roots Research Centre in collaboration with Eurochild (2015), Child Protection System Reform in the Hellenic Republic Call to Action

Ilinca, S., Leichsenring, K. & Rodrigues, R. (2015) From care in homes to care at home: European experiences with (de)institutionalisation in long-term care European Center policy brief

Inclusion Europe (2003) Achieving Quality, Consumer involvement in quality evaluation of services. Report. Brussels: Inclusion Europe

Inclusion International (2008) Key elements of a system for supported decision-making. Position paper.

Integration and participation of older persons in society, United Nations Economic Commission for Europe (UNECE), Policy Brief No. 7 (November 2010) Towards community long-term care

Jones, H. (2019) Deinstitutionalization for Children with disabilities: Technical guidance for UNICEF'S engagement in National Reform Efforts, UNICEF REPORT

Lerch, V. & Stein, M. (eds.) (2010) Ageing Out of Care: From care to adulthood in European and Central Asian societies, SOS Children's Villages International, Austria

LUMOS (2019), A GOAL WITHIN REACH: ENDING THE SINSTITUTIONALISATION OF CHILDREN TO ENSURE NO ONE IS LEFT BEHIND

Mansell, Jim and Knapp, Martin and Beadle-Brown, Julie and Beecham, Jennifer (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: main report. University of Kent, Canterbury, UK

McCarron, M., LombardVance, R., Murphy, E., et al. (2019), Effect of deinstitutionalisation on quality of life for adults with intellectual disabilities: a systematic review, BMJ

Measuring Better Care: Building the Evidence to Inform Policy and Practice Around Children's Care Mark Canavera¹ & Florence Martin² Published online: 26 April 2016 # Springer International Publishing 2016

Mechanisms: A discussion paper. London: Save the Children UK.

Mencap (2001) No ordinary life, London: Mencap

Mencap (2001), No ordinary life: The support needs of families caring for children and adults with profound and multiple learning disabilities

Ministry of Welfare (2016) Action Plan for Implementation of Deinstitutionalisation (in Latvia) 2015-2020

Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children' (2012), CELCIS at the University of Strathclyde; International Social Service (ISS); Oak Foundation; SOS Children's Villages International; and United Nations Children's Fund

- Mulheir (2012), Deinstitutionalisation–A Human Rights Priority for Children with Disabilities Equal Rights Review
- Mulheir, G. & Browne, K. (2007) De-institutionalising and Transforming Children’s Services. A Guide to Good Practice. University of Birmingham: Birmingham
- Mulheir, G., Browne, K. et al. (2004), De-Institutionalisation of Children’s services in Romania: A Good Practice Guide, Hope and Homes for Children, UK; High Level group for Romanian Children UK Government Department for International Development, Hope and Homes for Children Romania, Centre for Forensic and Family Psychology, University of Birmingham, UK , UNICEF
- Munday, B. (2007) Integrated social services in Europe. Council of Europe
- Nanou, K. Mapping institutional and residential care for children in Greece, Hope and Homes for Children UK and Eurochild
- National Deinstitutionalisation Strategy of the Republic of Macedonia for 2018–2027 (2018), ‘Timjanik’ & Action plan Skopje
- O’Brien, J., O’Brien C.L. & Schwartz, D. (1990), What Can We Count On To Make and Keep People Safe? Perspectives on Creating Effective Safeguards for People with Developmental Disabilities John from discussions with participants in the Pennsylvania Developmental Disabilities Planning Council Annual Retreat
- OHCHR (2010) Forgotten Europeans – Forgotten Rights: The Human Rights of Persons Placed in Institutions. Geneva: OHCHR
- Parker, C. & Bulic, I. (2010) Wasted Time, Wasted Money, Wasted Lives... A Wasted Opportunity? London: European Coalition for Community Living
- Parker, C. (2011), A community for all: Implementing article 19, Open Society Public Health Progr
- People First of Canada/Canadian Association for Community Living (2010) The Right Way – A Guide to closing institutions and reclaiming a life in the community for people with intellectual disabilities.
- Power A., (2011) Active Citizenship & Disability: Learning Lessons in Transforming Support for Persons with Disabilities Report, National University of Ireland Galway
- Ratzka, A. (2004) Model National Personal Assistance Policy, Cornell University ILR School
- Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009)
- Save the Children UK (2007), Child Protection and Care Related Definitions
- Save The Children, Community based social work with children and families Manual on Prevention and Reintegration Ruse, Bulgaria 2002-2005
- Schalock, R. et al. (2007) Quality of Life for People with Intellectual and Other Developmental Disabilities: Application across individuals, organisations, communities, and systems. Washington, DC: AAIDD
- Šiška, J.& Beadle-Brown,J. (2020) Report on the Transition from Institutional care to community-based services in 27 EU Member States

SOS Children's Villages International (2012) Assessment tool for the implementation of the UN Guidelines for the Alternative Care of Children. Austria: SOS Children's Villages International

SOS Children's Villages International, (2014), From a Whisper to a Shout: A Call to End Violence against Children in Alternative Care, University of Bedfordshire

Taylor, S. J. (2001), On choice, TASH Connections

Tomalak D., Barnett St. & Halloran J. (2011), Developing Community Care, European Social Network

UNICEF (2010) At Home or in a Home? Formal Care and Adoption of Children in eastern Europe and Central Asia

UNICEF (2010), At home or in a home? Formal care and adoption of children in Eastern Europe and Central Asia UNICEF Regional Office for Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS)

UNICEF (2010). At home or in a home? Formal care and adoption of children in Eastern Europe and Central

UNICEF (2010). Child protection system: Core mapping and assessment. Better Care Network

UNICEF (2010). Strengthening national child protection systems in emergencies through community based

UNICEF, Guidelines for Deinstitutionalization of Residential Homes for Children (RHC) Transitioning to Family Based-Care in Ghana (2020) UNICEF Ghana, Department of Social Welfare of the Ministry of Gender, Children and Social Protection

United Nations (2007) From exclusion to equality: Realising the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol, Geneva

United Nations (2009) Guidelines for the Alternative Care of Children. New York: United Nations

United Nations Economic Commission for Europe (UNECE), Policy Brief No. 4

WHO Quality Rights Tool Kit (2012) Available at: <https://www.who.int/publications/i/item/who-qualityrights-tool-kit>

WHO Regional Office for Europe (2007), De-Institutionalising and Transforming Children's Services: A guide to good practice, University of Birmingham

World Health Organisation (2010) European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families



European Association of Service providers
for Persons with Disabilities

CREDITS & RIGHTS

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

Copyright: Copyright © EASPD 2021. All rights reserved.
No part of this publication may be reproduced, stored
in or introduced into a retrieval system without the prior
permission of the copyright owners.

PHOTO CREDITS

©Patty Brito
©Nathan Anderson
©Cliff Booth
©Meruyert Gonullu
©Thinkstock



This publication has been produced with the financial support of the European Union
via the Structural Reform Support Programme of the European Commission.
The information contained in this publication does not necessarily reflect the official
position of the European Commission.