EASPD

European Association of
Service providers for
Persons with Disabilities

Independent Living
and Inclusion in the Community for Persons with Disabilities

Position paper in preparation of the Guidance towards
Member States on Independent Living and Inclusion in
the community by the European Commission

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I. Rationale

In March 2021 the European Commission launched the European Strategy for the Rights of Persons with Disabilities, outlining different initiatives that will undertake over the years to come. One of these initiatives, a flagship initiative as it is called, is the development of a Guidance towards Member States on Independent Living and Inclusion in the community. And more specifically it is stated that *"The Commission will, by 2023, issue guidance recommending to Member States improvements on independent living and inclusion in the community, in order to enable persons with disabilities to live in accessible, supported housing in the community, or to continue living at home (including personal assistance schemes)."*

The European Association of Service providers for Persons with Disabilities developed this paper, based on the knowhow, experience and expertise of our membership, representing over 20.000 organisations for persons with disabilities across 41 countries. This paper aims in providing support to the European Commission's work on the Guidance towards Member States to realise the right of independent living and inclusion in the community for persons with disabilities.

For many persons with disabilities, support represents an essential precondition for their active and meaningful participation in society, while preserving their dignity, autonomy, and independence. Thus, support services play a crucial role in further enabling people to fully enjoy their human rights, including their right to live independently, and being included in the community. However, for many years social services were developed with the objective to keep people safe and healthy. This resulted to the development of institutional settings, where people were isolated from the community and compelled to live together, they did not have sufficient control over their lives and the decisions that were affecting them, and the requirements of the organisation outweighed people's individual needs and wishes.

Nowadays, the emphasis is **on how we can develop support systems that** go beyond keeping people solely safe and healthy but focusing on how to **empower and enable people to live independently, to be active, and to have meaningful lives in the context of the communities in which they live in.** Despite this, people with disabilities and other support needs, children too, still reside in institutions, deprived from fully enjoying their human rights. The COVID-19 pandemic further revealed the harmful impact of institutionalisation for the lives and rights of persons with disabilities. Furthermore, the war in Ukraine further highlighted the immediate need, even in time of crisis, to realise the right of persons with disabilities to live independently in the community. Even when deinstitutionalisation strategies are in place in different Member States, we are witnessing that they tend not to follow a holistic approach. For example, they tend to leave outside persons with intellectual and psycho-social disabilities, they omit to implement the needed legal reforms or provide adequate resources to further support the DI efforts, among others.

To realise the right of persons with disabilities to live independently within the community, the European Commission on its guidance need to support first and foremost the **transition from large residential institutions to person-centred services based in the community**, the transition to services that empower people to enjoy their rights on an equal basis to others. This guidance needs to **support social services' move forward towards better quality, empowering and person-centred forms of support**, aligned with the UN Convention on the Rights of Persons with Disabilities (hereinafter UN CRPD). And this guidance should be **inclusive of all people with care and support needs**, such as older people, people with mental health problems, children, families, among others.

II. Introduction

A **holistic approach** going beyond services is what is needed to achieve independent living and inclusion in the community for people with disabilities. This requires both the transition of services from institutional forms of care to **person-centred services based in the community** and the **re-orientation of policies and resources towards this goal.** It requires **the transformation of the environment around people**, including building inclusive communities; achieving change on mindset and misconceptions towards disability; changes on the way we design and develop support systems for people; on the way we fund these systems; and on the legal frameworks that can support the equal enjoyment of human rights for persons with disabilities, among others.

Living independently in the community is about having adequate health, social care and support systems, personal assistance services, having access to employment, to education, to transportation, to buildings, to information, it is about having adequate income, the necessary assistive technologies, adaptable to ones needs housing, opportunities for self-advocacy and peer networks.

The right of persons with disabilities to live independently is enshrined in Article 19 of the Convention. Right, that equally recognises the full inclusion and participation of persons with disabilities in the community. As further explained on General Comment 5, *"Living independently and being included in the community...means exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society."* This interdependence notion of how an individual can further develop its personality by being part of the community further emphasises the need of developing **inclusive communities where people with disabilities can establish and maintain relationships that can support develop their personality and inspire their decisions in life**.

Support services for persons with disabilities, are part of these inclusive communities, and these are services **who empower and enable people to live independent and meaningful lives within the communities**. These may include a range of services which are home-based and community-based, services aiming at supporting people in daily living activities, from homecare and personal care to support in participating in activities in the community, in building and maintaining relationships, in employment, in education, personal assistance services, respite care services, supported living services, among others. Any support provided should be with the aim to generate **ordinary life outcomes**, to support people with disabilities to live an everyday life in everyday places, to regard persons with disabilities as citizens with equal opportunities to employment, education, having a family, having a home, friends, a community, like any other individual at similar stages of life.

Currently, **services face significant challenges**, including those related to the underdevelopment of person-centred and community-based services including personal assistance, outdated infrastructure, staff shortages and poor working conditions and a sector which often offers work opportunities that are seen as "unattractive". The demand for care and support is also continuously increasing but the legal and fiscal policies are not facilitating the response to the complex and evolving needs of individuals. All these and much more, pose threats on the resilience of the social sector and to its transformation.

Consequently, persons with disabilities and other support needs may not have adequate access to support services based in the community and are deprived from fully realising their human rights and more specifically their right to live independently in the community. Member States need to prioritise the development of support systems which are **available, accessible, known, affordable, acceptable and high-quality**. This

means services that enable people to live independently, while empowering and supporting them to live the lives they want, where they want and with whom they want, with choices and opportunities equal to others.

While acknowledging the complexity of deinstitutionalisation, EASPD put together the following guiding principles that can support Member States realise the right of persons with disabilities to live independently in the community. These principles cover many different aspects necessary for making this right a reality. The broad elements on the principles mentioned below, are not aimed in bringing ambiguity to the policy makers, but to emphasise that the right of persons with disabilities to live independently within the community cannot be realised if a holistic approach is not taken into consideration. EASPD believes that it is imperative, that this document is circulated among public officials within different Ministries and Agencies. This will raise awareness on the need of a holistic approach, on highlighting that this is not the solely responsibility of the Ministry of Social Affaires and relevant social protection units but of any Ministry and Agency and on initiating a discussion among public officials on how this can be realised.

These principles include:

- Building a deinstitutionalisation strategy and action plan
- Developing a range of support systems in the community
- Encouraging the development of well trained and adequate workforce
- Strengthening the role of informal support networks
- Forming adequate prevention mechanisms
- Creating accessible and inclusive mainstream services
- Guaranteeing choice and control of persons with disabilities
- Adopting clear and facilitating legal frameworks
- Ensuring a co-productive approach when designing a systems reform
- Establishing effective and sustainable funding models
- Forming Innovative Quality Assurance Systems
- Scaling up the use of technological aids

III. Principles facilitating independent living and inclusion in the community for persons with disabilities

1. Building a deinstitutionalisation strategy and action plan

Deinsitutionalisation (DI) reforms is the starting point to develop empowering and enabling support services that can realise the right of persons with disabilities to live independently and be included in the community. EASPD recognises the multi-layered process of DI and wants to emphasise the role that service providers can and are already playing in further supporting the DI processes in their respective countries. **For EASPD, the smart transformation of services to more enabling and empowering forms of care and support, needs to be based on the principles of participation, inclusion, non-discrimination, equality, choice and control over life and on the right to receive support adequate to individual needs.** It is essential that the DI process is inclusive of all people with support needs, even people with higher support needs. DI strategies and action plans should also include measures to prevent institutionalisation. Therefore, DI requires thoughtful planning to facilitate the transition while ensuring that will not lead to certain individuals being left without the care and support they need.

EASPD though the Technical Support on DI process project, supported Greece in developing processes and procedures to enable the effective implementation of the deinstitutionalisation process. The materials that were developed during this project can be a valuable resource for policy makers to identify the necessary steps and approach that will lead in supporting people with disabilities enjoy their right to live independently in the community.

Each of the principles described in this paper, need to be part of the DI strategy and action plan. Since DI is a complex and multi-layered process, the following elements are important to be considered during the planning for a successful transition from institutional forms of care towards person-centred support in the community:

- Having a **strategic vision of a holistic reform** is one of the most important factors behind any deinstitutionalisation reform. This strategic vision should be guided by the articles and principles of the UN CRPD, General Comment No5 on Article 19 – the right to live independently and be included in the community, as well as the recently published UN Guidelines on DI, including in emergencies. It should also be included in the DI strategy and communicated with all relevant stakeholders.

- This vision needs to be developed in a **co-production approach** with persons with disabilities, their families, their representative organisations while it is important to involve service providers.

- The **principles** of participation, inclusion, non-discrimination, equality, choice and control over life and on the right to receive support adequate to individual needs should be guiding any DI process.

- Key procedures need to be established to guide the development and implementation of a deinstitutionalisation process:

  - **Data collection** is essential, both qualitative and quantitative data will support in having a clear understanding of the situation, the needs of individuals in institutions and support the development of services in the community.

•• [Assessment processes](#) which focus on individual support needs. This means using assessment processes based on person-centred needs analysis to allow a clear overview of the types of services required (person-centred planning).

•• **Monitoring of the process and review of the strategy** are crucial to monitor how effectively the DI process is conducted and whether the needs and wishes of individuals have been met.

•• **Synergies with other policy areas** are necessary to ensure that all different Ministries are involved. Cooperations with other relevant Ministries, such as the Ministry of Health, of Justice, of Education, of Transportation etc, as well as clear cooperation should be set up between central government and local authorities.

•• **The development of an accompanied action plan** to operationalise the vision with specific goals, timeline, actions, indicators, financial resources allocated per action and identifying the responsible implementation authorities is key to make the vision a reality.

• A crucial part of the deinstitutionalisation reform is the **support towards people who are currently living in institutions**. Support shall be provided to them in any part of the reform, while they are residing in institutions, during their transition to independent living and as long as it is required after their transition to independent living in the community, based on their individual needs and wishes. Many persons with disabilities, especially intellectual disabilities have been institutionalised since they were children, and they may need more intensive support to develop independent living skills, at least in the beginning. However, this in no way aims to indicate that any reform for people with higher support needs should be delayed but it aims to clarify that the support they may require can be more intense and continuous. To accomplish this, support services and peer support networks should be established, as well as training programmes

to adequately prepare the workforce and facilitate the transition to independent life in the community.

Member States need to establish a DI strategy following a co-production approach and based on the principles of participation, inclusion, non-discrimination, equality, choice and control and the rights to receive adequate support. It is essential for the DI strategy to be accompanied by an action plan that will operationalise the vision set up. Crucial to this process is the involvement and cooperation with relevant Ministries and local actors, as well as monitoring the implementation of the DI process.

2. Developing a range of support systems in the community

Many persons with disabilities and other support needs require support to live independently within the community, and the development of home-based and community-based support services -away from large residential institutions- can support in making this a reality. This shall include a **range of support services in the community, services aiming at supporting people based on their needs and wishes**. This support can be translated in any type of daily living activities that a person may require, from homecare and personal care to support in participating in activities in the community, in employment, it can be personal assistance services, respite care services, supported living services, among others.

It is important to note that most [care and support providers in Europe](#) are private not-for-profit and that – by definition – they re-invest any of their profit back into the organisation; thus furthering their social impact or spending more locally. This is Social Economy at its best, and this is different from the growing number of for-profit care companies who re-invest their profit towards their shareholders. Last but not least, not-for-profit providers have a significant [impact on local economy development](#), including in rural areas where they are one of the largest employers.

What is imperative when developing any support system for persons with disabilities, is that the focus needs to be **in further improving the personal well-being of an individual with a disability by developing a range of resources and strategies** and this needs to include:

- **Choice and Personal autonomy**, opportunities to make choices and exercise self-determination, facilitated when needed through supported decision-making, moving away from guardianship regimes and substitute decision-making approaches. For people to have opportunities to make choices and decisions we need a range of support options available within the community, so people are encouraged to choose the service that they want and the person that they want to support them based on their needs and wishes.

- **Inclusive environments**, where persons with and without disabilities are included and valued, such as supported employment, supported living, inclusive education, inclusive leisure, arts and culture. Independent living and inclusion in the community is wrongly associated with simply moving people from one large setting to smaller ones within the community. However, living independently means that people can participate in any aspect of life within their communities, and this may include working and learning in an equal basis and together with other members of the community.

- **Generic support** which is mainstream and accessible to all people, such as technology, prosthetics, lifelong education opportunities, reasonable accommodations. For persons with disabilities the provision for example of assistive technologies and devices can further support them to lead an independent life within the community. These technologies and devices need to be available and provided through national insurance schemes or other social protection schemes.

- **Specialised support**, which refers to the development of support targeted to persons with disabilities and other support needs, such as speech therapy, occupational therapy etc. Many persons with disabilities, especially people with higher support needs, may require specialised support to develop skills that may further support them lead an independent life.

Furthermore, any support system needs to follow a set of criteria, essential to ensure that every person with a disability, even people with significant support needs, will be supported to enjoy an independent and meaningful life within the community. Therefore, any system of supports needs to be:

- **Available** to all people, regardless of disability and age and it should include a range of support schemes that facilitate their independent living and inclusion in the community. This can include formal support schemes and informal ones with the support of family, friends, and the wider community or a smart combination of both, based on individual needs and wishes. However, overreliance to informal support schemes can increase the pressure and responsibility of care that may be experienced by informal carers and thus it is crucial for Member States to ensure the availability of formal ones. Simultaneously, Member States need to ensure the **availability of reliable, skilled, and trained workforce**, which is a *crucial component in ensuring the availability of support*.

- **Accessible** to all people with disabilities, ensuring that also people living in rural and insular areas have access to adequate support. This also includes elements, such as physical accessibility of a building, providing information in an accessible way for all persons with disabilities.

- **Known**, dissemination of information about existing services and social protection schemes, in an accessible way, must also be ensured by Member States.

- **Affordable** to people with disabilities, as the cost of support can vary in different Member States, and it can further contribute to many persons with disabilities living in poverty. Social protection schemes can support in covering the cost and Member States need to ensure that care and support are offered in no cost or within a reasonable cost. The eligibility criteria for people with disabilities accessing support, need to be *transparent, proportionate, and reasonable*.

- **Acceptable**, designed and offered in a rights-based approach, respecting dignity, autonomy, choice and independence of persons with disabilities, in line with the principles and articles of the UN CRPD. This indicates that support shall be provided in a person-centred way, based on the needs and wishes of persons with disabilities, respecting choice and control, facilitated when needed through supported decision-making.

- **High-quality**, this requires the development of services who are acceptable and focusing on improving the well-being of the people they support. These requires monitoring systems, focusing not only on the quality of the services and their structures but also on how services improve the quality of life of the people they support. Member States should develop and implement innovative quality systems that can further support the development and delivery of high-quality support services. This also includes setting up the above-mentioned criteria when developing support systems, as well as, ensuring a well-trained and skilled workforce.

Member States shall develop a range of support services in the community. Services which are available, accessible, known, affordable, acceptable and of high-quality. These include specialised services, generic support, and inclusive mainstream services. Any support system shall be developed with the focus on improving the well-being of individuals with disabilities and promoting autonomy, independent living, inclusion, choice and control.

3. Encouraging the development of well trained and adequate workforce of support services

Support professionals are the foundation of social services. If well-trained, they not only support people to fully enjoy their human rights but they also support their informal carers, mainly family members and women, to improve work-life balance, their employment and career prospects. They are also key to the development and further functioning of the services, and they can fulfil their important role if they are well-trained and in sufficient numbers. Training professionals is considered also one of the key principles for promoting the implementation of the Convention and deinstitutionalisation more broadly. Training can ensure that institutionalisation practices will be discontinued in the newly development community-based services and it should be **one of the starting points of any deinstitutionalisation action plan**.

However, one of the consequences of the underfunding of social care is precisely the cuts to expenditures around the training of staff, as well as the diminishing number of trained staff available. Upskilling and reskilling of the workforce can both make the sector more attractive but also ensure the provision of high-quality support towards persons with disabilities. Continuing professional development throughout the career of a social care and support worker is crucial due to the evolving nature of the job. However, training can have different formats, and each of these formats are equally important to ensure a rights-based approach to support. Classroom-based formal training followed by mentoring, on the job training, training received by the disabled person and the family, are few of the examples.

The social care and healthcare sectors have the potential of creating 8 million new jobs over the next decade. However, we are far from making the most out of this potential. Staff shortages have exacerbated after the COVID-19 pandemic, with many moving towards the healthcare sector and better paid positions, often in other EU countries. The lack of attractiveness of the sector, poor working conditions, often absent career, and knowledge advancement opportunities further contribute to this trend. The sector also struggles to attract men and it also relies on migrants, either from within or outside of the European Union.

The single most important element and challenge in social service provision is staff and the detrimental impact all these challenges can have on

the transition to person-centred and community-based forms of care and support (rather than institutional), in line with the UN CRPD, cannot be underestimated.

The promotion of **social dialogue between employers and workers representatives** in social care services is crucial. The European Commission, as communicated in the recent European Care Strategy, recognises and it will continue exploring the setup of a sectoral social dialogue for social services at EU level. This together with policies aiming at **better working conditions**, **better wages**, **education**, and **training** can make jobs in the social sector more attractive.

In Austria, after the pandemic hit the country, a three-year agreement between the social partners was found in April 2020. The social partners agreed to wage increases for 2020 and 2021, and to a working time reduction to 37 hours from 1 January 2022 onwards.

Simultaneously, the **development of new occupational profiles** for the staff working in social services can benefit both the transition from institutional culture in service provision towards person-centred support and the attractiveness of the jobs in the sector. Work in social services should not be static but evolving, based on the needs and wishes of the people each staff member supports. Supporting a person with a disability to live independently is about living a life full of experiences, new opportunities, possibilities, and this also means that the role of support staff shall be about establishing and maintaining the social roles of the person they support. This also means enabling front-line social care workers spending more time working with the people they support, rather than largely engaging with the administrative aspects of their work, such as reporting.

Furthermore, the **development of person-centred and community-based services** can also be at the centre of solving the sector's staff challenges as organisations who are more successful at recruitment and retention also tend to be organisations which have human-rights values at the heart of their work.

Member States should create social dialogue structures to identify solutions to staff shortages and create more attractive workplaces, job opportunities and improved occupational profiles. The EU can support in building the capacity of Member States for social dialogue through the European Social Fund+.

Member States should invest in training the social services workforce. Continuing professional development will make the sector more attractive and ensure a rights-based approach to care and support. The Erasmus+ funding programme can be supportive to reach this objective.

4. Strengthening the role of informal support networks

Informal support networks significantly contribute to the life of persons with disabilities since they fill out the gaps in the absence of adequate formal care and support services. Families, and other informal carers, mostly women, usually take up this role and on many occasions, this is done not by choice but out of necessity. As mentioned in the EU Care Strategy, this can have negative effects on the mental health and the income of informal carers, since the lack of adequate social care and support services have an impact mostly on women, as informal care responsibilities fall predominantly on them. Their role is not recognised and not renumerated and consequently it can also have an impact on the quality of care and support offered to the person cared for and it can increase the chances of institutionalisation for people with significant support needs. As essential as informal care is it shall not replace the responsibility of public authorities in each country to provide the required services to ensure that persons with disabilities have adequate support to fully enjoy their human rights. This also has major effects to gender equality and, hence, to the economy more broadly. As, investments in the social care and support sector contribute to social fairness and gender equality and promotes women's participation in the labour market and job creation.

A smart combination for example of formal and informal support can further improve the quality of life of informal carers, mostly women, their career opportunities and work-life balance. This further emphasises the need to develop a range of service in the community to support persons with disabilities, including respite care services. These types of services can encourage informal carers take breaks from their responsibilities, while their loves ones are supported. At the same time, there is a need to **develop support services also for the informal carers themselves**, such as counselling, phycological support, support to return to employment, but also offer better working conditions when employed to improve work-life balance. Training is equally important to ensure a rights-based approach to caring and supporting and this is a role that service providers can play. Lastly, informal carers shall be formally recognised, renumerated, taking their caring role into consideration in the retirement and other benefits.

As imperative is for persons with disabilities to be included in the community and engage equally with different members within it, equally important is to have the opportunity to connect and exchange with their peers. Peers are the people with the same or relevant lived experience. **Peer support networks** can help build this connection among persons with lived experiences and their families and carers. This can also facilitate the sharing of information but also the formation of strong advocacy networks that can benefit persons with disabilities taking a more active role in their communities and form relevant to them policies. **Peer support networks are one of the pillars of independent living** and it can support the transition from institutions to community-based support, since people that used to live in institutions can offer support to people currently transitioning in the community or to people still residing in institutions. Peer support networks are an essential component of informal support in the community and their development should be encouraged.

The EU Care Strategy makes implicit that Member States shall design support measures for informal carers, e.g. counselling, psychological support, respite care and/or adequate financial support, which does not deter labour market participation, together with policies to formalise informal care.

5. Forming adequate prevention mechanisms

Fostering support to families to avoid the institutionalisation of their children is key to ensure that there won't be new admissions to institutions. Institutionalisation segregates the child from its community and is detrimental to children's health and development, as rotating staff cannot provide the stability, security, and sense of love a child can receive from a long-term bond that comes with having a family. Some parents place their child in an institution because they are uncertain how to address their child's disability or meet their needs. The most appropriate environment for a child to flourish is within their families or a family-based environment and Member States shall ensure that families in risk receive adequate support to avoid potential separation of the child from their family. This support can have different forms, based on the needs of each family. It can also be in the form of financial support -since poverty is one of the main causes of family separation and institutionalisation- or referring the family to appropriate family-based care and support arrangements, among others. However, when it is not possible for the child to remain or to return to live with their parents, then family-based alternative forms of care must be considered and must be adequately developed.

Early Childhood Intervention schemes are a key element in the deinstitutionalisation process as they empower families, contribute to prevent the placement of children in institutions and foster their inclusion in education. Early Childhood Intervention or ECI is a field of family-centred, individualised services for infants and young children (generally 0-3 or 0-6) and their families. They help to identify, prevent, overcome, or minimise at-risk situations. They promote achieving the child's potential, and family strengthening and wellbeing. These services are particularly critical for children with developmental delays, physical, intellectual or sensory impairments, or conditions such as autism, and mental health issues.

More specifically, family-centred ECI can empower parents and support them in fulfilling their role. They are integrated and interdisciplinary

services, with the full participation of the health, social, and educational sectors and all relevant disciplines in supporting each family and child. Without quality support families are at higher risk of social exclusion and have to fill in the gap of service provision, with their financial resources, energies and time. This makes societies more unequal with a higher risk for the children to be placed in institutions. The consequences for those children can vary but have to do with higher risks of a lower development of cognitive and social skills, poor health and nutrition, educational exclusion, adult institutionalisation, fewer opportunities for inclusion in community activities and of reaching their full potential; with the economic consequences this entails too.

Additionally, ECI facilitates inclusion in general pre-primary education, adaptation in inclusive educational settings, with less school dropout and grade repetition, and better future educational outcomes. Inclusion in quality Early Childhood Education and Care (ECEC) is very important especially for families that are in disadvantaged situations, as it helps compensate for disadvantage at home and enable children with developmental delays and impairments to have an equally strong start in life. ECEC is beneficial as it attends to children's developmental needs in a holistic manner and it can further create strong linkages with families and communities as partners in child development and learning, while being attentive to their backgrounds, needs and situations.

Preventing institutionalisation includes a variety of measures in different areas, such as the development of a range of support services in the community, creating accessible mainstream services and infrastructure, implementing reforms in health, education, employment, social protection, housing etc, establishing gate keeping mechanisms to halt new admissions in institutions, among others. Many of these measures will be further analysed among the different principles of this paper but we have decided to strategically focus here on the development of early childhood intervention schemes.

Member States shall form adequate prevention mechanisms and quality Early Childhood Intervention systems which are family-centred

need to be in the core of this process. The Technical Support Instrument can support Member States achieve this objective.

6. Creating accessible and inclusive mainstream services

Living independently and included in the community is wrongly associated with moving people from large residential settings to smaller ones within the community. It is about people living as equal members of the society, with rights and obligations as every citizen while receiving the support they need, and they wish to receive. Community-based services include both specialised services, such as personal assistance, respite care services, supported-living services, but also **mainstream services who are accessible and inclusive**, such as housing, healthcare, education, employment, culture and leisure etc.

Even if people with disabilities and children live outside of large residential institutions, they can still be segregated if there are not surrounded by an accessible and inclusive environment, such as accessible and inclusive mainstream services. And even if there are accessible and inclusive mainstream services in place, they can still be segregating in practice. Inclusive education for example, has been implemented in different countries and with different levels of implementation. However, when there are no adapted to the individual's needs educational materials, when the school building and its facilities are not accessible, among others, these can hinder the full participation of students with disabilities in the education system.

Along with developing accessible and mainstream services we also need to consider the staff working in these services. For all people to be fully included in mainstream services, it is imperative for the **staff working on these to have the right knowledge, skills, and attitude towards persons with disabilities.** And this is a role that service providers of persons with disabilities can support with. Service providers can collaborate

with mainstream stakeholders to further support them, they can develop open-resources centres to share their knowledge and expertise, they can promote positive attitudes towards inclusion and diversity, among others. Although, Member States are responsible to support staff working in mainstream services, this needs to be done in **collaboration with service providers and persons with disabilities**. This is not a one size fits all approach, since mainstream services cover a lot of different areas of life, from education to employment, from the judicial system to the healthcare system. Including disability relevant information to all high-level education curricula can support in preparing all future professionals.

Member States shall develop accessible and inclusive mainstream services that can benefit every member of the community and thus further enable people with disabilities to live ordinary lives in the community, with equal opportunities to others.

Member States shall develop awareness raising campaigns for staff working in mainstream services, training programs to ensure that staff has the right skills, knowledge, attitude to further support the inclusion of persons with disabilities in the community. These initiatives shall be developed with the collaboration of service providers and persons with disabilities and through EU funding programmes, such as Erasmus+, to ensure a comprehensive and high-quality approach.

7. Guaranteeing choice and control of persons with disabilities

Realising the right of persons with disabilities to live independently in the community, indicates that **people shall be able to control their lives, make choices** as to where to live, with whom, what type of support they want and need to receive, who they want to support them and how. As enshrined in Article 19 and General Comment 5 *"Independent living means that individuals with disabilities are provided with all necessary means*

to enable them to exercise choice and control over their lives and make all decisions concerning their lives". Persons with disabilities and mostly persons with intellectual disabilities are deprived from their right to make decisions. They often have legal guardians who makes some or all decisions for them, and often without consulting the people themselves. This situation not only infringes their right to legal capacity, but it also puts pressure and uncertainty on social services and their staff since the legal guardians may not always support the decisions of the individuals under guardianship. Furthermore, making decisions also involves taking risks, and support staff often struggles to find the right balance between ensuring the safety of the person they support and empowering them in enjoying their rights, including their right of making decisions which involve risks. Even more if they are legally responsible for these decisions.

A **legal reform** abolishing substitute decision-making and establishing supported decision-making is imperative. Based on the Convention, **equality before the law is a basic general principle of human rights protection and is indispensable for the exercise of other human rights**, therefore Article 12 is often referred to as the key article of the UNCRPD which can trigger full enjoyment of all other rights included in the UNCRPD. Non enjoyment of legal capacity, may interfere with the right to independent living, employment, health, etc. Supported decision-making comprises various support options which give priority to a person's will and preferences and respect human rights norms. The support provided to a person with a disability can have different levels of intensity, however, it shall always respect the wishes of a person and not what is perceived as being in the best interest of the person.

In Spain Law 8/2021 reformed their system into promoting respect for the will and preferences of persons with disabilities and advancing their autonomy. This Law reforms civil and procedural legislation to promote support for persons with disabilities in the exercise of their legal capacity, moving away from the guardianship model.

Along with the necessary legal reforms, Member States need to upskill and reskill service providers, and its respective workforce by developing specific training programmes about the right of persons with disabilities to legal capacity and how this shall be implemented via supported decision-making.

Self-Directed Support can further reinforce in achieving the right of persons with disabilities to make decisions and have control over their life. This is a new way of organising support to people with disabilities and families in order to better respect their human rights and advance their citizenship. This means shifting control to the person or the family in case of children, so they can shape the support they need to fit their needs and wishes. It has been proven that self-directed support can improve the lives of people as people have freedom to choose the support they need to achieve their aspirations in life. Self-directed support is an approach which puts the person in the centre of planning and can encompass different elements, one of these elements being personal budgets funding model. Self-directed support's components have been developing around Europe, personal assistance services in Sweden, personal budgets in Flanders, direct payments in the UK, are few examples.

> Scotland introduced the Social Care (Self-Directed Support) Act in 2013 which provided people with care and support needs four options for receiving support. Individuals can: Purchase their own support and use a direct payment to pay a person or third party; Direct their own support and the local council will arrange it; Allow the local council to direct and arrange their support or a combination of the previous options.

Member States shall establish legal frameworks abolishing substitute decision-making and institute supported decision-making. Self-directed support can further enable persons with disabilities to have control over their lives and the support they wish and need to receive.

Member States shall develop training on supported decision-making, and the Citizens, Equality, Rights and Values programme can be used for this purpose. These trainings can be provided through VET programmes, long-life education programmes, higher level education institutions that can increase the practical knowledge of current and future social sector professionals.

8. Adopting clear and facilitating legal frameworks

Since the introduction of the UN CRPD, the role of social services has transitioned to human-rights, empowering and person-centred forms of support. This transformation of support, however, needs strong foundations and legal frameworks are considered one of them.

Reality is that there are very few examples of legal frameworks in full compliance with the mandates of the Convention across the world. There is a big gap between the principles of the UN CRPD, the legal frameworks in EU Member States and the implementation of the Convention on the service provision level. Across Europe, we may identify innovative social services -following the principles of the Convention- with non-compliant legal frameworks or in certain cases even the opposite. Although, this does not suggest putting all the emphasis on policies and losing the scope, which is the actual implementation of the Convention on the service provision level. But rather wishes to emphasise the important role that policies play by either further supporting or restricting the application of the UN CRPD principles on the day-to-day delivery of support. Deinstitutionalisation reforms, Housing policies reform, Self-directed support are a few examples of facilitating legal frameworks that can support in realising the right of persons with disabilities to live independently in the community.

Housing policies reform

All people have the right to adequate housing, including persons with disabilities, based on article 28 on adequate standard of living and social protection. In late years, the housing and utility costs have imposed a financial burden on many households, and especially affecting those with low and middle income. Persons with disabilities are among these households, since they are suffering from higher rates of poverty, social exclusion and unemployment and after every crisis the recovery rates of persons with disabilities are much slower than of persons without disabilities. This makes them unable to access the right and affordable housing infrastructure. Persons with disabilities are at an increased risk of becoming homeless and socially excluded, due to institutionalisation, lack of available support services in the community, not available and not affordable housing options, among others. The overlap between homelessness and disability is clear since *disability leads often to homelessness and homelessness can create or exacerbate impairments and additional barriers*. Solutions identified for homeless people, can also benefit persons with disabilities, such as the Housing First approach, since it is based in principles linked to choice and control, person-centred planning, flexible open-ended support, including re-integration to the community.

Since, the pace of price increases in housing has accelerated and housing prices are currently even higher that they were in the financial crisis of 2008, social housing for persons with disabilities can also be a solution. However, social housing providers report the lack of affordable housing, especially in urban areas in many Member States and further emphasise that *the size of social housing is way too small compared to the demand, resulting in waiting lists*.

Member States need to recognise the housing crisis and revise relevant housing policies. While securing housing for persons with disabilities, **it is essential to ensure access to services and support**, further enabling people with disabilities realising their right to independent living and inclusion in the community. This includes in-home, residential and community support services. However, the provision of housing (contract with a regular landlord or the service provider overseeing the provision of personalised accommodation) **should not be tied** directly to the support services a person receives. Since, separating the provision of housing and support will ensure that individuals will not lose their support should they decide to change their living arrangements, for whatever reason or vice versa.

Based on the French legislation each housing development has the obligation to provide 25% social housing. Also, at least 25% of the housing stock over the territory of a commune must be provided by entitled social housing associations. It concerns communes of at least 1500 inhabitants in Île-de France and of at least 3500 inhabitants in the rest of France.

Mainstreaming disability in every policy

Living independently in the community for persons with disabilities requires a holistic reform approach to ensure that people with disabilities are equal members of the community and enjoy all their human rights on an equal basis with their non-disabled peers. This indicates that policy makers need to establish a human-rights approach to disability, and this can be done by receiving training on the Convention and learning by collaborating with persons with disabilities, their families, their representative organisations and service providers. The holistic reform approach further emphasises the need to establish cooperation mechanisms with inter-Ministerial agencies, as well as local actors. To realise the right to independent life and inclusion in the community, reforms need to be established across different Ministries and agencies. This is about living an everyday life in everyday places, to regard persons with disabilities as citizens with equal opportunities to employment, education, having a family, having a home, friends, a community, like any other individual at similar stages of life while receiving adequate to their needs and wishes support.

New Zealand has developed a toolkit to support policy makers consider how their policy actions can have implications on the enjoyment of human rights of persons with disabilities and how they can transform any policy into disability policy. The Convention brings change on how disability is perceived – as an interaction between an individual's personal condition and environmental factors which together lead to disability, and they either enhance or hinder an individual's participation in the society. This is translated into policy as any decision and action that can create an environment where persons with disabilities will enjoy equal opportunities, as their non-disabled peers. And with this toolkit, New Zealand aims to support policy makers consider every policy and service decision as an opportunity to create a place where *disabled people have an equal opportunity to achieve their goals and aspirations*. This can support any policy maker, from any Ministry and agency to identify how their decisions and actions can further support persons with disabilities enjoy their right to live independently in the community. This may include policy makers from the Ministry of Health, Transportation, Education, Labour, Finance, Justice, among others.

Member States need to establish clear and facilitating legal frameworks and ensure a human-rights approach to disability in any policy to further support persons with disabilities realise their right to live independently in the community and the development of person-centred services based in the community, following the principles of the Convention.

The new flagship project "Towards person-centred integrated care", of the Technical Support Instrument to the Member States as communicated in the EU Care Strategy, can further support Member States in putting people at the centre of policies and ensuring the development of an environment where people with disabilities will enjoy equal opportunities in an equal basis as others.

9. Ensuring a co-productive approach when designing a systems reform

The design, development and implementation of any reform should be guided by a **co-production approach** and centralised around the **"nothing about us without us"** principle. People can experience disability in different ways, based on their age, gender and other factors. Policy makers need to acknowledge and respect the diversity within the disability community and recognise the value it adds to the community. Therefore, persons with disabilities, their families and their representative organisations should drive and influence the reform process, but service providers and their representative organisations should also be a recognised voice, with the support of a broad diversity of relevant stakeholders. These stakeholders may include, researchers, Member States, regional and local authorities' representatives, among others. Building a shared vision is an important step in achieving the right of persons with disabilities to live independently in the community. And, adopting a co-production approach will ensure there is local ownership of the process and should result in a strong commitment to improving people's lives.

Establishing a co-production approach may be challenging at first, especially in states were self-advocacy or coalitions of different stakeholders have not been yet formed. However, it is essential when identifying stakeholders to focus not only on the leaders, the most fortunate among the stakeholders or the ones that are in favor of the reform. But to also identify people with higher support needs, people who are still residing in institutions, the professionals currently working in institutions or the less eager ones. This approach will not only strengthen the relationship between relevant stakeholders but it will

support in avoiding possible resistance to change, thus moving closer to realising the right to live independently and be included in the community for persons with disabilities.

Additionally, when designing a reform, setting up a **coordination agency within the Ministry** is necessary to encourage cooperation between Ministries and between central and local authorities. Synergies with different policy areas such as financial, healthcare, education, housing, accessibility and others are crucial to ensure the rights of persons with disabilities to live independently and being active member of the community.

Member States shall recognise people with disabilities as experts and putting in practice the "Nothing about us without us" principle should be the guidance to any action fostering inclusive living. Even those people with higher support needs shall be included in the consultation processes. Service providers, representatives of public authorities should also be involved, even the less eager to change.

10. Establishing correct and sustainable funding models

Living independently and be included in the community for many persons with disabilities means having adequate support based on their needs and wishes to realise this right. That demands a rather evolving funding model for support services to assist in meeting these needs and wishes. The economic decisions taken, as a result of the 2008 financial crisis, contributed to years of under-funding of services in the field of disability, and the ongoing structural weaknesses of the sector towards quality, innovation, staff shortages and outdated infrastructure. This was brought to light and worsened by the COVID-19 pandemic and its impact also on the financial continuity of many providers of services. The consequences of post-pandemic inflation are still being felt and the resilience of the global economy, as well as of social services, is still largely impaired. A re-

think is needed around how much is invested in care and support for persons with disabilities, how these investments are being used, as well as the funding model used and the continuity of the system itself.

The experience from Europe to date suggests that the type of funding model chosen to support social services can have a dramatic (and often adverse) impact on services and their quality. For example, in a competitive market (often found in public procurement) where price nearly always outweighs quality as a criterion for winning the contract, and regular (sometimes even annual) contract renegotiations result in an entirely short-term approach. There are also major challenges from when it comes to linking public procurement contracts to specific quality criteria which are generally very complex to measure and quantify; thus making public procurement an inadequate tool for quality social care and support. It has been characteristic to these models that procedures are made far from people. Individual needs and aspirations are often not taken into account, but the procedure is implemented for rather big groups of people. Then service providers are forced to make service offers based on this, without individual considerations. Also, people's needs and preferences are changing and they might need more or different kind of support than settled in the procurement process. Apart from the negative impact that this has on the people supported, it can create unstable employment for staff, insecure funding for providers and can lead to impossible demands on the capacity of small local providers to cope with delayed cash flows, with re-submission requirements and to create attractive jobs etc.

The European Commission should consider the following key principles for an effective national funding mechanism for disability services in line with international human rights standards:

- **Mindset first**: social services play a crucial role in further enabling people to full enjoy their human rights, in line with the UN CRPD. Therefore, the funding of social services needs to encourage and empower social services in this role.

- **Commitment** from public authorities to provide adequate and sustainable funding to give services the necessary space to transform their services towards better quality, more empowering and person-centred forms of support. This goes together with **Transparency** on the rules that define the funding mechanism.

- Based on **Partnership and dialogue**: developing trust between stakeholders, such as public authorities, service providers, persons receiving support, their family members is a key element to the correct implementation of any policy. This relationship supports in identifying solutions to effectively detect the needs and address challenges.

- **Flexible** to allow room to services to innovate and support people with disabilities based on a person-centred way, in line with their needs, and wishes. Too often, funding models tend to remove any room for flexibility and innovation as costings are linked to very specific tasks and consequently this has an impact on the support that persons with disabilities receive.

- **User-centred** to empower persons with support needs to have more choice and control over the care and support they receive, allowing them to meet their individualised needs, wishes and preferences and to live their lives as they want.

- **With established Quality and monitoring systems.** An effective funding model should be continuously monitored in terms of the quality of its impact over the well-being and quality of life of people it supports and improved accordingly. The Quality and Monitoring systems should also be developed and implemented, in partnership with all relevant stakeholders.

- **Providing the right Support and Capacity-building mechanisms** to ensure that all stakeholders have the right understanding and support to use the new policy in the best possible way.

Currently, there are many initiatives being taken by Authorities to create [alternative to public procurement funding models](#) which promote

effectiveness, user involvement and partnership approaches to services for persons with disabilities, which make the most of the significant advantages offered by Europe's strong network of not-for-profit social services.

> Promising examples of funding models across Europe:
>
> » **Personal Budgets** is an innovative funding model gaining the attention of public authorities across the EU. Sweden for example is one of the first countries to introduce the Personal Assistance Budget (PAB) in their national law and in 1993, similarly in the Netherlands, since 1995. In Flanders, Belgium the personal financing has been introduced since 2016. Many other EU countries, such as Ireland, Austria, Spain, and Finland have started pilot projects related to the personal budgets funding model.
>
> » **Partnership models**: In 2017 in Italy the "Code of the Third Sector" was enacted, introducing alternative models to public procurement for the provision of social services. Through a model of partnership and collaboration between services and public authorities there is a 3-step model that is implemented.
>
> »» Through **co-programming** the services together with the public authorities are investigating to identify the societal needs, the key areas of actions and the resources available.
>
> »» Followed by **project co-development**, they define the services/ interventions that are needed to meet the needs that they were identified during the co-programming stage. This is mainly happening through roundtable meetings between services and public authorities.
>
> »» Lastly, during the **accreditation phase**, the services with whom the public authorities will activate the project co-development partnership are identified.

Member States need to identify alternative funding models to public procurement that fully consider the needs, wishes of people with disabilities, as well as partnership approaches with not-for-profit social services, while ensuring the sustainability of the services.

11. Forming Innovative Quality Assurance Systems

High-quality services, as indicated also on the EU Care Strategy, have clear benefits for all ages. They can prevent institutionalisation or the need for increased support later in life, reduce the pressure and responsibility of care that may be experienced by family and informal carers, as well as providing them with more life choices, career options and work-life balance. From early childhood intervention to care and support services for older people, services play a crucial role in enabling and empowering people to live in dignity, fully enjoy their human rights and improve their quality of life based on their needs and wishes. Therefore, high-quality services have benefits not only for the people in need of care and support but also for their carers and a positive impact to the society.

As we are moving forward towards the development of person-centred services, services that are empowering and enabling people with disabilities to live independently within their community, **we need quality frameworks that are reflecting this rights-based approach to care and support.** The European Commission will launch by 2024, an EU Framework on Social Services of Excellence for Persons with Disabilities to improve service delivery for persons with disabilities and to enhance the attractiveness of jobs in this area including through upskilling and reskilling of service providers. This Framework can support in the **development for example of innovative quality assurance systems within Member States that can further support the development and delivery of high-quality support services.**

However, for this Framework to accomplish this objective, it needs to **encourage the development and delivery of services in line with human rights principles** as enshrined in the Convention, such as the right of persons with disabilities to live independently in the society. This further indicates that the focus, when developing a quality framework, needs to be on the **impact that the service has on the quality of life of the people it supports primarily**. This is referred to in the literature as outcomes and these outcomes need to be based on rights established in the UN CRPD and centred on the quality of life concept. The emphasis on quality of life of the people receiving care is also highlighted in the recent Proposal for a Council Recommendation on access to affordable high-quality long-term care by the European Commission. There are several indicators that can be used for this purpose and **people's experiences and perspectives should be at the core of a measurement** as such. This **combined with indicators that look at the structures** of a service, such as **the resources** available, staff ratio, equipment, facilities among others, as well as processes such as the way support is provided, will help in providing a comprehensive picture of the service's quality.

Additionally, the establishment of independent monitoring systems can further support in the development and assessment of DI processes. National human rights institutions, such as an ombudsperson's office can support to monitor that any reforms under the DI processes promote and protect the rights of persons with disabilities as established in the Convention. Civil society organisations play an equally important role in this process, they need to be actively involved from the designing – development phase to the monitoring phase.

Member States shall develop innovative quality frameworks, that support persons with disabilities to receive services that will further empower and enable them to live independently in their communities. The EU can support them with the development of an innovative EU Framework for Social Services of Excellence and EU funding streams, such as the European Social Fund+ and the Support for Reform programme, could be used to facilitate the take up of the Framework.

12. Scaling up the use of technological aids

One of the main barriers to human rights enjoyment for persons with disabilities is the issue of accessibility. The UN CRPD introduces a holistic and integrated human rights approach to address barriers faced by persons with disabilities and it calls for the removal of all socially constructed barriers which are the main cause of the social exclusion of persons with disabilities. Digitalisation has the power to increase accessibility of a number of products and services for people across their life; be -for instance- it to live independently. Equally possible is that digitalisation creates new barriers for persons with disabilities if the digital products & services that are developed are not accessible. For this reason, the Convention highlights, beside accessibility, the importance of Universal Design, Accessibility and access to Assistive Technology.

To support people with disabilities to live independently within the community we need products, environments, and services usable by all people, to the greatest extent possible, without the need for adaptation or specialised design (Universal Design). However, we also need to make necessary and appropriate modifications and adjustments so that persons with disabilities can enjoy and exercise on an equal basis with others all human rights and fundamental freedoms (Reasonable accommodations). As well as to specifically design products or technology-based services, to enable individuals with disabilities to participate equally in any aspect of life (Assistive technologies).

Technological developments have also provided care and support services with opportunities to develop new ways of delivering their services and for the people they support to benefit from them. Internet connectivity and the possibility to connect devices that gather independently data have opened different possibilities in the areas of communication, counselling, data acquisition and elaboration, remote monitoring and support, etc. This can have clear benefits for both persons receiving support but also the services and staff providing the support. New digital technologies can help to reduce the barriers that some persons with disabilities face in coming to work for example by allowing people to work from home and still be digitally connected to the office. Online platforms and support robots can bring persons with disabilities much closer to inclusive living and enjoying their human rights, especially the ones leaving in rural and remote areas were support in scarce. Electronic files to better manage workload and optimise workflows and processes, can create better and more attractive jobs in the sector. Apart of ensuring that the right infrastructure is in place to guarantee digital connectivity, there is a need for training and re-training of both people with disabilities, their families and service providers, staff on the possibilities of these technologies and the right use of these possibilities. This in no way aims to support over-reliance in virtual forms of support but to highlight that by ensuring the right use of technological developments in the field of care and support, Member States may further remove barriers for persons with disabilities that are impacting their access to services and their inclusion in the community and create more attractive job opportunities.

Member States need to ensure the development of infrastructure following universal design principles and whenever not applicable ensuring that persons with disabilities have access to reasonable accommodations. Assistive technologies can foster independent living in the community and their development and availability within different Member States should be encouraged. Social protection schemes and national insurance schemes should support persons with disabilities access the appropriate equipment that is needed to promote independent living and inclusion in the community.

IV. Recommendations to EU policy makers

The EU has several instruments in its disposal to support Member States in their efforts to realise the right of persons with disabilities to live independently in the community:

- The Guidance towards Member States recommending improvements to enable persons with care and support needs live independently in the community can support in providing a **clear vision and understanding** towards this goal. This can be achieved by:

  - •• **highlighting the impact that this transition away from institutional forms of care will have to the lives of persons with disabilities and the enjoyment of their human rights**. As well as, to their families, caregivers and the society and economy as a whole.

  - •• providing **clear definitions of community living and deinstitutionalisation**, strengthening the understanding of Member States towards what they should be working on. This can be further reinforced by accompanying the guidance with examples of promising community-based services and policy reforms that have been developed and implemented in different EU countries. The input of the European Expert group on the transition from institutional to community-based care shall be incorporated in the Guidance.

  - •• underlining the **holistic approach** that needs to be taken into consideration when designing reforms to achieve improvements on the right of persons with disabilities to live independently in the community, as well as key procedures. This needs to include the development of person-centred services based in the community and inclusive mainstream services by applying universal design and whenever it is not applicable by providing reasonable accommodations to ensure the inclusion of persons with disabilities in the community.

  - •• emphasising that for any reform strategy to be successful, governments need to ensure a **co-production approach** with relevant stakeholders and form **coordination mechanisms** between central government and local actors, as well as inter-Ministerial agencies.

  - •• clarifying that public procurement is not the right model to fund social care and support and the **need for Member States to invest in alternative funding models**, such as personal budgets and partnership approaches.

- The Technical Support Instrument can support Member States implement the first step towards realising the right of persons with disabilities to live independently in the community, among others. This first step is **setting up the appropriate vision in a DI strategy with an accompanied action plan** to operationalise this vision.

- This instrument can further support to **develop preventative measures to institutionalisation**, such as the development of early childhood intervention schemes, family-based support, and family-based alternative care.

- Though the European Social Fund+ programme the EU can build the capacity at national level for the creation of **social dialogue structures**. As it was proposed in the EU Care Strategy, effective social dialogue can help to address the workforce challenges

in the social care sector. **Upskilling and re-skilling the workforce in social services** is equally important, and the Erasmus+ funding programme can be used to support this objective.
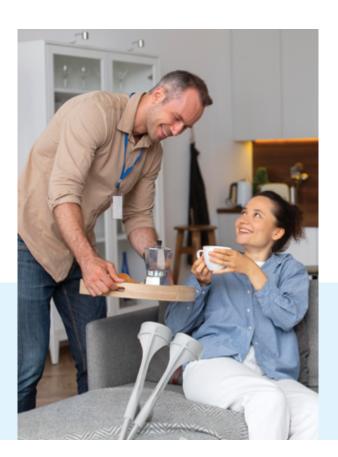
- The ESF+ programme can also be used to **fund social inclusion projects** in the field of social care and support, however, the EU needs to ensure that the funds are used in the right way and support the development or improvement of person-centred and community-based services. EU funds shall not be used for the development of new institutions or the refurbishment of old ones. The European Regional Development Fund can also facilitate the **development of inclusive infrastructure**, among others, to facilitate the inclusion of persons with disabilities in the community. The EU needs to dedicate 10% of the budget from ERDF to support deinstitutionalisation programmes.

- An innovative **EU Framework for Social Services of Excellence** should be established and EU funding streams, such as the European Social Fund+ and the Support for Reform programme, could be used to facilitate the take up of this Framework in Member States.

- InvestEU can also be used to fund the development of person-centred services in the community. However, the EU needs to ensure that this funding programme is not used to build outdated residential facilities, the **regulations, as set up in the ESF+ and ERDF on social infrastructure investments, need to also apply in the InvestEU programme.**

- The Recovery and Resilience facility is currently being used in a number of States to fund the development or refurbishment of large residential institutions. More recently, in Bulgaria, as part of their Recovery and Resilience Plan, the government has drawn up an "Ordinance on the Quality of Social Services" which has been approved by the European Commission. This Ordinance will support investments towards the development of institutions, housing up to 120 people when the house is intended for older people and up to 30 people when the house is intended for persons with disabilities. These

investments are not in line with the right of persons with disabilities to live independently in the community and **the EU needs to re-assess and monitor continuously the use of the RRF funds, to ensure that they won't be used by any Member State for the development of outdated residential infrastructures.**

- The creation of Knowledge Hubs -as mentioned on the EU Care Strategy- under the Horizon Europe partnership "Transforming health and care" can also be used to facilitate **transferability of knowledge and good practices** and act as an exchange forum for Member State representatives and other relevant actors for relevant with deinstitutionalisation elements.

- Additional research is needed at EU level to better understand the **state of play of deinstitutionalisation across Europe**, the number of people currently living in institutions, the number of people that have transitioned to Independent Living, among others. This will further support in the development of indicators for the Social Scoreboard and the European Semester to monitor improvements in this area.

- The Guidance on independent living and inclusion in the community towards Member States, and new or existing funding streams can also **apply and support improvements in Non-EU Member States**.

  - The war in Ukraine, further revealed the need for EU support in non-EU Member States. Currently, there are more than 2.7 million persons with disabilities affected by the war and the prevalence of institutions in the country calls for a disability-inclusive reconstruction process. EU funds and technical support can assist towards this objective by ensuring the development of a reform process aiming in deinstitutionalisation and the development of person-centred services in the community supporting persons with disabilities to live independently in the community. Humanitarian aid and emergency responses shall facilitate this transition away from institutionalised

forms of care and ensure the development of inclusive infrastructure and not the reconstruction of institutions.

•• There are several funding instruments that have already supported non-EU Member States in their deinstitutionalisation strategies. The Directorate General for International Partnerships, Directorate-General for European Civil Protection and Humanitarian Aid Operations, Directorate-General for Neighbourhood and Enlargement Negotiations and the European External Action Service are already playing a leading role in supporting the transition from institutional to community and family-based care and support in non-EU Member States

••• The Neighbourhood Development and International Cooperation Instrument (NDICI) for example has successfully supported deinstitu-

tionalisation strategies most recently in Armenia and Azerbaijan.

••• The Regulation governing the new Instrument for Pre-accession Assistance III (IPA III) 2021-2027 includes the transition from institutional to family and community-based care as a priority for investment.

••• These showcase the role that the EU can play in supporting non-EU Member States in realising the right of persons with disabilities to live independently, even in emergencies and crises, as the war in Ukraine. Therefore, all future EU external assistance initiatives and funding instruments, including those directed at migration and crises, need to continue working and prioritise actions linked to the transition from institutions to family and community-based care and support services.

EUROPEAN ASSOCIATION OF SERVICE PROVIDERS FOR PERSONS WITH DISABILITIES

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