GUIDE ON INDEPENDENT LIVING OF PERSONS WITH DISABILITIES

MONIKOM

έδρα social cooperative activities for vulnerable groups

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Table of Contents

Resume

Deinstitutionalization is both a political and social process which aims at transitioning individuals, especially persons with disabilities from institutional care in isolated settings to independent living units. Successful deinstitutionalization happens when a person previously residing in an institution is given the chance to become an active citizen and to take control of their life, with support if needed and how much it is needed. A key component of this process is the provision of affordable and accessible housing within the community, along with access to public services, personal assistance, and peer support. Additionally, deinstitutionalization involves preventing future institutionalization. The main objective of deinstitutionalization is to provide equal opportunities to persons with disabilities to live in their families and to achieve their full potential, and most of all access to autonomy of persons with disabilities to self-determination and independent life.

North Macedonia, Italy and Greece are implementing national strategies for deinstitutionalisation, and through this Guide for Independent Living the key challenges, priorities and opportunities will be provided insight on regarding the financial funds available. Another important aspect of the deinstitutionalisation is the active participation of the people with disabilities and hearing their

The aim of this Guide is to 1) to determine the current situation in North Macedonia, Italy and Greece on the progress of the implementation of the Deinstitutionalisation, analyze the current funding options, explore further options for financial support for improving the social services in the community and 2) to provide knowledge and best practices for self-determination, self-advocacy and supported decision-making of people with intellectual disabilities.

For the creation of this Guide the following 5 methodological tools were used: desktop analysis of available resources and overview of the legal framework on national and international level, conduction of guided discussions on focus groups with people with disabilities, parents and caregivers, conduction of survey for people with disabilities, parents and caregivers; organizations and institutions and case studies of best practices.

The recommendations related to this are in line with the Common European Guidelines on Deinstitutionalization and the strategies on international level.

Key Findings

1) The existing public national funds provided by the public institutions in each of the countries: North Macedonia, Italy and Greece are not sufficient in order to achieve full deinstitutionalisation and to implement all of the social services such as: living in the community, assistance in the home and personal assistance. Key step on the path to independent living for people with disabilities is the process of deinstitutionalization. In each of the three countries, the deinstitutionalisation's progress is on a different level. However no country has still developed full deinstitutionalization, inclusion and integration of persons with disabilities, and social services tailored to the individual needs of the beneficiaries.

2) Personal Assistance is essential for achieving independence of persons with disabilities in order to provide supported living, self-advocacy and decision-making. North Macedonia, Italy and Greece have developed to some level this social service, still in neither of these countries personal assistance is fully developed and funded in order to be fully available to all persons that need assistance. A critical step to implement the social service Personal Assistance is the person-centered approach in the design and delivery of personal assistance itself, in all aspects of support: self-care, education, work, leisure, and decision-making. However, the current national funds are currently insufficient to fully integrate this service.

3) Current living arrangements and social services for persons with disabilities can be better organized without requiring additional funds. This can be achieved through:

- Improved activities within living units for beneficiaries that are unpaid
- Increased outdoor activities and implementing occupational therapy through the network of caregivers working in the living units
- Creating a supportive network of friends for the beneficiaries in order to have better socialization, communication and communion

4) More allocated finances mean better living arrangements and social services with higher quality that can provide better support for persons with disabilities, their families, and caregivers. If more funds are allocated from national institutions, EU funds, and private sector companies. This can lead to:

- Better living condition within the living units: better housing options, more caregivers employed, better daily activities that are unpaid and paid
- Ongoing education and training for caregivers to develop higher levels of knowledge, skills, and competencies.
- Implementing the social services personal assistance and creation of strong network with personal assistants sufficient to be assigned or employed by persons with disabilities
- Regional dispersion of daily centers that will be available to all beneficiaries and their families equally

1.Introduction

Aiming to foster better and more efficient development of the process of deinstitutionalization which creates a better and more enabling environment for autonomos living of persons with disabilities, stable financial streams and platforms for self-advocacy is key for achievement of independence.

In this context, our research delves into an analysis of national and international public funds, current organization of deinstitutionalisation which contributes to the independence of persons with disabilities and active participation in the processes of policy making and decision making for topics concerning persons with disabilities. The current models of organizing the independent living of persons with disabilities covers only basic living arrangements and support. The financial programs are accompanied by different layers of conditions and requirements that are excluding for persons with disabilities to live more independently.

What is visibly missing in the discourse, however, is an equal participation of persons with disabilities themselves that will make the current platforms more efficient with no additional funds on one hand, but also will provide recommendations for even better and more opportunities with usage of additional finances by different resources available for organizations and institutions.

Through this research we attempt to fill critical gaps in understanding the success of the progress to independent living.

2.Methodology

In order to detailly analyze the legal framework of the national and international legislation for deinstitutionalization, as well as the acts and documents that are regulating the funding options of the deinstitutionalisation mechanisms, services and tools, the following methodology with four main components was conducted:

1. Analysis of the legal framework, strategic documents and international policies regulating the scope of social services and funding models and overview of secondary available resources of self-advocacy
2. Conduction of focus groups with parents, people with disabilities, caregivers
3. Conduction of survey on the digital platform Google Forms for measuring the experiences, perceptions and views of the following three target groups: people with disabilities, family, friends and family caregivers; professionals working with people with disabilities, professional caregivers and staff and organizations providing social services for the target group.
4. Analysis of case studies with best practices for self-advocacy of people with disabilities from North Macedonia, Italy and Greece

2.1. Desk analysis of available resources

Overview of the national laws that are regulating the rights of the persons with disabilities was conducted and analysis of bylaws, regional laws, national strategies and action plans dedicated to the rights of the persons with disabilities, national strategies and action plans for deinstitutionalisation, laws regulating the social services for people with disabilities. Additionally, the international conventions signed and ratified by the governments of North Macedonia, Italy and Greece were analyzed. In parallel to the overview of the legal framework, analysis of secondary available resources regarding self-advocacy was conducted.

2.2. Conduction of Focus Groups

Three focus groups were conducted with the following target groups: people with disabilities, beneficiaries of social services, parents and legal guardians, family caregivers and professional caregivers, and representatives of organizations working with people with disabilities. The focus groups were conducted in North Macedonia, Italy and Greece.

2.3. Conduction of a survey on the platform Google Forms

A survey for determining the key problems, challenges and priorities was conducted for the following target groups: people with disabilities, parents and legal guardians, family caregivers, professional caregivers and organizations. The mapped problems, challenges and priorities were needed for rethinking the current funding models of the social services of the beneficiaries, providing better understanding of the financial funds on national and international level and further analysis of potential untapped funding options for developing better services tailored to the needs of persons with disabilities and their families. The survey was disseminated through the social media channels of the partnering organizations, mailing lists of the target groups and with direct contact with mapped participants relevant to the objectives of the survey,

2.4. Case Studies on Self-Advocacy

Case studies with best practices of self-advocacy of persons with disabilities were mapped from each of the partnering countries of the project North Macedonia, Italy and Greece. The Case studies aim to promote the positive changes, impact and results made in the local communities of the people involved in the actions undertaken, and to recommend enabling inclusive participation in the processes of policy making and decision making together with the persons with disabilities.

3. Desk Analysis of Available Resources

People most often do things completely on autopilot, either by habit or reflex, without giving much thought to or preparation for it either in advance or in the moment. They turn over in bed, get up, dress themselves, wash up, go to the bathroom, eat something, and set off towards their job or whatever else they have to do. More intimate tasks can be included here, such as shaving/hair removal, scratching, cutting nails, dying one's hair, etc. It is implied and assumed that they have done such things forever and will continue to do them. In their everyday lives, they generally do not even think about such things, do not second-guess them, and do not concern themselves with them. Things that go without saying for the majority, however, constitute a true challenge for the disabled. In order to live independently, such people must seek a workable solution.

The principles of independent living are:

- Taking responsibility for your life and actions,
- The right to life in a community,
- The right and responsibility to speak on your own behalf,
- Universal design,
- Access to PA and other services in the community, which facilitate inclusion in all aspects of life (education, employment, culture, sport, politics, free time, sexuality, parenting, etc.).

In the 1960s, disabled people began taking a stand against the idea that they were a special category of people to care for. Society was of the general belief that disabled people cannot care for themselves. The beginnings of the independent living movement took root in the battleground of the fight for the rights of other disadvantaged groups (women's rights, LGBT rights, student movements, the fight against racism and xenophobia, consumer movement, etc.), which encouraged disabled people to fight for the right to independent living.

The movement contributed significantly to making a new and different reality, one that meant a departure from categorizing the disabled as passive, helpless, and hopeless patients who need help. To affect their desired changes in nomenclature and treatment, disabled people.

first needed to develop the concepts that identified their identity and position as completely different. They realized that the legal and political systems would not take their demands seriously, and that their voice lacked clout. Bureaucracy was too slow to respond, and so they decided on more decisive, radical ways of demonstrating their ideas. The result was a direct and effective way of informing and educating the general public about the inequality in which they found themselves. Politicians could no longer ignore the problem when the public realized the discrimination and even violence that disabled people faced on a daily basis. Having exhausted all normal legal avenues, disabled people took a cue from civil rights' movements and tried their hand at other forms of social protest, such as demonstrations, boycotts, traffic blockades, and sit-ins.

UCLA Berkeley was one of the first colleges in the USA to accept disabled students. However, the university administration housed them in a hospital on campus, functionally cutting them off from their peers and thus student life. The students resisted this and forced the administration into providing equal opportunities for disabled students’ life and education. The students actively joined efforts to remove barriers on and around campus. They gained the skills and knowledge they needed for performing everyday activities. They learned how to hire and train assistants to provide the physical aid that they needed for everyday life. This group found that living in an institution stripped disabled people of their ability to make decisions about their own body and lifestyle, and along with it stripped their freedom, dignity, and self-respect. Their conclusion is that it is wrong to segregate or institutionalize the disabled, regardless of their lifestyle or disability.

In 1972, a group on campus moved into a collective and opened the first independent living center. They demanded individualized support – not as a luxury, but as a fundamental human right. Their battle was for “the impossible”: the right to housing, PA, and accessible public transportation, buildings, and peer counseling. Throughout the country they opened independent living centers.

This earned them the right to determine where and with whom they would like to live, and who would support them in their efforts. It was precisely the activism of these disabled students at Berkeley that stoked the flames of the civil rights movement, which later led to the adoption of the Americans with Disabilities Act, which prohibits discrimination against the disabled in a wide range of settings, including employment, transportation, public housing, communication, and access to municipal services and programs.

While the roots of the independent living movement indeed took hold in the USA, similar ideas and movements were brewing in Europe, especially in England. It was the many English activists who developed the theory known today as the “social model of disability”. In April 1989, ENIL (European Network for Independent Living) held an international conference in Strasbourg that focused on the services of personal assistance. They identified PA as the very core of independent living, making it possible for disabled people to choose where to live, to be mobile, active, and included in all facets of life (from education to employment, politics to family life, recreational options, and more), and to finally enjoy economic and social security, along with political clout. In this light the attendants decried segregation and institutionalization as a direct infringement on their human rights, calling upon the government to pass legislation protecting disabled people’s rights.

In the following sections, this Guide will analyze the legal framework in North Macedonia, Italy and Greece that is regulating the financial support and resources for social services, with a focus on services that help persons with disabilities gain independence.

Overview of legal framework regulating the funding models of independent living

3.1. North Macedonia

The independent living in North Macedonia is under the process of deinstitutionalization. The process started in the beginning of 2000 but the number of beneficiaries transferred from the institutions in the communities increased in 2017. The process is giving an opportunity to private stakeholders and the institutions also to provide the social service for living of people with disabilities in the communities. The private stakeholders are being licensed by the Commission for Licensing of the social services which works under the Ministry for Labor and Social Policies. The institutions are not going into any licensing process, they just established the group home units. The deinstitutionalization process in North Macedonia started in the year 2000. The process has many different aspects, but the independent living of people with disabilities is part of it. Until then, all of the people with disabilities which were lacking family care, or their families are no longer with them, were living in big institutions. The resettlement of the beneficiaries from the institution into living in communities is one of the main aspects of the DI process. For the people with disabilities who are living with their families, only the other services are available (daily centers and personal or educational assistants).

The legal framework regarding the process of deinstitutionalization and independent living of people with disabilities is the following: National Deinstitutionalisation Strategy of the Republic of Macedonia for 2018–2027 “Timjanik“ North Macedonia is bound and committed to realize deinstitutionalisation as it has signed and ratified the above stated UN Conventions and the European Convention on Human Rights.

North Macedonia is committed to the process of EU accession and thereby is taking active measures to accord with EU principle and practice.

In addition to this National Strategy on Deinstitutionalisation 2018–2027, North Macedonia has a number of other strategies of relevance and in support of the deinstitutionalisation including – the National Strategy for Equalisation of the Rights of Persons with Disabilities (Revised) 2010–2018, National Strategy on Equality and Non-discrimination 2016–2020, Strategy for Demographic Policies 2015–2024, National Employment Strategy 2016–2020, National Strategy for Old People 2010–2020, National Strategy for Reduction of Poverty and Social Exclusion in the Republic of Macedonia (revised 2010–2020), and the Employment and Social Reform Programme 2020.

Licensed social service providers for independent living of people with disabilities:

Poraka Negotino: 18 group homes, 9 in Skopje, 9 in Negotino with a total of 85 beneficiaries.
Association Humanost: 4 group homes with 20 beneficiaries.
Association for people with Cerebral Palsy: 2 group homes with 10 beneficiaries.
Center for Youth Activism - KRIK: at the moment is managing 3 units for assisted living (small group homes) with 24/7 support with 5 beneficiaries in each and a total of 15 beneficiaries, and is in the process of opening an additional 4th unit for assisted living with 24/7 support.
Daily centers for people with disabilities: private or public, established by the Ministry for Social Work, total number of 32 and 6 centers coordinated by the service provider Poraka. Total number of people using the service is approximately 450 beneficiaries.

3.1.1 Legal framework that regulates the funding resources of social services

The primary legislative framework regulating the available social services for persons with disabilities in North Macedonia is the National Law on Social Protection, 2019. This law outlines the requirements for licensed and authorized providers of social services, funding mechanisms, and emphasizes the equal participation of beneficiaries in the social service process.

The National Law on Social Protection, through Article 8 mandates the Ministry of Labor and Social Policy (MLSP) to establish a network of authorized social service providers. This network includes public social protection institutions and other authorized entities (such as associations and other domestic and foreign legal entities) that have administrative agreements with the MLSP, municipalities, the city of Skopje, and its constituent municipalities. Additionally, individuals with permits for social protection work and agreements with social work centers can also provide services. Entities outside this network can offer social services if they obtain the necessary permits.

Article 10 further elaborates the Ministry's responsibilities, which include: Establishing standards and norms for social services; Managing the social protection data system; Providing financial resources to municipalities, the city of Skopje, and its constituent municipalities; Concluding administrative contracts with authorized social service providers; Issuing licenses to legal and natural persons for social protection work.; Determining the prices of social protection services annually.

Through Article 17, the law further introduces the principle of participation, giving beneficiaries the right to participate in the assessment of their needs, be informed about available services, and choose their service providers. Children and persons deprived of legal capacity have specific participatory rights in accordance with their abilities.

The law provides definitions and regulations of the social services through services provided in the home, including help and care for individuals with temporarily or permanently reduced functional capacity, aiming to allow them to continue living at home and prevent the need for institutional care. Home services include help and care in the home and personal assistance. Further it describes community services, such as daily and temporary residence, resocialization, rehabilitation, reintegration, postponement of family care, and halfway houses, all aimed at enabling beneficiaries to remain in their homes and communities.

The law also covers day care services, which include activities for acquiring life and work skills, social, cultural, and recreational activities, education, and social support for users and their families. These services are available to at-risk children, people with disabilities, marginalized individuals, the elderly, and others with specific social problems. The law addresses non-family care services, providing basic protection (accommodation, expert support, care, nutrition, clothing, health care) for those who lack living conditions in their families or need extra-family protection. Non-family care services include supported living, care in another family, and institutional placement.

Article 87 defines supported living as assistance in separate housing units with professional or other help for daily activities. This service is intended for persons with disabilities and children without parental care, helping them prepare for independent living and social integration. Supported living units can accommodate up to five individuals or seven children without parental care.

The funding of social protection services is regulated in the Articles 308, 309, 310 and 311, and are further developed through funding methodology in the Rulebooks provided by the Ministry of Labour and Social Affairs.

Article 308 specifies that the prices of social protection services are determined by the minister based on a methodology for forming service prices, considering the established standards and norms. Article 309 outlines that funds from the national budget are allocated for social protection based on an annual program.

Article 310 states that these funds cover social protection rights, activities of social protection institutions, and maintenance, construction, and equipping of social protection facilities. Article 311 mandates that the work program of social protection institutions determine the type, scope, content, and quality of services provided. The public social protection institution must outline the necessary funds for these activities, which are then approved by the minister.

The following Rulebooks provided by the Ministry of Labour and Social Affairs further regulate the terms and conditions for financing the social services for persons with disabilities:

1. Regulations on the way and scope of social services, norms and standards for providing social services, assistance and home care
2. Regulations on the way and scope of social services, norms and standards for providing social services personal assistance
3. Regulations on the way, scope, norms and standards for providing social services of day-care, rehabilitation and resocialization and for space, funds, staff and the necessary documentation for a day-care center, rehab center and resocialization center
4. Rule on the way and scope of social services, norms and standards for providing social services supported living
5. Regulations on the detailed conditions for the allocation of funds, the scale form and the method of providing social services by the municipalities.

The number of licensed social service providers is continuously increasing. By March 2023, a total of 118 service providers are licensed. In the Budget of the Ministry of Labor and Social Policy for 2023, an additional 5.5 million euros more than in 2022, i.e. a total of 7.8 million euros, have been provided for the financing of social services. An amendment was made to the Decision on the price of social services for 2023, where the price for an individual hour and the price for daily treatment for a child by a professional worker in licensed day care centers was determined, i.e. 997 denars for individual treatment and 1,185 denars per day per user paid through the Centers for Social Work.

3.1.2. Implementation and Monitoring

The following institutions are responsible for implementation of the National Law on Social Protection, and monitoring of implementation of the activities and services regulated in the Law:

- Ministry of Labour and Social Policies
- Centers for Social Works
- Non-State Social Service Providers
- Institute for Social Affairs (Zavod za socijalni dejnosti)

Although this legal framework ensures that social protection services in North Macedonia are structured and adequately funded, still the social services are not tailored to the individual needs of beneficiaries.

3.2. Italy

On May the 13th, 1978 Law n. 180 on the subject of "Voluntary and mandatory health checks and treatments", (more commonly known as Basaglia law), was made. This law imposed the closure of mental hospitals and established public mental health services. Many young doctors had begun their training under the enthusiastic drive of a reform that was not only a health intervention, but above all a revolutionary way of thinking and thinking about one another. The training of the operators was imposed as an instrument to care for the patient and his suffering and in parallel, alongside the individual intervention and pharmacological support, attention was drawn to the context in which the patient was born, formed and lived. While in some places institutions were replaced with other alternative forms of institution (a process given different labels such as deinstitutionalism and anti-institutionalism), Trieste was one of the places where law n. 180 was put into practice. The slogans that popped up all over the hospital were those of the movement: ‘la libertà e terapeutica’ (‘freedom is therapeutic’) or ‘la verità è rivoluzionaria’ (‘the truth is revolutionary’).

Community housing was also set up, at first inside the hospital complex itself, as wards were unlocked and closed down. The Trieste experience mobilized thousands of people. Links were forged with the city and strengthened with student activists all over Italy, and internationally. Volunteers began to arrive hoping to work at the site, some from local schools and universities, others from abroad, as well as psychiatrists and medical experts influenced by Basaglian thinking.

The law "Dopo di Noi" (means “After Us) n.112 / 2016 has entered into force in June 2016 and it has its focal point on the protection and the inclusion of people with severe disabilities. The use of the word “deinstitutionalization” is frequent, which, for some experts in the sector, has a similar appeal to that of law 180/1978, with the psychiatric reform.

The term refers to the desire to favor the subjectivity of every person, including those with severe and very serious disabilities, avoiding their isolation and confinement. As mentioned before, the Basaglia Law (180/1978) allowed the closure of institutions with the aim of restoring dignity to psychiatric people who until then were considered irrecoverable.

In Italy there is a national framework law that provides guidelines, but the management of services of co-housing and group apartments are managed by the Region, which can in turn supplement the available National funds. In addition to this, thanks to the Trust Institute, apartment groups and Cohousing can also be activated privately, so it is not possible to define how many projects are activated at the Italian level by 2022.

However, the law establishes common rules for realization of apartment groups: they must have the characteristics of a home, they can accommodate a maximum of 5 people plus a bed to be used in emergency situations. They must be set up with assistive technology and home automation and should preferably be placed in residential areas.

Residential services dedicated to people with disabilities are activated and managed in Italy by the local social services together with the Health System. The Law on After Us has provided new possibilities that put families as a central point in order to start small apartment groups.

One of the modalities implemented is the institution of the “Trust”, which is an act that allows the settlor to express their wishes, clearly defining the purpose of the trust, the tasks and powers of the trustee, and beneficiaries. This means that a private service provider can also activate services by communicating directly with the families privately. There is no ministerial accreditation to manage independent living projects, but private provider could offer small group apartments projects and families could apply to public funds in order to support the costs of the project dedicated to their children.

3.2.1 Legal framework that regulates the funding resources of social services

Law 104/1992 (Framework Law for the Assistance, Social Integration, and Rights of Handicapped Persons): regulates the rights and services available to persons with disabilities, including measures for social integration and support for independent living.

Law 162/1998 (Support Measures for Personal Autonomy and Independent Living): promotes personalized projects to support the autonomy and independent living of persons with disabilities, as well as personal and individualized assistance and care plans.

Law 112/2016 (After Us - Dopo di Noi): addresses the needs of persons with severe disabilities who are without family support, provides measures for the care, support, and independent living of such individuals, including the establishment of a specific fund (Fondo Dopo di Noi).

National Fund for Non-Self-Sufficient Persons (Fondo Nazionale per le Non Autosufficienze): provides support non-self-sufficient persons, including those with severe disabilities, by financing social and health services.

Regional Funds and Services: Many regions have their own funds and services aimed at supporting independent living, often supplementing national initiatives.

Social Vouchers (Buoni Servizio): Vouchers provided to families to purchase specific social services.

Direct Payments (Contributi diretti): Financial assistance provided directly to persons with disabilities or their families to enable them to purchase services that support independent living.

Community-Based Services: Funding is also directed toward community-based services that allow individuals with disabilities to live independently within their communities. This includes home care services, personal assistance, and day centers.

3.2.2 Implementation and Monitoring

The following institutions are responsible for implementation and monitoring of services and activities of the laws and programs:

- Ministry of Health (Ministero della Salute)
- Ministry of Labour and Social Policies (Ministero del Lavoro e delle Politiche Sociali)
- National Institute for Social Security (INPS - Istituto Nazionale della Previdenza Sociale)

3.3. Greece

The Strategy for Deinstitutionalization is implemented by the Greek Ministry of Health and it is based on the principles of participation, inclusion, of non-discrimination, equality, choice, of life control and the right to receive personalized service support.

The goal is twofold and includes both the gradual closure of institutions and promotion of living in the community as well as prevention from institutional type care. The satisfaction of these purposes takes place within integrated actions to a very wide range of development services and programs to strengthen the family cohesion, education/training, support in living and employment, early intervention, strengthening of adoption and foster care, etc. thus strengthening the social integration of the beneficiaries.

Small steps have been done so far and an example is the pilot program "Personal Assistant for people with disabilities" is part of the wider framework of a system of social support for Persons with Disabilities, with the aim of improving the quality of life of them and their families, through the achievement of their independent living and their equal participation in all aspects of social, economic, political, cultural of life. The "Personal Assistant" was established by the law 4837/2021.

The legal framework and policies for the independent living of Persons with Disabilities (PWDs) in Greece are overall regulated by various legislative acts and policies aimed at protecting the rights of PWDs and enhancing their independent living. Some of the most important legislation and policies include:

- The Constitution recognizes the equal value and protection of the rights of all citizens, including the disabled.
- Law 3843/2010 - "Social Protection and Support of Persons with Disabilities": This law defines the rights and benefits for the disabled and provides measures to strengthen their independent living. It includes issues such as access to education, employment, and social participation.
- The Action Plan for the Rights of Persons with Disabilities (2012-2021):was prepared in accordance with the requirements of the "United Nations Convention on the Rights of Persons with Disabilities" and includes measures to promote the independent living of persons with disabilities.
- National Strategy for the Disabled (2016-2021) includes measures to promote the social integration, employment, and autonomy of the disabled.
- European Union Programs: Programs and initiatives of the European Union often support programs for the independent living of the disabled in Greece.

In Greece, the provision of social services for the independent living of Persons with Disabilities (PWDs) falls mainly under the responsibility of the Ministry of Labor and Social Affairs. Specifically, the General Secretariat of Social Solidarity of this ministry is responsible for coordinating and implementing policies related to social protection and support for vulnerable groups, including Persons with Disabilities. In addition, services and programs that support the independent living of PWDs can also be provided by municipalities, which have the ability to undertake local initiatives and programs in this direction.

3.3.1 Legal framework that regulates the funding resources of social services

National Action Plan for the Rights of Persons with Disabilities: includes measures to support deinstitutionalization, develop community-based services, and strenghten accessibility in various aspects of life.

Operational Program "Human Resources Development, Education and Lifelong Learning": this program is funded by the European Social Fund (ESF), and supports the social inclusion of people with disabilities by promoting access to education, vocational training, and employment. It also includes actions to support independent living and community-based services.

National Strategic Framework for Social Inclusion: focused on combating poverty and social exclusion, with a focus on vulnerable groups, including people with disabilities, by developing integrated social care services and support for community-based living.

Law 4488/2017 (Measures for the Implementation of the UN CRPD): aligns Greek legislation with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). It emphasizes the rights of people with disabilities to live independently and participate fully in society, supporting the development of community-based services and deinstitutionalization initiatives.

National Fund for Social Solidarity (Εθνικό Ταμείο Κοινωνικής Αλληλεγγύης - ΕΤΚΑ): provides financial support for social care services, including people with disabilities, and supports development of programs on independent living and community integration.

Program for Deinstitutionalization and Development of Community Services: Implemented with the support of the European Union, focuses on transitioning persons with disabilities from institutional care to community-based living arrangements, and includes development of supported living residences, personal assistance services, and other community-based support.

Law 4074/2012 (Ratification of the UN CRPD) ratifies the UN CRPD, committing Greece to uphold the rights of people with disabilities, including the right to live independently and be included in the community.

Law 2646/1998 (Development of the National System of Social Care) establishes a framework for social care services in Greece, and includes integrated social care services that support the deinstitutionalization and independent living of people with disabilities.

Law 4067/2012 (New Building Regulations) ensures accessibility in the infrastructural field, supporting the independence and inclusion of people with disabilities in the community through building regulations.

3.3.2 Implementation and Monitoring

The following institutions are responsible for implementation and monitoring of the national laws, bylaws, strategies and programs:

- Ministry of Labour and Social Affairs
- National Confederation of Disabled People (ESAmeA)
- Independent Authority for Quality of Social Care Services

3.4. A Comparison of available funding resources of social services that contribute to independent living of persons with disabilities in Italy, Greece (EU Member States), and North Macedonia (EU Member Candidate)

The financing of social services for the independence of persons with disabilities and deinstitutionalization varies significantly between EU countries like Italy and Greece, and a non-EU country like North Macedonia. There are different approaches and funding mechanisms used by these countries that are available for implementation of services and policies that are contributing to gaining independence of persons with disabilities and implementation of the process of deinstitutionalization.

3.4.1. Italy

Italy benefits from European Social Fund Plus (ESF+ which supports initiatives aimed at improving employment opportunities, educational access, social inclusion, and poverty reduction. This fund is instrumental in financing projects that promote independent living and deinstitutionalization for persons with disabilities. European Regional Development Fund (ERDF) provides financial support for infrastructure projects, including those that enhance accessibility and develop community-based services, facilitating the transition from institutional to independent living.

Italy’s National Health Service (Servizio Sanitario Nazionale) plays a critical role in delivering healthcare and social services to persons with disabilities. The service includes comprehensive care and support to promote independent living. Italy’s regional administrations have significant autonomy in managing social services funding. They are responsible for implementing local initiatives tailored to the specific needs of their communities, often with substantial regional budgets. Organizations such as ANFFAS (National Association of Families of People with Intellectual and/or Relational Disabilities) receive funding from public sources and private donations.

Programs like "Io Cittadino" and "Liberi di scegliere" are examples of initiatives that empower individuals with disabilities to live independently and participate actively in society. Corporate social responsibility (CSR) initiatives by private companies contribute additional funding for disability services. These contributions can support innovative projects and provide resources for NGOs working in the disability sector.

3.4.2. Greece

Similar to Italy, Greece utilizes ESF+ and ERDF to support projects that promote social inclusion and independent living for persons with disabilities. These funds are crucial for financing initiatives aimed at deinstitutionalization and community integration. Greece’s National Health System (Εθνικό Σύστημα Υγείας) provides essential healthcare and social services, including services tailored to persons with disabilities. This system ensures access to necessary medical care and support services. Local governments in Greece play a huge role in delivering and funding social services. Municipalities implement national policies at the local level and often receive additional support from regional and national budgets. NGOs in Greece are active in providing services and advocating for the rights of persons with disabilities. These organizations often operate through a combination of public grants and private donations, supporting initiatives that promote independent living and social inclusion. Similar to Italy, the private sector in Greece also contributes through CSR initiatives. These contributions can enhance the resources available for disability services and support innovative programs.

3.4.3. North Macedonia (Non-EU Country)

United Nations Agencies: UN agencies such as UNDP and UNICEF provide critical funding and technical support for projects in North Macedonia that focus on disability inclusion. These projects often aim to improve infrastructure, accessibility, and social services. World Bank and Regional Development Banks offer loans and grants for infrastructure development and social services improvements, including initiatives that support persons with disabilities.

North Macedonia receives significant bilateral aid from EU member states and other developed countries. This aid is often targeted at enhancing social services and promoting deinstitutionalization, helping to bridge the gap in national funding. The financial support is received mostly through the Embassies of the countries that are providing aid. The national government allocates resources for social services, though the budget is often limited compared to EU countries. This funding is used to support basic services and initiatives aimed at promoting independent living. NGOs and international foundations and development organizations play a crucial role in North Macedonia. They provide essential services and advocate for the rights of persons with disabilities, relying heavily on international funding and granting. Collaborations between the government, private sector, and NGOs are essential: licensed non-state providers (mostly organizations working with persons with disabilities) are implementing the social services having the best professional knowledge, competencies and expertise.

3.4.4. Key Differences in the funding resources in Italy and Greece, compared to North Macedonia

Italy and Greece: Benefit from substantial EU funding through ESIF, complemented by national budgets, established NGOs, and private sector contributions. North Macedonia relies more on international aid, development programs, and bilateral aid due to limited national budgets and less access to EU funds. In Italy the Regional governments have significant autonomy and resources to implement local initiatives tailored to community needs, while in Greece the Local municipalities play a key role, but the central government maintains more control over social services funding. In comparison, in North Macedonia there is a centralized governance with limited regional autonomy and resources compared to EU countries, relying heavily on international support.

As for institutional capacity and infrastructure, Italy and Greece generally have better-developed infrastructure and institutional capacity for delivering comprehensive social services, while North Macedonia is still in the process of developing infrastructure and capacity, often with support from international organizations to improve services and accessibility.

Italy and Greece leverage substantial EU funds and have more developed infrastructures and institutional capacities, North Macedonia relies heavily on international aid and development programs.

Despite these differences, all three countries are committed to improving services for the independence of persons with disabilities and promoting deinstitutionalization, working within their respective frameworks and resources to achieve these goals.

3.5 Self-Advocacy, supported decision-making and personal assistance

3.5.1. Self Advocacy

While important for everyone, it is especially important for people with intellectual and developmental disabilities. When people do not advocate for themselves, they may be pushed to do things that don't feel right to them or become depressed. They may also lack self-confidence and feel as though their life is out of their control. Learning to advocate for yourself may seem daunting, but you don't have to do it alone. There are many resources available to help people become confident in their self-advocacy skills and express themselves authentically.

The term "self-advocacy" and its philosophy was born in Sweden in the 1960s, when young adults with disabilities began speaking out and taking control of their own lives by forming their own leisure clubs. National conferences for these club members were held in 1968 and 1970, wherein participants developed statements about how they wanted to be treated.

For thousands of people with disabilities around the world, self-advocacy is a term of personal identity that comes with a multitude of benefits. It focuses on their political power and right to self-determination. Further, people who self-advocate ultimately enjoy a higher quality of life, as they have confidence in themselves, know how to properly express their feelings, and are empowered to make their own decisions.

Because no two people are exactly alike, each individual will have a different set of needs, abilities, and goals. Often, the type of disability or disabilities that a person has plays a role. For example, someone with physical disabilities caused by cerebral palsy might speak at a city council meeting and advocate for curb cuts or wheelchair ramps in parks and shopping malls.

On the other hand, a student who is living with a learning disability might write a letter to the school principal about improving inclusivity during extracurricular activities. Let’s not forget those individual choices that brighten our day, such as listening to music that we like or choosing what we want for dinner! It should be emphasized that it’s not necessary to become completely independent without any type of support in order to be successful. Rather, the self-advocacy journey involves exploration and problem-solving regarding the types of support that would allow that person to achieve their life goals. Supports can be in the form of various types of human services professionals, or assistive technology devices.

Here are just a few examples:

- Alternative format textbooks, training manuals, articles (e.g., Braille, screen readers)
- Direct Support Professionals (DSPs) that assist with medication management and other aspects of self-care
- Transportation vehicles equipped with lifts
- Adaptive self-feeding tools

Policy advocacy occurs when advocates and self-advocates band together to push for changes and improvements in laws, regulations, or policies. During such processes, they negotiate with and lobby politicians and regulators to influence the political decision-making process.

3.5.2. Supported decision-making

Everyone has the right to make decisions about their own life, but sometimes we need help and support to make decisions. What clothes should I wear? Where do I want to live? Where do I want to work? How can I get Apple TV? What does this letter mean? When we get help to understand or make up our mind, we receive what is called decision support. Making decisions with such support is called supported decision-making.

Disabled people who want organized support to make decisions about their life should have this choice. But Norway has no system for such support today. Instead, many people have guardians. The guardians are supposed to talk to the people they are guardians for about what they want, but not all guardians do that, and it is the guardian who has the power to make decisions. That is not how it should be. It is a violation of the human rights of disabled people.

Being in control of your own life is a human right. The UN Convention on the Rights of Persons with Disabilities (CRPD) acknowledges that some of us may need a formalized form of decision support in order to achieve self-determination. In Norway, however, we have no legislation, system or models for supported decision-making. The UN, Equality and Anti-Discrimination Ombud (LDO) and human rights organizations such as Uloba are calling for Norway to introduce legislation and a system for supported decision-making, but so far, disabled people have had to do without.

Personal Assistance helps disabled people to the same starting point as others in their ability to pursue and fulfill all the roles in their lives. In short, disabilities can no longer serve as an excuse for being inactive or feigning inability.

3.5.3. Personal Assistance

Personal assistants help individuals with disabilities perform daily activities that might otherwise be challenging or impossible. This includes tasks such as bathing, dressing, eating, and mobility. By providing this support, personal assistants enable people with disabilities to live more comfortably and with dignity. Personal assistance allows individuals with disabilities to make their own choices about their lives.

This support empowers them to live according to their preferences and values, rather than being restricted by their physical or cognitive limitations. With the help of personal assistants, individuals with disabilities can participate in social, educational, and recreational activities. This inclusion is crucial for mental health and overall well-being, as it fosters a sense of belonging and community. Personal assistants can provide the necessary support for individuals with disabilities to pursue education and employment opportunities.

This assistance can include transportation, note-taking, or job-specific support, which can lead to greater economic independence and professional fulfillment.

Additionally, personal assistance can help individuals with disabilities live independently in their own homes, rather than in institutional settings. This independence is vital for personal freedom and can lead to a higher quality of life. Family members often take on the role of caregivers for individuals with disabilities.

Personal assistants can relieve this burden, allowing family members to focus on their own lives and reducing stress and burnout Personal assistants can monitor the health and safety of beneficiaries, to make sure they take medications, attend medical appointments, and follow health regimens.

Providing personal assistance aligns with the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which emphasizes the right to live independently and be included in the community. Personal assistance is a practical implementation of these rights, promoting equality and non-discrimination.

3.5.4. A comparison of the funding of the social service Personal Assistance in Italy and Greece to North Macedonia

In Italy, despite the presence of a national law stating the right of independent living and personal assistance for people with disabilities, allocation of funding and direct payments are still very insufficient in Italy. At a national level, people with severe disabilities receive a monthly allowance. The amount received does not depend on the severity of the impairment, income or the fact of having a job and it is highly insufficient to cover costs for people requiring many hours of personal assistance.

Extra support for independent living is almost entirely dependent on decisions made by regional governments and municipalities, which make decisions depending on available funds and family income, rather than acting as if independent living was a legal right.

There are extensive differences in how direct payments are allocated across big and small municipalities, as well as across Northern and Southern regions, with the Independent Living philosophy not being completely spread over the whole country yet. Allocation of funding for independent living can also dramatically change from year to year, thus making it very difficult to plan a live outside the original family or outside group-homes, also known as “family-homes”.

Given the current situation, self-determination of people with disabilities is still very far from having being achieved, with the majority of people with disabilities having to rely on family members, caregivers, and social and health care services aligned with the medical model of disability. According to Italian legislation dated February 11, 1980, No. 18, individuals with severe disabilities may be eligible for an "indennità di accompagnamento" (accompaniment allowance). This allowance is approximately $475 U.S. per month, which recipients can use to directly pay personal assistants of their choice, allowing for 50-60 hours of personal assistance each month. The primary law governing disability rights in Italy is the legislation from February 5, 1992, No. 104. Key provisions include:

Paragraph 5.1.e): Ensures that beneficiaries can choose from various assistance options and allows local authorities to provide personal assistance.

Article 9.2.l-ter): (added by the law on May 21, 1998): States that regional authorities can issue regulations to enable local authorities to make direct payments for independent living. These payments are partially funded by the national government, but individuals can only receive these funds if regional authorities have established the necessary regulations.

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Paragraph 5.1: Ensures that beneficiaries can choose from various assistance options and allows local authorities to provide personal assistance.

Article 9.2.l: (added by the law on May 21, 1998): States that regional authorities can issue regulations to enable local authorities to make direct payments for independent living. These payments are partially funded by the national government, but individuals can only receive these funds if regional authorities have established the necessary regulations.

Currently, the only regional authority that has issued such rules is "Regione Toscana" (regional law of October 3, 1997, No. 72). In this region, individuals with severe disabilities who request direct payments receive about $300-500 U.S. per month, equivalent to 35-65 hours of personal assistance. Funds from laws No. 18 and No. 104 can be combined. The allowance under law No. 18 is guaranteed as a legal right by a national board, ensuring consistent funding. However, funds from laws No. 104 and No. 162 are provided by local authorities and are not guaranteed, meaning they could be discontinued if funding runs out. Combining these sources of support, individuals with severe disabilities can receive 3-4 hours of personal assistance per day through direct payments.

In Greece, the Law 4837/2021 of the National Action Plan for the Rights of Persons with Disabilities, gives the possibility of providing a personal assistant of their choice to persons with disabilities. An important support service for those who need it, which contributes to preventing their institutionalization, improving the quality of life for themselves and their families, and their equal participation in all aspects of social life.

The implementation of the two-year pilot program will be also covered by credits from the Recovery and Resilience Fund. Each recipient selected after the assessment is supported by a personal assistant of their choice, who will be the competent and necessary means to enhance their independent living according to their needs and interests and will support them in activities such as: Activities of daily living such as feeding, clothing, personal hygiene, work and studies, participation in leisure activities and activities of participation in social life.

Prospective personal assistants, after successfully attending 50 hours of disability training, are registered in a special register, to which beneficiaries selected to receive the benefit will also have access. In Greece, personal assistance services for individuals with disabilities are funded primarily by the national government through the Ministry of Labor and Social Affairs. Funding is also provided through the National Health Insurance system (EOPYY) and various social welfare programs. Important part of the funding of this social service in Greece are the benefits from EU funding, the abovementioned European Social Fund (ESF). Additionally EU-funded projects often aim to improve the quality and accessibility of personal assistance services.

Compared to Italy and Greece, in North Macedonia, the funding for personal assistance services is less developed compared to Italy and Greece, as well as the overall availability and development of the service. The national government provides some funding through the Ministry of Labor and Social Policy to licensed social service providers, which is regulated in the Rulebook. However, the service personal assistance is not as widely available, and the system is still evolving. What is really important is that the social service personal assistance is not available for persons with intellectual disabilities, and the categories who should be eligible for this social service are very limited and excluded.

In the Law on Social Protection it is stated that the service personal assistance [...] beneficiaries of the service are persons with severe physical disabilities and completely visually impaired persons. Beneficiaries of the service have a combined disability, if it is based on one of the disabilities from paragraph 4 of this article. [...]

According to the Law on Social Protection, persons with intellectual disability can be beneficiaries of the service Personal Assistance only if they have a combined disability with severe physical disabilities or at the same time are completely visually impaired.

This is very limiting, since the main objective of the deinstitutionalisation is not for persons with disabilities to live in the community in smaller living units, but to live in their families and to be as much independent as possible. This can be possible with personal assistance available to all persons with disability that need assistance as much or as little as they need, in order to live autonomously.

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4. Analysis of the Survey conducted on the platform Google Forms

The personal experiences, challenges and problems faced by the persons with disabilities, their families and legal guardians, family caregivers, friends, and professional caregivers are of key importance for creating targeted policies and actions provided by the social service providers, the public institutions and the organizations.

Through answering the Survey, the respondents provided insights on their perceptions, experiences and challenges on strengthening and improving the independence of persons with disabilities. Majority of the answers are provided by parents/caregivers of people with disabilities, and organizations working with people with disabilities.

Additionally, the experiences of the caregivers, organizations working on independent living of people with disabilities and at the same time managing units for assisted living in the community, as well as organizations working with people with disabilities gave valuable input on how can the current funds be better organized and what can be improved with no additional funds, as well as what can be included as much as possible, without any fund limitations or restrictions.

4.1. Main aspects of the conducted Survey

The majority of responses come from parents and caregivers of people with disabilities. Their perspectives are crucial as they directly engage in the daily lives and care of persons with disabilities. A significant portion of responses also comes from organizations dedicated to working with people with disabilities. These organizations often have a broader perspective on systemic issues and community-level challenges.

The survey collects detailed personal opinions and perceptions from respondents, highlighting day-to-day experiences, successes, and setbacks on the path to gaining independency. Specific challenges faced by persons with disabilities and their support networks are identified. These include issues related to accessibility, healthcare, education, employment, and social inclusion.

A core focus of the survey is on the barriers to achieving greater independence for persons with disabilities. These barriers might be physical, attitudinal, or policy-related. The effectiveness and availability of support systems, both formal (public services, professional caregivers) and informal (family, friends), are evaluated. Insights from the survey aim to guide the development of policies that directly address the needs and challenges identified by respondents. Recommendations are provided for social service providers to enhance their support mechanisms.

Suggestions for public institutions and organizations on how to better support persons with disabilities and their families with the current and additional funds were provided.

The survey gathers opinions on how existing funds can be optimized to better serve the needs of persons with disabilities without requiring additional financial resources. Practical suggestions are provided on what improvements can be made with the current budget. This could involve reallocating resources, streamlining processes, or enhancing efficiencies. Respondents also share their visions for ideal support systems and services if funding were not a constraint. This helps in understanding the aspirational goals and potential areas of significant impact.

The survey aims to contribute to the creation of more effective support systems for persons with disabilities, creating platforms for inclusion in the process of policy-creating and decision-making in gaining independence and better quality of life.

4.2. Findings of the conducted Survey

4.2.1. Organization and Funding of social services that are strengthening the independence of persons with disabilities

On **Table 1** it is represented by the composition of the Survey sample. Most of the respondents are experts/educators working with people with disabilities 30%, followed by the other categories: 25% are parents/caregivers of person with disabilities, 20% are representatives from organizations working on independent living of people with disabilities, 15% are licensed service provider for assisted living of persons with disabilities and 10% are representatives of organizations working with people with disabilities.

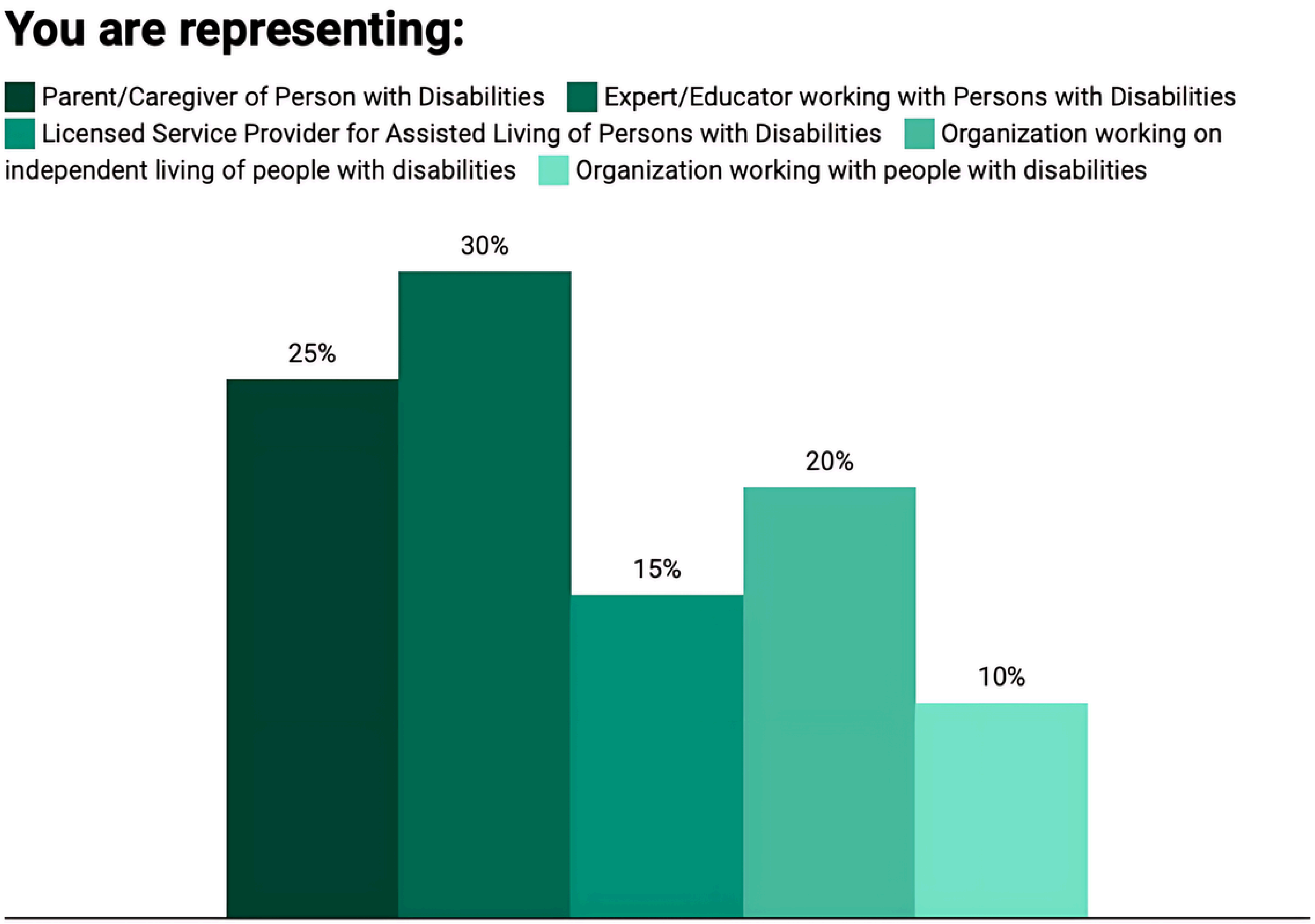

Chart 1: Question 1 of the Survey

The majority of the questions of the Survey were unstructured i.e. open ended with possibility for flexible answers.

Table 1 consists of answers on the question: What are the biggest challenges faced by the respondents and people with disabilities in the process of independent living? The respondents highlighted insufficient societal support and understanding, particularly for those over 26 years old. There is a significant lack of support centers, financial resources, and opportunities for independent living. The respondents also reported economic instability, limited job opportunities, and inadequate assistance from families and institutions. Additionally, the acceptance of disabilities by society and connection to healthcare systems remain problematic. Challenges also include bureaucratic obstacles, legislative issues, and the need for better-trained caregivers and tailored social services.

Based on the experience of the respondents the following challenges were stated that PWD and their caregivers are facing on the path to independent living	
1	"Insufficient support and understanding from society, especially for people over 26 years old, insufficient number of people who would offer support, supporting centers and activities for people with special needs, insufficient financial resources for independent living of people with special needs, etc."
2	"Leaving them alone so they can cook or get their meal. Have friends over while I am at work. She is all alone all day. She can't read or write. She can not function by herself alone."
3	"Uncertainty, economic unsustainability of the person with a disability, the lack of support and understanding from the environment"
4	"We do not receive enough assistance as a family. We need personal assistant who will be part of the daily life and responsibilities in order the beneficiary to live independently, but also for the family to live independently."
5	"Many, firstly same as every young person has in the Balkans, lack of funds, lack of job opportunities. If we over pass this, then is the lack of assistance provided, lack of support from the families to even start thinking about it, because of the many fears and challenges there are."
6	"The key challenges are the skills for self care, the skills for education, learning and working, the financial skills - how to use money, how to use cards and atms, how to decide what to buy.".”
7	"First is acceptance by other people in society and the second is the connection to the health system."

8	"Process of adaptation, socialization and implementation of occupational therapy. The essential problem is that after the adaptation process, the users are not concentrated enough or they are focused for a short period of time on occupational therapy, which is essential in the whole process."
9	"Lack of daily centers, Lack of provision of the social service personal assistance tailored to the specific needs of the beneficiary, Lack of contemporary education for licensed social workers Lack of higher education - faculty for graduated Occupational Therapists, therefore no job positions in the public institutions for occupational therapists, Lack of financial resources for better services provided by the licenced organizations (more employees, more caregivers, better living conditions overall, finances for more activities outside the small group homes)"
10	"For me a big challenge is to help their parents accept that their sons and daughters have adult needs. I think for people with disabilities it's important to work on their self esteem and self - efficacy, especially because they don't perceive themselves as able to experience independent living and mostly fell anxious of what it can happen. One thing that I think it's important to work on is the fact they always put their own needs in front of everything, while, when you shared a house with someone else, you have to start talking about compromises and mediation."
11	"Try to make people with disabilities understand the meaning of autonomy and independence as also the ability to take their own decisions which shouldn't be entirely a responsibility of the parents. They normally see autonomy as something that, in some way, will force them to take more responsibilities, more duties and in general more things to do, which they're not always committed to do."

12	"Bureaucratic and legislative complications and the prejudice of some customers."
13	"Institutions don't recognize personal needs but they just offer pre-packaged programs and projects."
14	"The resistance of families for the most varied reasons, lack of accessible information for people with disabilities, lack of social service resources"
15	"Innovation of the therapeutic models, and no access to modern assistive technology in the schools and the living units"
16	"Daily individual improvement in key independent living issues"
17	"Challenges related to creation of new policies, programs and action plans for development of new and improved social services according to the latest methods"
18	"Lack of financial resources to finance the operation of the Housing, Lack of properly trained staff (caregivers), Access to the labor market"
19	"The quality of life and living conditions for persons with disabilities. Not enough services that are covering all the different categories of disabilities."
20	"The consequences that are permanent from the disability itself"

Table 1: Mapped challenges people with disabilities and their parents/caregivers are facing on the path to independent living

Table 2 consists of answers provided by the respondents related to the basic skills needed by the persons with disabilities in order to live more independently, to function more autonomously and to try to reach the full potential and capacity. The survey responses indicate several key areas where persons with disabilities require support to develop essential skills. These include:

- Acquiring working habits, socialization, obedience, and communication.
- Practical skills like cooking, ironing, folding, washing up, using a computer, reading, writing, and using public transport.
- Shopping independently.
- Building independence, self-confidence, and feeling accepted by their environment.
- Enhancing memory and working towards economic sustainability.

The respondents noted that every individual has unique skill requirements, often dependent on the type of disability. Common areas of focus are self-care, cooking, household management, hygiene, health, medication management, employment, education, and meal preparation. The importance of support in daily activities, personal hygiene, living space arrangement, budget management, and occupational therapy was also emphasized. Skills such as employability, self-determination, self-advocacy, and financial literacy are critical. Improving problem-solving abilities, group interaction, and self-awareness are vital.

Training for independent work, understanding necessary steps, and recognizing one's own skills and responsibilities are also key areas of development. Socialization and autonomy in eating, using the toilet, dressing, and footwear are important for those recovering from institutionalization.

Beneficiaries of supportive services see improvements in independent living skills, community relations, family relationships, quality of life, socialization, autonomy, extroversion, and self-confidence. Participation in activities helps individuals acquire life control, independence, self-service, power, and confidence, fostering a sense of self-care and independence from family.

Based on the experience of the respondents the following skills were stated that PWD and their caregivers are facing on the path to independent living	
1	“The following skills are needed: acquiring working habits, socialization, collaboration, and communication.”
2	“People with disabilities need to learn as much as possible basic life skills: cooking, ironing, folding, washing up, working on a computer, writing,reading, using public transport, shopping independently.”
3	“Independence, self-confidence, feeling accepted by the environment, developing and encouraging memory, working for economic sustainability”
4	“Every person Is different regarding the skills, they acquire different levels of independence. Some of the people learn better and faster, others need more attention, reminding and assistance. However, they need to learn how to eat, dress-up, cook, wash and take a bath, shop basic products and to learn space orientation in their neighborhood and local environment.”
5	“Self care, cooking skills, taking care of the household as much as possible, learn how to make friends, learning how to use digital devices such as phones (how to make phone calls, how to text), learn how to read and write as much as possible.”
6	“Hygiene, health, taking pills, employment, education, preparing meals.”

7	“In my opinion the skills mostly depend on the type of disability. Most important skills are: hygiene skills, social skills, and emotion skills. Communication, cooperation, literacy and if possible gaining professional skills suitable for employment.”
8	“Support in daily activities, maintenance of personal hygiene, arrangement of the space in which they live, the possibility of budget management and shopping, focus on occupational therapy and cooperation with the professional team.”
9	“Better personal life skills, employability skills, self-determination skills, skills for self advocacy, skills for financial literacy.”
10	“We're trying to improve the skill of problem solving. Also the important skills to stay, work and interact in a group. Lately, we are working on the awareness of their own potentials and limits.”
11	“The ability to organize work independently, verifying the necessary steps.”
12	“Work training, a path of awareness and security of one's skills and responsibilities.”
13	“Relating to others by knowing how to listen, respect the rules, maintain appropriate behavior.”
14	“Paths of awareness of one's own abilities and limits, acquisition of knowledge on territorial possibilities.”
15	“Socialization is most important, they need to learn not to be afraid of new people, new teachers, new friends, new coworkers.”

16	“Autonomy in eating, waking up, dressing up. Autonomy in preparing a simple meal, washing the dishes, taking care of themselves.”
17	“Most of the social skills are lost through the years of institutionalization. This is important because most of the people with disabilities that lived in big, closed institutions are already adults and they did not use all of those years in gaining independence and autonomy. So, the social skills are most important in order to signal how they feel, what they need - to communicate with the caregivers about their needs. Vocational skills are also very important in order to find employment and to have financial income which will prevent poverty.”
18	“The benefits that the beneficiaries get from the services, concern the skills of independent living, the improvement of skills in relation to the community, the improvement in going out of the house, the improvement of relations with the family, the quality of life of the beneficiaries and their family and the contribution to their deinstitutionalization. They also show improvement in their socialization and interpersonal interaction skills, autonomy, extraversion and self-confidence.”
19	“These individuals can acquire skills related to their life control, their independence and self service, to gain power and confidence in themselves and the only way is to participate in occupational therapy activities.”
20	“Self-care skills, support from the family and caregivers, exposing them to new experiences, some of them may feel uncomfortable and new at first, but through cheering them and motivating them to continue they will feel more empowered.”

Table 2: Mapped skills for independent living that the people with disabilities are lacking

Parents, legal guardians, caregivers and organizations are providing different services for helping persons with disabilities gain the needed skills for living independently and more autonomously navigating in the environment. **Table 3** is providing insights into how the respondents from diverse backgrounds and care settings shared their approaches.

Across responses, a recurring focus was on nurturing independent living skills. Caregivers consistently reported teaching essential tasks like eating, bathing, dressing, and exercising. Encouraging physical activities, including nature walks, was highlighted as crucial for holistic skill development and enhancing individual autonomy.

Another significant highlight was the provision of independent living units with round-the-clock support from licensed caregivers in meal preparation, hygiene assistance, and household management. Centers specializing in occupational therapy emerged as pivotal settings for skill development respondents reported the most frequently implemented activities such as painting, jewelry making, and pottery to teach cooperation, communication, and task completion. Practical skills like meal preparation and cleaning were integrated into therapeutic programs, enhancing both cognitive and functional abilities. An important aspect noted by respondents was socialization and active citizenship. Organizing discussions on rights, independent living, and self-determination fostered community engagement. The respondents stressed the importance of encouraging independence and initiative of the persons with disabilities and creating an environment that is supportive and where individuals feel safe to experiment, fail, and retry in order to build resilience and self-efficacy.

Based on the experience of the respondents the following everyday ways of support of PWD in the process of independent living were stated	
1	“By helping with daily activities, reminding, assisting, working together on daily tasks, walking, shopping together”
2	“I call her friends and organize a get-together on her behalf. I do the shopping, washing, and cleaning together with her. I help her with studies and homework.”
3	“Setting reminders, help in making decisions, help in working with material values, psychological support.”
4	“Learning my child to do some things independently: eating, washing, taking a bath, clothing, exercising, physical walks in nature and outside in the neighborhood.”
5	“Providing 3 independent living units where 5 beneficiaries are living together in each of the units, 15 beneficiaries total. The beneficiaries are living with 24/7 support provided by licensed caregivers, coordinator and assistant coordinator. The caregivers prepare meals everyday, help them with the hygiene, do the shopping and manage the households.”
6	“Direct support and assistance with all of the daily tasks.”
7	“We help them in their daily life until they acquire skills and knowledge that will help them in independent living. Support in the social and health system, finances support.”

8	“Support in the implementation of basic and instrumental activities, support in socialization, the educational process and the work process.”
9	“Center for Occupational Therapy - In the Center, the beneficiaries learn new skills in a group or individual sessions. By art occupational therapy: painting, making jewelry, pottery they are learning how to cooperate, communicate, concentrate on a task, finish the task successfully. The beneficiaries are also learning how to listen, read, answer; how to prepare meals, clean the dishes and take care of themself.”

Table 3: Everyday ways of support of people with disabilities in the process of independent living

All of the activities that are building the skills of persons with disabilities in independent living, and that are helping their parents, caregivers, and organizations in order to be more efficient can be better supported with and without additional financial funds.

Table 4 is giving an overview of the collected answers on the personal experiences and challenges faced with the current setting and organization of independence, and how it can be organized with no additional financial funds.

The general conclusion is that the current funds are already not enough, and the majority of the activities proposed by the respondents are implementing more diverse activities such as art, music, horticulture, recreational activities and occupational therapy in the daily schedules of the beneficiaries. These activities will be provided through the network of caregivers that are already employed in the living units where beneficiaries are living. That way there will be no need of additional funding.

The majority of respondents emphasized the importance of enabling individuals to stay in their own homes with professional support. This approach not only promotes autonomy but also facilitates integration into community life. A recurring recommendation was the organization of courses aimed at teaching practical skills such as cooking, cleaning, using public transport, and digital literacy with no additional funds. These courses are seen as essential for enhancing daily living capabilities.

Advocacy for legal changes, including expanding personal assistance to cover intellectual disabilities, is identified as crucial for ensuring comprehensive care under national social protection laws. Experts stressed the need for legal recognition and support services, particularly expanding personal assistance services to include individuals with intellectual disabilities. Updating regulatory frameworks under national social protection laws was identified as crucial and no additional funds are needed for this action.

Another activities that can strengthen the independence of persons with disabilities are social interaction and community integration which are very important to combat isolation and to develop social skills. The collected answers highlighted the individual-centered approaches based on individual abilities and preferences, will provide best and personalized and effective support. Encouraging work experience, activation on the labour market or even volunteer opportunities is also highlighted as important.

The professional caregiving staff and ongoing collaboration with families of persons with disabilities, frequent visits of the families, friends and nurturing the community of the persons with disabilities is very important as well.

Based on the experience of the respondents, the following opinions were given for enhancing the independent living of PWD with no additional funds	
1	“To have the needed support and personalized assistance that will allow them to stay in their homes (if they have their own home) with the support of professionals, those who are able to work to get a job and of course the state to borrow and find a way to financially support these people.”
2	“In the current living setting, organizing different courses that will be on an annual program as mandatory for the caregivers to conduct them on cooking, washing, ironing, making crafts or jewelry, shopping and using public transport, cleaning courses, digital skills, photography, art, horticulture.”
3	“To live in their own home (if they have one) together with other people, of course with support, to have their own source of income (if they are able to work).”
4	“Without additional funds, there is not much that can be done, because the current funds are already not enough.”
5	“Implement more activities to be creative, to do drawings, music, videos, watch movies etc.”
6	“Support and different activities inside and outside: horticultural activities such as occupational therapy and other activities that will help them to work on their concentration, focus and abilities.”

7	“Without additional funds, the best way for independence is in small group homes, supporting not only the basic needs of beneficiaries but implementing various other activities that will benefit them.”
8	“This type of service must be supported by the state due to the complexity of the service itself, if this is not the case then the service should be charged by the families of the users if they have or independent income that they have. The sustainability of the service can also be seen in the production of certain products and their sale (if this can be achieved according to the type and degree of disability of the user).”
9	“In North Macedonia, personal assistance is licensed by the Ministry for Labour and Social Service. The beneficiaries from this service are only people with physical disabilities, visually impaired people and people with hearing loss. Without additional public funds this social service can be available for people with intellectual disabilities as well, only with adding them as potential beneficiaries in the Rulebook for Personal Assistance, by the Ministry. The Social Service Personal Assistance is regulated in the National Law for Social Protection, and in the Law as potential beneficiaries are included people with intellectual disabilities. However, in the mentioned Rulebook this target group is not enlisted, therefore with no additional funds this service will vastly improve the independence of people with disabilities and will allow them to continue to live in their families with tailor made assistance. “

10	“I think the best way is to give them the spaces to promote aggregation so, first of all, they learn how to interact, because, from my experience, a big issue is the isolation a lot of peopole with disabilities experience during their life, or the fact that most of them see the world through their parents eyes. So I would say that fill the absence of social experiences and interactions is a good way to start.”
11	“Work to identify their actual abilities and difficulties with concrete activities, create daily, weekly and monthly schedules to work on overcoming the difficulties: taking a bath, going outside, speaking, self-care, gaining knowledge, managing money”
12	“We (caregivers) are doing the cooking, cleaning and maintaining the overall hygiene and living of the beneficiaries. Even though there is a premade schedule for monitoring and assessment of the progress of development of the beneficiaries there are no instructions or program on how to achieve those milestones with the beneficiaries. I think if we are given more precise training modules with detailed descriptions and steps on implementation that we will have significantly better progress with no additional money needed.”
13	“Be open to listen to the person's needs while putting aside your own ideas and expectations. This way the activities will be created in consultation with the needs of the beneficiaries and not only prepared by the caregivers and the other professionals leaning only on their perception but tailored to the actual needs of the persons with disabilities.“
14	“Starting from awareness and desires of the person, helping them to self-determine. This is a starting point for any next step.”

15	“By gaining work experience: many persons with disabilities are capable to work and to gain work competencies through programs for education.”
16	“Holistic intervention by people with subject knowledge and empathy.”
17	“Taking into account the opinion and experience of the recipient and not just staying on the opinions of each therapist and caregiver.”
18	“Possibility for tenants to participate in more external activities, with the aim of better contact with the community and therefore their psychosocial development Support of the assisted living facilities from the Municipalities, especially from the social structures for the implementation of programs with the participation of the beneficiaries of the assisted living facilities (sports, entertainment, social actions, holidays). Need to develop quality criteria for the operation of assisted living facilities through an extensive consultation process with all parties involved. Creation of an assisted living facility quality control committee with the participation of SYD residents, who will be trained as self-advocates and quality controllers”
19	“Properly trained staff, good cooperation with family environment, understanding of the needs and wishes of the beneficiary.”
20	“Better prepared professionals, but also families. Professionals need to work with families of the persons with disabilities in order to help them understand that their children have potential that needs to be developed because in the future they will need to be more independent.”

Table 4: Enhancing the independent living of people with disabilities with no additional funds

Majority of all social services, activities that will improve the independence of people with disabilities and that will strengthen their autonomy, programs that will train and equip professionals that work with people with disabilities to be more prepared, but also hiring more people in the care economy - they all need additional funds and can be better organized with more financial support and bigger budgets.

Table 5 shows how additional funds can contribute to better organization and implementation of the independence of people with disabilities. The survey responses show that there is an existing need for better-trained caregivers, more personalized support, inclusive environments, and more effective use of financial resources.

Many respondents highlighted the necessity for better training programs for caregivers and other support staff, continuous education and more up-to-date training methods. Higher salaries for professionals working in social services, including caregivers, therapists, coordinators, and assistants, were suggested to attract and retain qualified personnel. The respondents also advocated for a more personalized approach to social services, focusing on individual needs and preferences. This includes more one-on-one support and tailored programs. Engaging people with disabilities in meaningful employment was also recurring topic, as well as mentorship programs, where a person with a disability is paired with a mentor, were suggested as a way to facilitate learning and support.

The responses also stressed the need for more accessible and adapted public spaces, including streets, public transportation, and facilities like libraries, schools, and universities. Effective and rational use of funds was highlighted, with suggestions to invest in adaptive and re-equipment of facilities, use of renewable energy sources, and food production to enhance self-sufficiency.

Implementing a system of personal assistance was frequently mentioned, allowing individuals to live independently while receiving the necessary support at home. Increasing the number of specialists offering daily life skills training and reinforcing housing structures with more staff and specialized roles (e.g., physiotherapists, gymnasts) were suggested as ways to improve support systems.

Based on the experience of the respondents, the following opinions were given for enhancing the independent living of PwD with additional funds	
1	“Better training program of caregivers, more occupational therapists engaged in the living units in the community that will work together on individual and group sessions with the persons with disabilities. Higher salaries for the professionals that are working in the provision of social services: caregivers, therapists, coordinators and assistants. Educational programs for parents that are supporting people with disabilities, parents, families and friends of persons with disabilities to be engaged continuously into programs that will teach them new skills. More public spaces that will be available and adapted to persons with disabilities.”
2	“Engage them, employ them with a person as their mentor from which they can learn and help. Be their assistant.”
3	“Implementing more personalized approach of the social services, integrating more inclusive approach in the educational system, creating better programs adapted to the needs of the people with disabilities in all levels of the educational system in order to gain competencies, implementing programs for professional trainings of people with disabilities, employment of people for support”
4	“Leaving independent with 24h support: this service can be improved on several different levels: better understanding of the personal needs of the persons with disabilities contemporary training and new programs of the caregivers more support staff working in one group home”

5	“Personal Assistance - this service can be better with additional funds because the main objective is for the persons with disabilities to live in their homes with their families, but the beneficiaries as well as the families need support so they can live together with all of the activities in the home.”
6	“More support and materials for individual work - persons with disabilities need more 1 on 1 individual work, training and education especially if they were not exposed to work or occupational therapy before. The parents of the beneficiaries very often try to "protect them" from the outside world, but this action most of the times makes them disservice.:
7	“With additional funds, the best way for the people with disabilities are more small group homes with less beneficiaries and more caregivers and psychologists, connected together by a strong network to help and support all areas of their life.”
8	“Good and rational use of the funds even if the facilities themselves are owned by the organization, possibility of adaptation and re-equipment of the facilities, use of photovoltaic systems, food production, opportunity for the users to get more than what is said only exercise of basic rights. Also, the price should meet the costs that are imminent and enable the insurance of the employees.”
9	“Social Service - Assisted Living in the Community - Additional financial streams in the methodology for forming the prices that will include finances for sport, recreational and leisure activities, art activities outside the living units. Social Enterprises - Voting the National Law for Social Enterprises - this will allow organisations,

	teams, individuals to start new legal entities - social enterprises that will be beneficial for people with disabilities as employees, but also as beneficiaries of the products and services. New national law on taxation of the companies - this will regulate the employment and activation of persons with disabilities on the labor market and will provide terms and conditions for companies to create job positions adapted to the specific needs and capabilities of people with disabilities, will employ people with disabilities and will directly improve their financial income. Additionally, according to the best practices of many democratic states in the European Union, the finances accumulated from the penalties will directly fund state projects (infrastructure, transport etc) adapted to the people with disabilities. Adapting all public spaces (streets, vehicles, buses and trains, infrastructure, living facilities, staircases, libraries, schools, universities) to all the different disabilities. This will directly improve the independence of people with disabilities. Employment of people for personal assistance in public institutions, healthcare facilities, banks, universities, schools, post offices, shops, public transportation. This will also directly improve the independence of people with disabilities, will create safe spaces for mobility of people with disabilities, will improve their access to different kinds of services, and will create a supporting environment. This will also contribute to the Care Economy Concept.” (North Macedonia)
10	“If we had endless funds I would invest them in building apartments that have specific devices and precautions that can give people with disabilities as much support as they need to do their daily tasks. Also it would be useful, at least at the beginning, to have the support of different operators that can identify and work on personalized working paths, in parallel with the group work.”

11	“Once you have identified what their needs are, find the right support so they can fill the gap between what they can do and the goals they want to achieve.”
12	“Specialized operators who can dedicate themselves ad hoc to the various needs of the children”
13	“That there could be more funding for individualized projects, less packages and pre-packaged ones.”
14	“That pre-packaged packages are no longer offered.”
15	“Specializing in personal assistance - this is the ultimate support for persons with disabilities to be autonomous. Each person with disability has the right to have assistant - the world should be designed to the needs of each of the marginalized groups that are vulnerable, not only to the majority.”
16	“Joint approach to people taking action and strengthening of benefits to improve the quality of service delivery.”
17	“Concerning their livelihood by strengthening the already civil provisions of financial support, creating independent living housing structures or additional mobile units where therapists will have a more supervisory role. Reinforced with subsidies, business id. character so that they hire people with percentages proportional to their total employees.”

18	“Increase of a special hospital - boarding school in order to have the possibility of staffing the structures with more staff. Exchange visits with other assisted living facilities, visit to companies/structures, where the beneficiaries could potentially offer work. Implementation of Programs through NSRF or the Region's own resources to cover the purchase of apartments, in order to have privately owned assisted living facility.Promotion of numerically small housing structures, modification of the institutional framework, so that the Shelters with 1-2 people are also sustainable Strengthening the structures with other specialties (physiotherapist, gymnast, etc.).”
19	“Appropriately trained staff to be trained regularly, properly configured residential spaces with all prerequisites for the living of people with disabilities, state budget contribution to welfare.”
20	“Increase in assistants offering daily life skills training. Create laws as the example in Italy that will create obligations for all legal entities to employ persons with disabilities. Use the concept of social enterprises in order for more persons with disabilities to be employed. Develop more the concept of part time in order to be more adapted to the needs for a professional job position.”

Table 5: Enhancing the independent living of people with disabilities with additional funds

4.2.2. Self-Advocacy programs for persons with disabilities

The second part of the questions of the Survey is dedicated to the self-advocacy of persons with disabilities. This section provides more insights about the process of implementation of the self-advocacy programs by the respondents, the key challenges faced, the adaptations according to the specific abilities of the participants, the positive results and the overall outcomes of the programs.

When asked about participation or implementation of a self-advocacy program for persons with disabilities, a significant number of the respondents answered that they have never participated in a self-advocacy program for persons with disabilities, a high percentage of 75%, as shown on **Chart 2.**

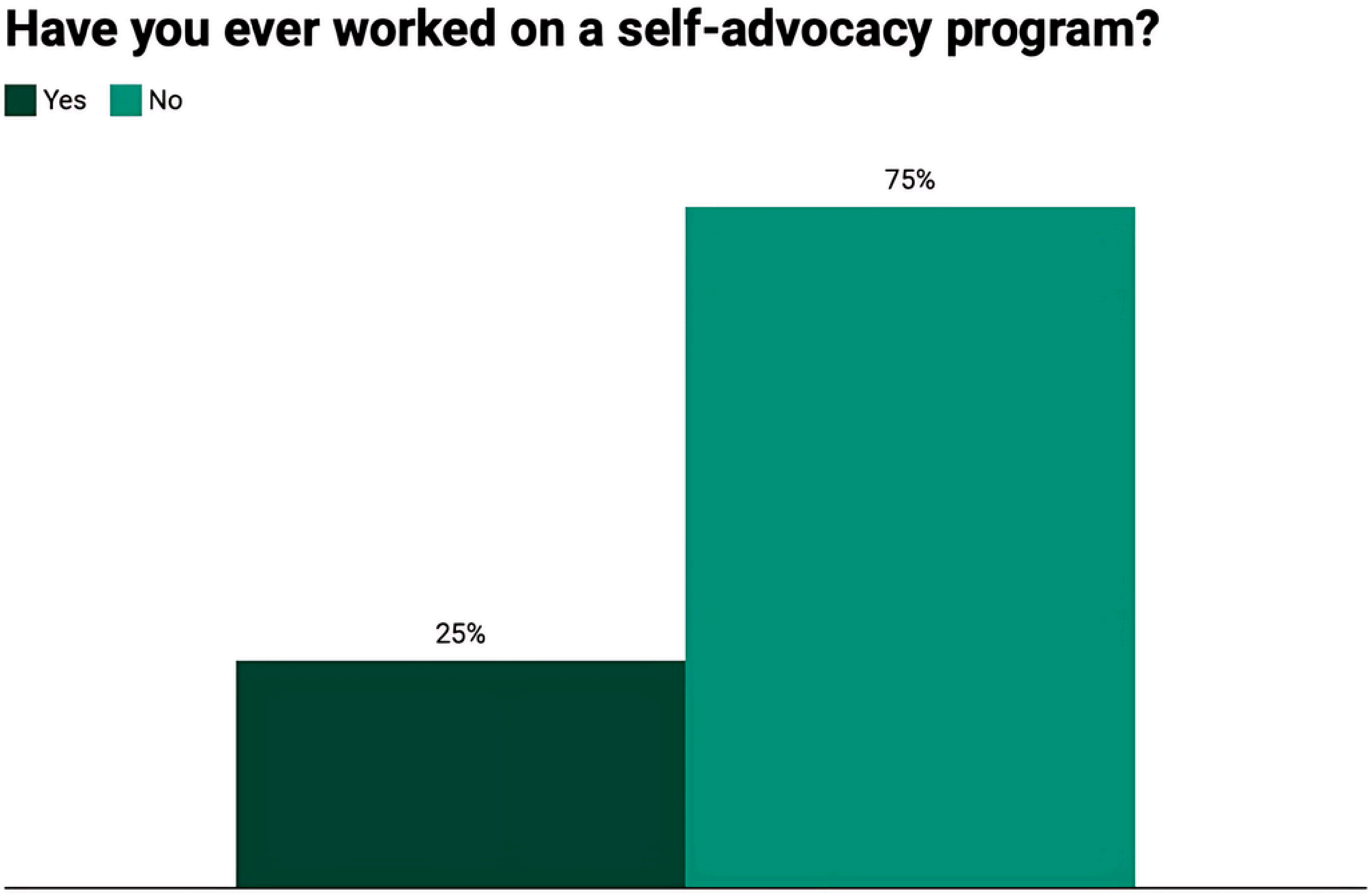

Chart 2: Have you ever worked on a self-advocacy program?

Table 6 provides more detailed information about the self advocacy program that the participants organized, attended or collaborated on.

Based on the experience of the respondents, the following self-advocacy programs were conducted	
1	“Our organization implemented a self advocacy program in a period of 2 months. The persons with disabilities were working together with persons without disabilities on creating recommendations to the national institutions about the legislation towards young people, youth unemployment and youth standard.“
2	“We organized with the beneficiaries from our daily center many activities for self advocacy: tribines, public discussions, round tables.”
3	“We organized an activity that was called Liberi di Scegliere and it was promoted and organized by the Ministry of Labor and Social Policies in collaboration with ANFFAS, an association of families of people with disabilities.”
4	“We implemented a program supported by Erasmus + about self advocacy of people with disabilities around Europe. Persons with and without disabilities across a couple of countries were participants. The participants were self-advocating for better accessibility and assistive technology in the highschools.”
5	“The program we participated in negotiated the participation of people with disabilities in the political, democratic and community system of their country.”

Table 6: Conducted self-advocacy programs by the respondents.

Table 7 shares insights from the collected answers on the different adaptations of the self-advocacy programs depending on the type of disability of the persons that were undertaking the program. In order to achieve maximum level of participation, the programs should be tailored according to the specific needs of the participants, and not to be pre-made. This way the risk of unadapted support services, technology and assistance will be avoided.

Based on the experiences of the respondents, the following differences and modification in the implementation of the self-advocacy programs for verbal and non verbal participants were shared	
1	Yes, there was a difference in the program. For all of the participants we implemented descriptions of the activities with more pictures. For the non-verbal participants we were using more time, more visual instructions and more patience when working.”
2	“Non-verbal persons need different approaches. We worked together with them and with their personal assistants, because they have already established way of communicating with the assistants.”
3	“This program was different because it was implemented by using a program called "matrici". One of the main goal was to experiment with the establishment of offices for individualized planning for concrete access to the measures provided for by Law no. 112/16, a law that establishes a stable National Fund for assistance to people with serious disabilities without family support.”

4	“Usually we use instructions that are verbal, instructions that are visual (we prepare short descriptions of the activities even if it is a simple one such as playing with a ball), and also we use assistance through all of the activities that we implement, we do not lean only on the explanations at the beginning. We try to remind together with the participants in order to continuously implement the activities.”
5	“The participants in our program were all verbal, so we can not give empirical comparison.”

Table 7: Differences and modification in the implementation of the self-advocacy programs for verbal and non verbal participants

Table 8 shows that the self-advocacy program results with success and are best implemented together with the persons with disability. This is the right way to create an enabling environment, to engage and include persons with disabilities to be part of the solutions for the problems that are concerning themselves, and to provide platforms for them to be part of the decision-making processes.

Based on the experience of the respondents the following positive benefits of the implemented self-advocacy programs were stated	
1	“It is a long term process. First, the positive thing was that the persons with disabilities have the right, space and platform to speak for themselves. Then, they are having fun because they are working together with persons without disabilities and they learn a new environment, new way of communication and collaboration. Specifically, for the project we implemented all of the recommendations created to the institutions that were inclusive for all persons, including different abilities.”
2	“When we organized the tribunes, public discussions and round tables the persons with disabilities that were participants were not only speakers, but also they were included in the organization of the events so they had actual tasks to work on: lists of participants, taking photographs, assisting with the seating orders.”
3	“We achieved a higher level of involvement of families and of participants from the public sector through the program.”
4	“The highlight of the programme was the interactions between participants, breaking stereotypes, exposing people to different disabilities and learning new ways of communication, patience. “
5	“The organization and participation of people between them was really great during the meetings as well as the way they identified their real needs through their self involvement and equal participation”

Table 8: Positive benefits of the implemented self-advocacy programs

For each of the programs, there are challenges that can be avoided in future, but also each of the challenges are lessons learned that will vastly contribute to the design of the method for self-advocacy. **Table 9** illustrates some of the problems that can come up in the process of self-advocacy.

Based on the experiences of the respondents the following challenges in the process of implementing the self-advocacy program were mapped	
1	“In our case, we did not have many challenges, the participants enjoyed the whole process.”
2	The challenges were that the participants, some of them, were scared to make a decision, since they are not used to making decisions for themselves.”
3	“The multidimensional evaluation was long and exhausting, some of them didn't understand the topics of the questions for evaluation at the end of the activity.”
4	“The challenge was the language (English), because the participants with disabilities knew only their native language.”
5	“Learning to work together for a common purpose and empowering them to achieve their goals.”

Table 9: Mapped challenges in the process of implementing the self-advocacy program

Self-Advocacy and supported decision-making are essential in the process of gaining independence of persons with disabilities. **Table 10** gives an overview of some of the positive benefits these programs can have on persons with disabilities on their path to independent living.

Based on the experience of the respondents, the following level of impact of the implementation of the self advocacy programs was shared	
1	“The debates contributed to raise public awareness among young people that all of the policies should be accessible, inclusive and to promote higher level of engagement of persons with disabilities.”
2	“The program helped participants to learn that they have not only the right to speak for themselves, but also to learn about responsibilities that should be delivered by them.”
3	“I think the main contribution of the program was to bring attention to the rights of the people with disabilities and to make them think of themselves as adults.”
4	“Stimulating conversations between participants and sparking a public debate about inclusion and investing finances for tools, technology and knowledge for persons with disabilities in the educational system, especially in schools.”
5	“Through therapeutic processes and activities to understand their real needs and be able to create their own self-goals, so that they themselves participate in their self-organization.”

Table 10: Impact of the implementation of the self advocacy programs

5. Analysis of the conducted focus groups

3 focus groups with 15 participants in total were conducted in each of the partnering countries, in a heterogenous setting with persons with disabilities, parents/legal guardians, caregivers, professionals working with persons with disabilities, organizations working on independent living of persons with disabilities, organizations working with persons with disabilities.

The focus groups provided valuable insights and allowed us to perceive the individual perceptions of the participants, delving into the subjective experiences of the path to gaining independence of the persons with disabilities. These experiences captured a multifaceted view of the perspectives and attitudes of the participants, who have already started the path to independence of persons with disabilities.

The identity of the participants will remain anonymous, but known to the experts who conducted the focus groups. The participants were asked to share their experiences with gaining or supporting autonomy, explaining the whole process and key challenges, problems and obstacle faces, but also the positive impact and results. The participants answered pre-prepared questions and at the end they were given space to share their own additional information/comments.

5.1. Funding models of social services and programs strengthening the independence of persons with disabilities

In order to better understand and further analyze the current challenges and needs for strengthening the capacities for independence of persons with disabilities, three focus groups were conducted. The responses of the participants of the focus groups showed that the current living organization can be better organized even without additional funds:

“Implementing more activities for socialization of the persons with disabilities that live in the small group homes requires no additional finances. They are happy to go outside and be around the people in the park or anywhere else. That is the only way to motivate them to have friends and their own circle of people they communicate and share”

Their shared opinions and thoughts correspondent with the answers provided in the Survey, regarding the social service personal assistance:

“The main objective of deinstitutionalisation is for persons with disabilities to live with their families. The best way to organize this is with personal assistance that will adapt to every specific needs that the beneficiaries and their families have. This process of enabling this service in North Macedonia can be enabled without additional funds because the change of the Rulebook does not require budget ”

Many of the skills needed for more autonomous living of the beneficiaries can be improved with occupational therapy activities. With no additional funds, the beneficiaries that are already living in the living units can have access to learning activities provided by their caregivers:

“We as caregivers that are working everyday in the small group homes with the beneficiaries can be educated on how to include the beneficiary in some learning activities. The centers for social works can create tasks and activities for us, and we can teach those activities to the beneficiaries.”

However, with additional funds the organizations of living, the implementation of all social services and different kinds of everyday activities can be implemented that will directly affect positively the independence skills of persons with disabilities.

“Mostly all of the public policies that need to be implemented require additional finance of the public institutions, of the organizations but also of the private sector. For example, there should be a law that will require all of the companies to hire persons with disabilities. But this will require adaptation of the job positions for the persons with disabilities, assistants that will be additionally employed to support them. This means opening more job positions and employment of more people. In all of the public institutions there should be person for assistance, no matter if the other person that needs to be supported is with intellectual, physical disability, older person or different kind of disability. This will also require more finances for salaries of the newly employed people.”

“The lack of daily centers is a huge problem. There are disproportionately opened across the country. The do not work second shift, only until 17pm. I think that if there are bigger finances, this will partially solve the problem.”

“My son had a personal assistant. It was a project by the municipality in partnership with an NGO. They became very close, the assistant had activities with him everyday, they went out to eat, to take a walk, to swim. We had the assistant for 10 months. Then the project finished, and there was no assistant for my son, because there were no finances for support.”

5.2. Self-determination, self-advocacy and supported decision-making of persons with disabilities.

Self-advocacy is a very important part of the process of gaining autonomy and independence of persons with disabilities. The support system has to create systematic opportunities for active participation of people with disabilities in the decision making process, for problems that are concerning them. The organized way for participation should be adapted to the specific needs and capabilities of the participants, and to include as much as possible different heterogeneous groups.

"As a parent of a child with autism, self-advocacy has been vital. I have to ensure that my child’s educational and social needs are met, which often involves pushing for appropriate resources and accommodations in school and extracurricular activities.”

Overall, self-advocacy is organized by non-governmental organizations working with persons with disabilities, or by informal groups of persons with disabilities and their parents. Most of the self-advocacy activities are only short-term because they are active when there is a burning problem that needs to be resolved. After that, these informal groups stop existing.

“As a personal assistant to a person with an intellectual disability, I see how important it is for public institutions to include people with disabilities in decision-making processes. Public institutions should regularly ask people with disabilities what they need and want. This can be done through surveys, meetings, or interviews. But what is important to remember is that the inclusion does not stop with having ramps or large print materials. Every person with disability needs a different kind of support: assistive technology, translator, assistant, presentation in a simple and clear language that is easy to understand, to be more patient - they need extra time to express their thoughts and opinion.”

6.Training Program on Key Components of Self-Advocacy

It is of crucial importance for persons with disabilities to feel empowered, encouraged and supported how to self-advocate for themselves, alone, with support or in a group. The first step in this process is to learn about themselves, what are their wishes and needs, how to recognize their needs, strengths and weaknesses, how to decide if they can implement the activities alone or with support, and how to recognize who can be their support person.

In the following part titled **"Training Program on Key Components of Self-Advocacy"** will be explained in detail to the potential implementers of the training (friends, family, caregivers, professionals) how to implement workshops step by step with persons with disabilities.

Day 1: Learning about self advocacy

The first day focuses on participants to get to know each other, to create the group as a safe space and encouraging atmosphere. The first workshop of the day is focused on teaching the participants what is self-advocacy through a set of questions for guided discussion, followed by the workshop 3 which will explain the different types of assisted and not assisted self-advocacy. The first day finishes with questions for evaluation and reflection of the day.

Day 1: Learning about self advocacy	
AM	Introduction of the group and facilitators
	Workshop 1: Knowing each other: Speed Dating
PM	**Workshop 2**: What is self-advocacy?
	Evaluation and Reflection of the day

Day 1: Title of Workshop 1: Knowing each other through Speed Dating

Description of the activity: This activity will be implemented at the beginning of the training, on the start of Day 1 as a first workshop. Through implementing the speed-dating activity, the participants will get to know each other better.

Details	
Duration	45-60 minutes
Participants	Minimum 10 participants
Facilitators	1, 2 or more facilitators depending on the group size
Equipment	Chairs, lazy bags, seating setting in pairs
Space	Indoors of outdoors

OBJECTIVES:

- To encourage communication and cohesion of the group
- To create friendly environment that will enable participants to get to know each other better
- To spark a discussion among participants
- To encourage participants to share information about themselves, and at the same time learn something new

COURSE

Preparation	Prepare the seating setting in two concentric circles, and ensure that each of the participants has a pairing partner in front of them. Each 3 minutes, in a circle the pairing partners are changing. **The rules:** 1. The educator will ask a question. 2. Participants should ask and answer the question for 3 minutes. 3. After 3 minutes, the educator stops the group and asks the outer circle to move to the right/left – to the next person and asks a new question for discussion. 4. This cycle is repeated as many times as time allows **Questions that could be asked:** 1. What is your favorite colour? 2. What is your favorite food? 3. Where do you live? 4. Which famous person is your favorite? 5. What colour are your eyes?. 6. What is the name of your best friend. 7. Compliment your pairing partner in the game. 8. What is your favorite sport? 9. What is your favorite song? 10. What is your favorite pet?

Implementation	Start the workshop with an introduction of the participants. Ask them to share their names and surnames. Create a safe environment and make the participants feel comfortable. Encourage a round of applause to motivate the participants. Facilitate the coordination of the speed dating game.
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter • Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group • Use writing materials for non-verbal participants that prefer to express themselves in a written form • Use assistive technology
Evaluation and reflection	After the workshop is finished, ask the participants the following questions in order to understand their experience and to improve the next workshops: 1. How did you feel in the workshop? 2. Did you feel safe to share your thoughts? 3. Did you feel heard? 4. Did you feel comfortable through the session? 5. What was your favorite question? 6. Was the session sensitive to your needs?

Day 1: Title of Workshop 2: What is self-advocacy?

Description of the activity: This activity is for persons with disabilities, it can be implemented in small or bigger groups, with homogeneous or heterogeneous groups together with persons with and without disabilities. This activity is organized with a group that has no previous knowledge or experience regarding self-advocacy.

Details	
Duration	45-60 minutes
Participants	Minimum 10 participants
Facilitators	1, 2 or more facilitators depending on the group size
Equipment	Chairs, lazy bags, circle setting for seating, tailored to the group's preferences
Space	Indoors of outdoors

OBJECTIVES:

- Participants learn what is self-advocacy
- Participants learn about the different ways for self-advocacy
- Participants learn how they can self-organize to advocate
- Participants learn about different types of assistance and support for self-advocacy

COURSE

Preparation	Organize the group in a circle. Prepare enough seating places. Adapt the seating organization to the needs and preferences for each of the participants. Create motivating, friendly and supporting informal atmosphere. Print out the question-set in order to lead the guided discussion. Print visual cards that will help you to better describe the questions and topics for discussion. **Questions:** 1. Where was the last time that you faced a problem/challenge/issue or situation that was difficult for you? 2. [choose one of the problems of the participants that is most suitable] and ask the participants to come up with possible solutions of the problem. 3. List all of the solutions of the problem. Ask the participants for each of the solutions if they can do it themselves or if they need assistance. 4. Explain the term self-advocacy to the group. 5. Provide examples to the group in the everyday life situation and connect them with the previously shared problems of the group.

Implementation	Start the workshop with an introduction of the participants. Ask them to share their names and surnames. Implement a short ice-breaker in order to create a safe environment and to make the participants feel comfortable. Encourage a round of applause to motivate the participants. Start asking the questions, and guide the discussion. Try to ask each of the participants a question, in order to make them feel included, but be mindful and do not pressure the participants who do not feel comfortable to share their thoughts.
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter • Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group • Use writing materials for non-verbal participants that prefer to express themselves in a written form • Use assistive technology
Evaluation and reflection	After the workshop is finished, ask the participants the following questions in order to understand their experience and to improve the next workshops:

	1. How did you feel in the workshop? 2. Did you feel safe to share your thoughts? 3. Did you feel heard? 4. Did you feel comfortable through the session? 5. What was your favorite question? 6. Do you have a better understanding of the term self-advocacy? 7. Was the session sensitive to your needs?

Day 2: Title of Workshop 1: Self-Discovery Bingo

Description of the activity: This workshop is dedicated to learning about self-advocacy and its main parts. The first key step is for participants to learn about themselves, their needs, their preferences, their likings, their abilities, challenges and strengths.

Details	
Duration	45-60 minutes
Participants	At least 6 participants
Facilitators	1 to 2 facilitators depending on the size of the group
Equipment	Premade cards with images of different activities or subjects or, empty cards, pen or pencil
Space	Circle setting, indoor or outdoor

OBJECTIVES:

- Participants will learn about their personal preferences
- Participants will learn how to recognize what they like and not like
- Participants will learn how to recognize their feelings
- Participants will learn how to express their feelings

COURSE

Preparation	Prepare the group setting together with the participants. Prepare the cards and the working materials.
Implementation	Repeat together with the group participants about the topics you covered on the previous day. Ask the participants what they liked the most, and what they liked least. Continue with a short ice breaker to create a better working environment. Create the Self-Discovery Bingo cards. Each card should contain a different subject, activity or statement related to self-discovery (e.g., "I enjoy painting," "I have traveled to another country," "I am good at public speaking" and the cards should be visual depiction of the statement book, paintbrush, airplane). In a circle, let each of the participants to raise their chosen card and share what they like.
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter

	- Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group - Use writing materials for non-verbal participants that prefer to express themselves in a written form - For participants with visual impairments, use assistive technology or cards with braille letter
Evaluation and reflection	Try to learn what was achieved through this workshop. Ask participants to reflect on the first session: 1. Did you learn more about yourself? 2. Did you learn how you can make a difference between what you like doing and what you do not? 3. Do you know how to express yourself? 4. Do you know who to express yourself to?

Day 2: Title of Workshop 2: Map your needs

Description of the activity: The second workshop of the second day is dedicated to participants identifying and learning about their needs, how to ask for assistance, and how to ask for support.

Details	
Duration	45-60 minutes
Participants	At least 5 participants
Facilitators	1 or more facilitators depending on the group size
Equipment	• Large sheets of paper / flipchart or whiteboards • Markers • Sticky notes • Pens
Space	Indoor or outdoor

OBJECTIVES:

- Participants will learn about their needs
- Participants will learn how to express their needs
- Participants will learn how to decide if they need a support
- Participants will learn how and who to ask for support

COURSE

Preparation	Prepare the flipchart and the materials. Give each of the participants a sticky note. Prepare large sheets of paper or whiteboard with different categories written: Physical Needs, Emotional Needs, Social Needs, Professional Needs, Personal Development Needs.
Implementation	Prepare the group seating in a circle. Start with a short ice-breaker. Continue with the questions and the guidelines for discussion. Encourage the participants to write down one need per sticky note or for each category. **For example:** Physical Needs: "I need eight hours of sleep." Emotional Needs: "I need to feel appreciated." Social Needs: "I need regular time with friends." Professional Needs: "I need clear instructions on tasks." Personal Development Needs: "I need opportunities for learning new skills."

	Gather everyone and discuss the needs that emerged on the table. **Ask questions like:** • Were there any needs that surprised you? • Did you find common ground with others? • How do you currently address these needs in your life? Facilitate a discussion on the importance of recognizing and communicating these needs in different contexts at work, in relationships with family, friends, caregivers. Ask participants to choose one or two needs that are most important to them. Have them write down specific steps they can make to better meet these needs.
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter • Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group • Use writing materials for non-verbal participants that prefer to express themselves in a written form • Use assistive technology

Evaluation and reflection	Reflect together with the participants to understand better if the workshop achieved its goal: 1. How did this session make you feel? 2. Did you understand better how to make a difference what activities do you enjoy doing? 3. Did you understand better what are your needs while doing the activities you enjoy doing? 4. Did you understand better how to recognize your needs to do something, be somewhere or needs adapted to you while you are doing the activity you enjoy doing?

Day 2: Title of Workshop 3: Make decisions and Know how to get what you need

Description of the activity: The third workshop of the second day focuses on helping participants learn decision-making skills, how to evaluate their needs, and how to receive the necessary support and resources to fulfill those needs.

Details	
Duration	60 - 120 minutes
Participants	At least 3 participants
Facilitators	1 to 2 facilitators depending on the group size
Equipment	Decision-making scenarios, questions and guidelines for discussion prepared, visuals
Space	Indoor or outdoor

OBJECTIVES:

- Participants will learn decision-making skills
- Participants will learn how to evaluate their needs
- Participants will learn how to identify resources to meet their needs
- Participants will learn how to request and obtain support

Preparation	Prepare decision-making scenarios and guidelines for discussion Prepare visuals for describing the activities **Questions and guidelines:** • What is an important decision you have made recently? • How did you make that decision? • What information did you need to make that decision? • Did you ask for help or advice? If so, from whom? • How do you know if a decision is good for you? • What resources do you need to make decisions? • How do you ask for the resources or support you need? • Can you think of a time when you needed something but didn’t know how to get it? • Who can you ask for help when you need something? • How do you know if you need assistance with a task or decision? **Scenarios:** **Scenario 1: Choosing an Extracurricular Activity**

Roles:

- **Participant**: John
- **Parent**: Sarah

Scenario: John is deciding which extracurricular activity to join this semester. He is interested in both the art club and the soccer team but is unsure which one to choose.

Discussion Points:

- What are your interests and talents?
- How much time do you have to commit to an extracurricular activity?
- Have you asked your parent or caregiver for their opinion?
- What do you need to participate in each activity (e.g., equipment, time, transportation)?
- Who can you ask for more information about each activity?

Scenario 2: Choosing a Healthy Snack

Roles:

- **Participant:** Emily
- **Friend:** Alex

Scenario: Emily wants to choose a healthy snack but is tempted by a chocolate bar. She sees her friend Alex who often talks about healthy eating.

Discussion Points:

- What are your goals for eating healthy?
- How do you decide if a snack is healthy?
- Can you ask your friend Alex for advice on choosing a healthy snack?
- What resources (e.g., nutritional information, advice from friends) do you have to make this decision?
- How will you feel after choosing a healthy snack versus a chocolate bar?

Scenario 3: Planning a Leisure Activity

Roles:

- **Participant:** Anna
- **Support Worker:** Kevin

Scenario: Anna wants to plan a fun activity for her weekend but is unsure whether to go to a movie theater or a local park. She needs to consider accessibility, transportation, and personal preferences.

Discussion Points:

- What activities do you enjoy the most?
- How accessible are the movie theater and the local park?
- Have you talked to your support worker, Kevin, about your preferences and any assistance you might need?

	• What transportation options are available to you for each activity? • How do you feel about being indoors at the theater versus being outdoors at the park?
Implementation	Prepare the group seating in a circle. Start with a short ice-breaker. Continue with the decision-making scenarios and guidelines for discussion. This is a longer session, include short breaks and concentration games.
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter • Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group • Use writing materials for non-verbal participants that prefer to express themselves in a written form • Use assistive technology
Evaluation and reflection	Questions for evaluation and reflection of the session:

	1. How did this session make you feel? 2. Did you understand better how to make decisions? 3. Did you understand better how to evaluate your needs? 4. Did you understand better how to identify and request the resources you need? 5. Did you understand better how to ask for support?

Day 3: Self-advocacy in the workplace

Day 3 of the program is created with a more practical approach through exercising scenarios with different assigned roles. Day 3 is dedicated to learning about the rights of persons with disabilities, their role, their preferences, their needs, their accommodations, the needed support, the decisions they create and the impact they make in the professional working environment. .

Day 3: Self-advocacy in the workplace	
AM	**Workshop 1:** Workplace Navigator: What is self-advocacy in the workplace?
	Workshop 2: Self-Advocacy for better working conditions.
PM	**Workshop 3:** How to self-advocate for a higher salary in the workplace?
	Evaluation and Reflection of the day

Day 3: Title of Workshop 1: Workplace Navigator: What is self-advocacy in the workplace?

Description of the activity: This activity is for persons with disabilities, it can be implemented in small or bigger groups, with homogeneous or heterogeneous groups together with persons with and without disabilities. This activity is organized with a group that has no previous knowledge or experience regarding self-advocacy.

Details	
Duration	45-60 minutes
Participants	Minimum 4 participants, or even number of participants
Facilitators	1 or 2 facilitators depending on the group size
Equipment	Chairs, lazy bags, circle setting for seating and two seats in pair in the middle Role Cards, Scenarios
Space	Indoor or outdoor

OBJECTIVES:

- Participants learn what is self-advocacy in the workplace
- Participants learn how to solve problems through self-advocacy in the workplace
- Participants learn how they can self-organize to advocate in the workplace

COURSE

Preparation	Organize the group in a circle. Prepare enough seating places. Adapt the seating organization to the needs and preferences for each of the participants. Create motivating, friendly and supporting informal atmosphere. Add two seats in pair for role playing in the middle of the circle, for role playing. Prepare cards with the roles for the game picture of type of HR Manager/ Sales Assistant/ Manager/ Employee/ Intern and the name of the role above the picture) Prepare scenarios with the roles of the cards. **Illustration for a scenario:** **Theme:** New Project Assignment **Situation:** A new project has been assigned to the team, and roles need to be defined. The team must decide on the project plan and allocate tasks. **Challenge:** One team member needs specific accommodations to participate effectively, according to their abilities.

Implementation	Implement a short ice-breaker in order to create a safe environment and to make the participants feel comfortable. Distribute the role cards to each of the participants. Explain each of the roles and the responsibilities in the workplace. Choose the first pair. See the roles, and accordingly explain imaginary scenarios of a real type situation. Encourage the participants to be in character and to play the roles of what would happen after the scenario. Observe the discussion in roles of the participants. After the scenario is finished, participants should discuss their experiences and feelings: • What decisions were made, and why? • How did communication impact the outcome? • What challenges did you face? • How did you feel in your role?
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter • Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group

Evaluation and reflection	After the workshop is finished, ask the participants the following questions in order to understand their experience and to improve the next workshops: 1. How did you feel in the workshop? 2. Did you feel safe to share your thoughts? 3. Did you feel heard? 4. Did you feel comfortable through the session? 5. What was your favorite question? 6. Do you have a better understanding of the term self-advocacy? 7. Was the session sensitive to your needs?

Day 3: Title of Workshop 2: Self-Advocacy Quiz

Description of the activity: This activity is for persons with disabilities, it can be implemented in small or bigger groups, with homogeneous or heterogeneous groups together with persons with and without disabilities. This activity is organized with a group that has no previous knowledge or experience regarding self-advocacy.

Details	
Duration	45-60 minutes
Participants	Minimum 4 participants in order to form a group setting
Facilitators	1 or 2 facilitators depending on the group size
Equipment	Chairs, lazy bags, cinema setting or tailored to the group's preferences
Space	Indoors or outdoors

OBJECTIVES:

- Participants learn and share different challenges in the workplace
- Participants learn how to deal with discrimination in the workplace
- Participants learn about legal anti-discriminatory bodies in the workplace and outside of work

COURSE

Preparation	Organize the group and prepare enough seating places. Adapt the seating organization to the needs and preferences for each of the participants. Create motivating, friendly and supporting informal atmosphere. Prepare: • Quiz Question Cards • Sheets for writing the answers • Pens • Timer • Whiteboard or Flip Chart (optional for scorekeeping) • Small prizes for winners (optional)
Implementation	Divide participants into small teams (2-3 people each). Each team should have a mix of skills and experiences. The quiz is divided into rounds, each focusing on different aspects of self-advocacy. Facilitator reviews answers, provides feedback, and keeps track of scores. Announce the winning team and distribute prizes (optional). Example of Quiz questions: **What is self-advocacy?** a. Speaking up for others b. Speaking up for yourself

	c. Avoiding conflict d. Seeking help from friends **Which of the following is a key aspect of self-advocacy?** a. Aggression b. Passive behavior c. Assertiveness d. Indifference **What is an accommodation?** a. A place to live b. A change that helps you succeed c. A type of job d. A financial aid
Variations	**For non-verbal participants:** • For hearing impaired participants ensure sign language interpreter • Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group
Evaluation and reflection	After the workshop is finished, ask the participants the following questions in order to understand their experience and to improve the next workshops:

	1. How did you feel in the workshop? 2. Did you feel safe to share your thoughts? 3. Did you feel heard? 4. Did you feel comfortable through the session? 5. What was your favorite question? 6. Do you have a better understanding of the term self-advocacy? 7. Was the session sensitive to your needs?

Day 3: Title of Workshop 3: How to self-advocate for a higher salary in the workplace?

Description of the activity: This activity is for persons with disabilities, it can be implemented in small or bigger groups, with homogeneous or heterogeneous groups together with persons with and without disabilities. This activity aims to empower people with disabilities to understand salary dynamics, be more aware of their values and develop strategies for effective advocacy.

Details	
Duration	60 - 80 minutes
Participants	4 participants minimum
Facilitators	1 to 2 facilitators depending on the group size
Equipment	Salary negotiation scenarios, questions and guidelines for discussion prepared, visuals prepared
Space	Indoor or outdoor

OBJECTIVES:

- Participants will understand their value and contributions in the workplace
- Participants will develop strategies for effective self-advocacy for higher salaries
- Participants will practice asking for a salary raise confidently

COURSE

Preparation	Prepare salary negotiation scenarios and guidelines for discussion Prepare visuals for describing the activities **Questions and guidelines:** • What are your current job responsibilities and achievements? • How do you determine the value of your work and contributions? • What information do you need to prepare for a salary negotiation? • How do you plan to present your case for a salary increase to your employer? • Who can you ask for advice or support in preparing for a salary negotiation? • How will you respond if your request for a higher salary is declined? **Scenarios:** **Scenario 1: Presenting Accomplishments and Value** **Roles:** • Participant: Alex • Supervisor: Sarah

Scenario: Alex has been working diligently as a sales assistant for two years. Despite his achievements and increased responsibilities, he hasn't received a salary raise. Alex schedules a meeting with his supervisor, Sarah, to discuss his contributions and advocate for a higher salary.

Discussion Points:

- What specific tasks and achievements have you completed successfully?
- How have your contributions positively impacted the team or company?
- Have you researched industry standards for your position's salary range?
- How will you communicate your value and accomplishments to your supervisor?
- What accommodations or support might you need during the meeting to ensure effective communication?

Scenario 2: Negotiating Salary During Performance Review

Roles:

- **Participant:** Emily
- **HR Manager:** John

Scenario: Emily, who has a visual impairment, has her annual performance review coming up.

She believes her work as a customer service representative has exceeded expectations and warrants a salary increase. She plans to discuss her achievements and advocate for a higher salary with the HR manager, John.

Discussion Points:

- What specific feedback have you received on your performance throughout the year?
- How have you contributed to improving customer satisfaction or team efficiency?
- Have you prepared evidence of your achievements and contributions?
- How will you address any concerns or questions the HR manager might have about your request?
- What assistive technology or accommodations might help you during the negotiation process?

Scenario 3: Requesting Salary Adjustment Due to Increased Responsibilities

Roles:

- **Participant:** Michael
- **Manager:** Lisa

Scenario: Michael, who uses a wheelchair, has recently taken on additional responsibilities as a project coordinator. He notices that his workload has increased significantly without a corresponding adjustment in his salary.

	Michael schedules a meeting with his manager, Lisa, to discuss his expanded role and advocate for a salary adjustment. **Discussion Points:** • How have your responsibilities changed since taking on the role of project coordinator? • What new skills or competencies have you developed to fulfill these responsibilities? • Have you researched similar positions within the company to benchmark your salary expectations? • How will you communicate the impact of your expanded role on team or project outcomes? • What accommodations or support might you need to ensure the meeting is productive and focused on your advocacy?
Implementation	Start the session with a short ice-breaker. In between, take short breaks for concentration with the participants. Start the sessions with the questions and the guidelines, using the visuals for better description. Follow - up with the scenarios. While you are practicing the scenarios, allow everyone to be included, and make it more comfortable and informal.

Implementation	**For non-verbal participants:** - For hearing impaired participants ensure sign language interpreter - Invite the personal caregivers of the participants that are non-verbal who understand their needs in a best way and can assist them participate in the group - Use writing materials for non-verbal participants that prefer to express themselves in a written form - Use assistive technology
Evaluation and reflection	- How did this session make you feel? - Did you understand better how to evaluate your value and contributions at work? - Did you learn more about self- advocating for a higher salary? - How confident do you feel about asking for a salary raise now compared to before the workshop? - Did you learn who to speak to for this topic in the workplace? - Did you learn how to decide if you need support? - Did you learn how to ask for the support you need?

7. Case Studies for Self-Advocacy Best Practices

The following section is dedicated to sharing different practices regarding gaining independence of persons with disabilities that were either living in big, closed institutions with hospital characteristics, or were part of grassroot self-advocacy programs that made a positive change and created results.

7.1. North Macedonia: "Change Comes from the Youth": Advocating for Inclusive Development in Kisela Voda Municipality

The project "Change comes from the youth" exemplifies a transformative approach to community development, specifically targeting the active involvement of young people, including those with disabilities, in shaping the future of Kisela Voda municipality. Implemented by the Center for Youth Activism KRIK and supported by the SEGA Coalition of Youth Organizations, this initiative was funded by the European Union under the project "Youth participation for strong and sustainable development of the community."

The primary goal of the project was to empower 20 young people with and without disabilities from Kisela Voda, to actively participate and advocate in identifying and addressing local problems. Young individuals in heterogeneous groups with and without disabilities were organized into 5 groups. Each of the groups had a task to map the challenges faced in the municipality by themselves.

Under the guidance of KRIK, the participating youth engaged in a structured process of research, brainstorming, and initiative implementation. These issues ranged from accessibility barriers to educational and employment opportunities, reflecting the diverse needs of young people in Kisela Voda. Afterwards, the groups developed and implemented targeted initiatives aimed at addressing these challenges. These initiatives were not only innovative but also inclusive, whether it was advocating for improved infrastructure accessibility, promoting inclusive educational practices, or fostering greater social integration.

The initiatives were presented directly to relevant municipal institutions and stakeholders TMoreover, the project empowered the participants, especially young people with disabilities, to share their voices and contribute meaningfully to their community's development.

7.2. Italy: “Io Cittadino” / "I Citizen" Program by ANFFAS

ANFFAS, the Italian association founded by relatives of Persons with Disabilities (PWD), has been instrumental in promoting rights and fostering active citizenship among individuals with disabilities through various initiatives.

Io Cittadino ("I Citizen") Program: ANFFAS organizes the Io Cittadino program, a series of bi-weekly meetings held over the past seven years. These meetings serve as forums for discussing rights, exploring concepts of independent living and self-determination, and engaging in active citizenship activities. Participants, including PWD and their supporters, interact with local communities by visiting schools, meeting with government officials such as mayors, and addressing societal barriers—be they physical, social, or attitudinal.

A crucial aspect of Io Cittadino is its school outreach program, where ANFFAS representatives educate students about the daily challenges faced by people with disabilities. This initiative aims to raise awareness and foster empathy among younger generations, thereby promoting inclusivity and understanding. The Io Cittadino groups, spread across the country, maintain a network that facilitates sharing of accomplishments and strategic planning to further enhance their impact nationwide.

Liberi di Scegliere ("Free to Choose") Project: In collaboration with the Ministry of Labor and Social Policies, ANFFAS promotes the Liberi di Scegliere project. Utilizing the "matrici" system—an advanced, scientifically validated tool—the project conducts multidimensional assessments of needs and outcomes related to various domains of quality of life for PWD. This holistic approach ensures tailored support and advocacy for enhancing the overall well-being and autonomy of participants.

Erasmus + Supported Projects: ANFFAS also participates in Erasmus + funded initiatives that harness art as a powerful medium for disability advocacy on a global scale. Through these projects, participants from different European countries use artistic expression to raise awareness about self-advocacy among PWD. These endeavors not only empower individuals but also promote international dialogue and cooperation in advancing disability rights and inclusion.

7.3. Greece: Gaining freedom and independency: The Case of K

K., a 52-year-old woman, shared her experience transitioning from a psychiatric hospital to a protected apartment managed by EDRA during Greece's deinstitutionalization period. K.'s journey highlights the profound impact of mental illness on her life and the significant improvements in her quality of life after moving to a protected living environment.

K. was diagnosed with schizophrenia 17 years ago, leading to a prolonged period of hospitalization. She spent three years in a psychiatric hospital, where her basic freedoms were severely restricted. She was unable to take walks at her discretion, had no control over her dietary choices, and felt that her life was dictated by others. This lack of autonomy caused her significant discomfort and distress, exacerbating the challenges posed by her mental illness.

Following her hospital stay, K. moved to a protected apartment provided by EDRA, an organization supporting individuals with mental health issues. This transition marked a turning point in her life, offering her a level of freedom and autonomy she had been deprived of during her hospitalization. K.'s life in the protected apartment contrasts sharply with her hospital experience. Here, she enjoys greater freedom and independence. She can take walks whenever she feels stressed, cook her own meals according to her preferences, and even work to earn her own money. This newfound autonomy has significantly improved her mental well-being.

K. reports feeling free and in control of her own life, which brings her immense pleasure and strengthens her resolve to enjoy everyday life. The ability to manage her own affairs and make personal choices has empowered her to cope more effectively with the challenges posed by her illness.

K.'s story underscores the transformative impact of deinstitutionalization and the importance of supportive living environments for individuals with mental health issues. The shift from a restrictive hospital setting to a more autonomous living arrangement has not only improved her quality of life but also enhanced her ability to manage her mental health more effectively. K.'s experience is a testament to the positive outcomes that can arise from providing individuals with the freedom and support they need to thrive.

Concluding remarks

With this Guide on Independent Living the following conclusions are stated:

1. The process of deinstitutionalization which enables independent living of persons with disabilities is on different level of progress in each of the countries: North Macedonia, Italy and Greece

2. The current living arrangements and social services towards persons with disabilities can be better organized with no additional funds through implementation of better activities in the living units organized for the beneficiaries, more outdoor activities, creating a network of friends with the beneficiaries.

3. The current living arrangements and social services can be enhanced, made more efficient and better support persons with disabilities, their families and caregivers with more funds from the institutions, EU Funds and Private Sector Companies: Higher quality of living through better organization of the social service living in the community, on-going education and qualification of caregivers in order to develop higher levels of knowledge, skills and competencies

4. The current social services can be upgraded with change of legislation which will allow to incorporating additional support and assistance to the beneficiaries

5. Major step on the path to independent living is the social service Personal Assistance which allows persons with disabilities to be supported in their everyday life: self-care, education and work, leisure and decision-making. The national funds are insufficient to fully integrate this social service.

6. The concept of Self-Advocacy is not entirely explored, organized and practiced. The parents, caregivers and organizations are not familiar with the meaning of self-advocacy. The persons with disabilities are not familiar with the concept as well.

7. Self-advocacy can be a powerful tool for achievement the goals and objectives in the process of independent living of persons with disabilities.

Recommendations

The Guide on Independent Living provides the following recommendations:

1. The National Governments of North Macedonia, Italy and Greece need to take stronger action in order to fully implement the national strategies and action plans.

2. The appointed institutions should provide better in-depth analysis and create better allocation of the funds together with more targeted policies

3. Organizations working with persons with disabilities should advocate for increased funding from national institutions, EU funds, and private sector companies to improve the quality of services

4. Institutions, organizations and professionals should implement ongoing education and training programs for caregivers to elevate their knowledge, skills, and competencies, leading to higher quality care. However this will need additional funds and change of the methodologies for financing the social services with the ongoing education included in the calculations.

5. Enable Personal Assistance for all categories of disability, including intellectual disability to be accessible for all beneficiaries.

6. Implement training workshops for introducing the concept of self-advocacy of persons with disabilities with the beneficiaries, parents, families, caregivers, organizations.

7. Include persons with disabilities in the process of creation of solutions of their everyday challenges and problems, through self-advocacy program that will allow to make decisions for themselves according to their needs.

Annexes

Questions for Discussion for Conduction of Focus Groups

1. What are the most significant challenges people with disabilities face in achieving and maintaining independent living, from the perspectives of both individuals with disabilities and their caregivers/families?

2. How do societal attitudes and perceptions impact the ability of people with disabilities to live independently, and what can be done to address and change these attitudes?

3. From your experiences, what skills do you believe are essential for people with disabilities to develop in order to lead an independent life?

4. How can these skills be supported?

5. In what ways can digital technology play a role in enhancing the independence of people with disabilities? Are there specific technologies that have been particularly effective or challenging for independent living?

6. What barriers exist in terms of accessibility and inclusivity in the community, and how can these barriers be overcome to create a more inclusive and supportive environment for people with disabilities?

7. From the perspective of caregivers and families, what resources and support systems are most crucial in assisting people with disabilities in their quest for independent living?

8. How can education and awareness campaigns contribute to breaking down stereotypes and misconceptions surrounding disabilities, fostering a more inclusive society that supports independent living?

9. What role do employment opportunities play in promoting the independence of individuals with disabilities, and what steps can be taken to increase employment opportunities and workplace inclusivity?

10. How can public policies and institutional programs better address the unique challenges faced by people with disabilities and their families in achieving and maintaining independent living?

11. In your opinion, what are the most pressing issues that need to be addressed to create a more inclusive and accessible society for people with disabilities, and what actions can be taken at both individual and societal levels to address these issues?

Questions from the Survey

1. What kind of services do you offer for people with disabilities?

2. What are the challenges you and people with disabilities are facing when it comes to independent living?

3. What are the skills connected with independent living that the people with disabilities need to gain?

4. How do you support the independent living of people with disabilities?

5. According to your experience, what is the best way to organize the independent living of people with disabilities? (in today world, without additional funds)

6. According to your experience, what is the best way to organize the independent living of people with disabilities? (with additional funds present as much as needed)

7. Have you worked on a self advocacy program until now?

8. Tell us a bit more about the self advocacy program you organized. If possible share with us some links/pictures

9. Were there any differences in the program when you implemented it with verbal and non verbal participants? If yes, tell us the experience

10. What were the modules/topics of the program?

11. What worked well in the self advocacy program?

12. What were the challenges the participants faced during the program?

13. How did the program support the participants in their independent living? Tell us a bit more.

14. Do you have anything else to add?

Overview of literature

Publications used:

1. Katrin Modic, Elena Pečarič, Domen Retelj, PERSONAL ASSISTANCE, Handbook for understanding independent living
2. My life, my choice! Empowerment through Supported Decision-Making
3. A Look at Personal Assistance in Italy, ENIL
4. Common European Guidelines on the Transition from Institutional to Community-based Care; European Expert Group on the Transition from Institutional to Community-based Care, November 2012
5. Towards Dignity and Autonomy: A Comprehensive Look at Personal Assistance Policies for Persons with Disabilities Worldwide; ENIL

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2. https://mtsp.gov.mk/content/pdf/2019pravilnici/New%20node/Pravilnik_normativi_standardi_2019.pdf
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