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Particip.AGE Project

Supporting community participation and social inclusion of Ageing People with Intellectual Disabilities

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Ageing people with intellectual disabilities:
A pathway to their social inclusion

Particip.AGE

Project Partners:

European Platform for Rehabilitation, Belgium; **Fundación INTRAS**, Spain; **Mariaberg e.V**, Germany; **Medea**, Italy; **University of Galway**, Ireland; **Panagia Eleousa**, Greece

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Abstract

This final report (study) gathers a summary of the findings outcome of three major analyses done throughout the research activities of the project, such as: good practices and case studies on the topic of policy and regulations on support to ageing persons with intellectual disabilities (specifically over 50 years of age, without discrimination based on gender, age, social status or other characteristics); questionnaire on the topic of social inclusion of ageing persons with intellectual disabilities conducted both with the target group – ageing persons with intellectual disabilities and the staff working with ageing persons with intellectual disabilities; stakeholder needs analysis on supporting community participation and social inclusion of ageing persons with intellectual disabilities.

Summarizing the findings this report showcases the barriers and facilitators that ageing persons with intellectual disabilities face on their path to social inclusion and provides policy recommendations for policy-makers (both on national and European levels), users (ageing persons with intellectual disabilities) and staff (service providers for ageing persons with intellectual disabilities).

In order to elaborate this study, both the project consortium and the project's Policy Advisory Board were involved by providing their feedback expertise.

Introduction

According to Article 5 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)[1] people with disabilities have the right to be included in the community and live independently with quality, accessible, person-centred and affordable, community- and family-based services comprising personal assistance, medical care and interventions by social workers. More precisely, the UN CRPD Art. 5 refers to the right to equality and non-discrimination of people with disabilities, with the support of Art. 19 of the Convention referring to the right of Persons with Disabilities to live independently and be included in the community and Art. 25 (b) referring to the provision of health services needed by persons with disabilities specifically because of their disabilities including services designed

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[1] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

to minimize and prevent further disabilities including among children and older persons. The EU as a signatory party of the Convention is obliged to ensure these rights are met within its territory. In this respect, the new European Strategy on the Rights of Persons with Disabilities 2021-2030 is the main instrument to monitor its implementation and thus, to recognize that people with invisible disabilities, such as people with intellectual disabilities do not always receive the tailored support they need, which has been also aggravated by the Covid-19 crisis.

Another legal document referring to inclusion of persons with a disability is the European Pillar of Social Rights. On its Principle 17 addresses the need to include people with disabilities in our society: "People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs[2]" and the Principle 18 on Long Term care which states that "everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services[3]".

Over the past three decades, advancements in medical care, therapeutic interventions and growing social support has allowed for a remarkable shift in the life expectancy of ageing people with intellectual disabilities (APWID). With the exception of Down Syndrome, the collective increase in life expectancy has been substantial, nearly aligning with that of the general population (Coppus, 2013). A longitudinal cohort study by Patja (et al., 2000) lends further support to this trend, revealing that individuals with mild intellectual disability (ID) exhibit a life expectancy on par with the general population. Conversely, those with severe and moderate ID experience decreased life expectancies relative to the general population, which is presumably linked to severe neurological deficits and associated disorders (Patja et al., 2000).

Yet, in tandem with these encouraging developments, the concept of age and ageing within this community has given rise to a series of novel challenges. Due to limited attention, the response framework to ensure optimal health and social care for ageing persons with intellectual disabilities in their later years remains lacking (Holland, 2000). Many factors contribute to this, including ageism and negative attitudes (David et al., 2015), diagnostic overshadowing and the resultant healthcare disparities (Bishop et al., 2013), the risk of age-related physical health issues, mental disorders and dementia (Sinnai et al., 2012), alongside

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[2] https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2021%3A102%3AFIN&qid=1614928358298#PP1Contents

[3] Ibid.

the nuanced responses of caregiving staff to age-associated health changes for those with intellectual disabilities (Webber et al., 2010). These factors collectively impede the process of 'successful' ageing within this demographic. As the life expectancy of ageing persons with intellectual disabilities continues to approach that of the general population, it is imperative to develop and implement policies and resources designed to optimise quality of life (QoL) for this population.

However, nowadays, persons with intellectual disabilities are living way longer than previous generations due to advances in medicine, rehabilitation, technology, etc. As a consequence, there is an increased likelihood of secondary medical conditions to ageing and/or to an individual's particular disability. Ageing persons with intellectual disabilities experience a high rate of medical, functional, and psychosocial complications and/or changes about 20-25 years sooner compared to aging individuals without disabilities; specifically, "…as persons with disability reach age 50, many show the kind of functional ages that would not be expected until age 70-75 in people without disabilities " (Campbell et al., 2017). Therefore, health, functional, and psychosocial changes not only impact the individual but the family as well, adding emotional and financial stress. Same applies to people with intellectual disabilities. These data highlight that this specific target group is facing a double vulnerability: early ageing and intellectual disability. Consequently, such conditions expose them to suffer from the combined effect, with a negative impact on their social inclusion, health, quality of life, etc. The early ageing of persons with intellectual disabilities puts them in the position that requires more and more support and care in the everyday life activities.

Furthermore, there are not sufficient studies on this specific target group, on their need, the challenges and barriers they face, etc. Even if these studies are available, they do not consider the fundamental elements, such as, for example, the impact of the digital transition on their support services and their lives, as well as their relationship with the community (the territorial one as well as the digital one). Also, on the other hand, the specific training courses for professionals who should support them and meet their specific and changing needs are lacking. This leads to the paradox of having very inadequate answers to the need of a doubly vulnerable group that, more than others, would need specific and effective support. All these shortcomings consequently have a devastating impact on one of the fundamental aspects of human's life: social inclusion and participation in the community. Taking part in community activities is regarded to be crucial for the wellbeing of every person, although, in fact, it is very difficult, if not impossible, for the specific group of ageing persons with intellectual disabilities.

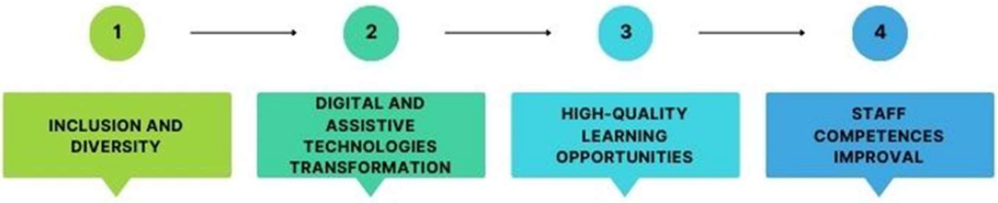
This further element feeds a negative spiral that exposes the ageing persons with intellectual disabilities to a further worsening of their quality of life and health.

For this reason, the main objective of this project is: establishing enhanced community and ensuring social inclusion of ageing persons with intellectual disabilities where their rights are fully protected.

To achieve the main objective the project will involve the major stakeholders, identified in the context analysis and, directly, the final target group which is ageing persons with intellectual disabilities, specifically above 50 y.o., without discrimination of gender, age, social status, or other characteristics.

Expected actions to be taken to achieve the main objective:

Main project's priorities:



Key messages, aims and challenges

Due to a substantial inefficacy of the legislation and policies that can assure the protection of ageing person's with intellectual disabilities rights, this target group faces a lot of challenges and barriers on their way to social inclusion and community participation.

According to the analysis conducted, although many policy documents on persons with intellectual disabilities and ageing (separately) have been published, there is still a clear lack of attention to the issue of 'double vulnerability' (ageing with an intellectual disability). Namely, research and data collection on the specificities of ageing persons with intellectual disabilities are lacking, meaning, for example, that the real needs of stakeholders are not taken into consideration on policy- and regulations making level. Even if available, research on this topic is not sufficiently considered in the policy making process. Policy recommendations that are produced often lack impact, failing to lead to regulations and legislations changes. Therefore, the existent regulations are considered to be ineffective and incapable of supporting the rights of ageing persons with intellectual disabilities.

As a particularly vulnerable group, ageing persons with intellectual disabilities have unique and differing characteristics that must be handled by highly specialized personnel which rises another barrier for ageing person's with intellectual disabilities inclusivity – inadequate competences of service providers' staff to support this vulnerable group.

The pursuit of social inclusion for ageing persons with intellectual disabilities is marked by many gaps and inequities, emphasising the need for theory-driven and population-motivated policies. The distinctive trajectory of this target's group ageing process can make them prone to marginalisation and exclusion from society. While policy and legislation can be tailored towards specific populations, there is an unfortunate tendency to overlook the diversity within the ageing persons with intellectual disabilities population, therefore limiting the quality of life (QoL) improvements which could be reached by promoting social inclusion (Turner & Cooper, 2015).

Previous qualitative research focusing on the perspective of individuals with intellectual disabilities (ID) on social inclusion highlight a variety of perceived barriers and facilitators. Namely, Abbott and McConkey (2006) identified four prominent barriers:

- lack of necessary knowledge and skills;

- role of support staff and service managers;
- location of house;
- community factors, such as amenities and the attitudes of key groups.

Participants in this study also suggested several solutions, for example, increasing access to appropriate skills training, being listened to by staff, increased support to access activities available locally and promoting volunteering to accompany individuals with intellectual disabilities in community activities.

Moreover, the target group – ageing persons with intellectual disabilities are characterised by such features that their social inclusion and participation in the community is much more difficult than that of the regular population. In particular, due to the following factors:

- the interpersonal network (family, friends, relatives, etc.) that often bridges the rest of society which tends to be weak and continues to weaken as the person ages;
- ageing persons with intellectual disabilities often live in isolated structures, physically far from the city center that is, therefore, constitutes a problem related to the institutionalization and consequent ghettoization of the target group;
- ageing persons with intellectual disabilities are also isolated from the online community, not just the physical one (internet access and its use are often prevented or the target group does not have the basic digital skills to use digital devices; they also lack the knowledge and skills to use social media safely, thus, they don't have any possible access to the digital community);
- ageing persons with intellectual disabilities often aren't aware of the assistive technology which is of significant importance nowadays as it constitutes a fundamental resource for improving the lives of vulnerable people, including their participation in society;
- existing approaches and tools for social inclusion of ageing persons with intellectual disabilities are not exploited in the daily practice.

Methodology

The provision of effective training modules to promote social inclusion for both staff/carers and ageing people with intellectual disability requires collating of high-quality information from key target groups (e.g. carers/service users/staff). One single method may not be effective in collecting useful data to provide a context within which to design training modules, rather a combination of methods across partnership sites should provide valuable information to facilitate this.

Therefore, the first months of the project were dedicated to collecting of further data for integration into the context analysis implemented in the project planning phase. In particular, the good practices on the topic of policy and regulations on support to ageing persons with intellectual disabilities (11), case studies on service provision (15) and questionnaires (278 responses in total) on the topic of social inclusion of ageing persons with intellectual disabilities conducted both with the target group – ageing persons with intellectual disabilities and the staff working with a target group and stakeholder needs analysis on supporting community participation and social inclusion of ageing persons with intellectual disabilities were collected.

The good practices and case studies have shown the diversity of participants, including both ageing persons with intellectual disabilities with mental and physical disabilities or even in combination. They also showed participants' growing need of socialization, especially due to its significant reduction as a consequence of COVID-19 social distancing measures. In the studies examples we observe that, besides of communication with family members, participants are eager to widen their communication circle and strive to be a part of larger community. They also demonstrated that a lot of participants have various hobbies as a part of their everyday life – it could be either something very simple like visiting a favourite café, going to cinema, theatre or museum, participating in city walks and excursions or something more complex like helping at day care centre as a volunteer. However, there are some cases where participants suffer from severe disabilities and are fully dependent on support from the caregivers. On the other hand, in the situations where users have a broader level of autonomy and their health conditions are not very severe, the case studies showed a positive impact of participants' autonomy facilitation.

Both good practices and case studies reflected a particular importance of interaction between the caregivers (service providers) and the users based on a mutual understanding and consideration of user's personal needs and wishes. They also highlighted that not every user is well-aware of the assistive technology enhanced possibilities, that is why this aspect shall be notably taken into consideration.

The questionnaire, in its turn, aimed to prioritise key barriers and facilitators that were identified through both a literature review and preliminary stakeholder meetings with the project partners. The questionnaire went through three revisions using the feedback from topic experts and project partners, before being sent to partners for translation and dissemination. Consequently, two separate questionnaires were designed – one that investigated the perspectives of ageing persons with intellectual disabilities and the other investigated the perspectives of staff who support the target group. Eligible participants for the questionnaire were recruited online or in-person through each organisation's professional networks. The first sample consisted of ageing persons with intellectual disabilities, who were required to be the minimum age of 50 years and have a formal diagnosis of intellectual disability with no exclusion criteria which referred to socioeconomic status or cultural background. As this is a population with cognitive difficulties, caregivers of the sample were asked to provide any required assistance to the participants when completing the survey form. The second sample consisted of staff who support the target group, who were required to be the minimum age of 18 years and to be formally employed in a support role for ageing persons with intellectual disabilities. There were no exclusion criteria which referred to socioeconomic status or cultural background. Both staff and ageing persons with intellectual disabilities were recruited exclusively from four organisations: Panagia Eleousa (Greece), Mariaberg E.V. (Germany, Fundación Intras (Spain), and Rehab Group (Ireland).

Overview of findings

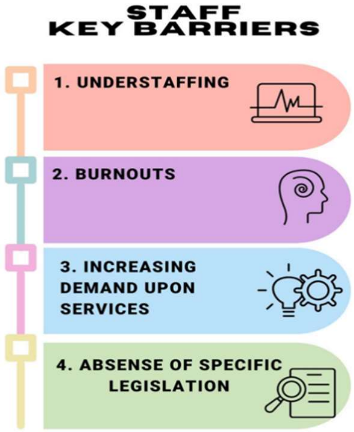
The research results have shown a significant interdependence of health conditions of the participants and the activities planned for them to take part in. The health conditions are usually the ones to reflect the need of assistance as well as the kind of it. For example, for participants with severe health conditions, it is not possible to participate in the activities aiming at increasing the level of autonomy as they are in a constant need of high supervision. On the other hand, for participants with higher level of flexibility as well as good physical and verbal skills, these activities may have a positive impact.

Furthermore, it is always useful to reflect the needs of participant and to examine their hobbies, habits and fears in order to know in which kind of environment they will feel themselves comfortable. The activities planned may also take into consideration the therapies and care schedule participant might already have in order not to cause any overlaps for him/her. What is also important, all the planned activities shall be adjusted to the preferences and mobility levels of the participants in order not to cause any disparities. In case where it is possible, it is always useful to engage the family members or close persons to the participants to collaborate in these activities for participants to feel themselves more comfortable and confident.

On the one hand project's findings demonstrated some differences between organisations, such as the perception of residential care as a facilitator rather than a barrier in some countries, indicate that cultural and contextual factors play a substantial role in shaping the experiences of ageing persons with intellectual disabilities. Trust in staff, emotional support, and greater staff connections are identified as crucial facilitators for social inclusion. This suggests that the human element plays a pivotal role in the journey of ageing persons with intellectual disabilities towards social inclusion. It is not merely about providing choices and activities; rather, it's about creating an environment that fosters trust, emotional well-being, and meaningful activities. Overall, it appears that the freedom to choose meaningful activities, while important, is not as critical as the openness of the community and the willingness of ageing persons with intellectual disabilities to participate in community-based activities. This implies that active inclusion within the existing social circle holds more significance in facilitating social inclusion than the diversity of available activities. These common facilitators underscore the importance of empowering ageing persons with intellectual disabilities and ensuring that the communities, policies, and support systems are inclusive, diverse, and responsive to the unique needs and perspectives of this type of population. Fostering a sense of belonging and trust within the community, coupled with promoting emotional well-being, can significantly contribute to enhancing social inclusion for ageing persons with intellectual disabilities.

The examination of ageing person's with intellectual disabilities experiences in sixdifferent European countries (Austria, Germany, Greece, Ireland, Italy and Spain) sheds light on both common and distinct challenges and opportunities they face. The target group consistently faces barriers that encompass limited choices, exclusion from their communities, and limited opportunities to engage in activities that match their preferences and values, often leading to feelings of isolation and exclusion. Namely, main challenges were described as follows:

As from the staff's side, one prevailing issue is the widespread problem of understaffing, a concern pervasive across all organisations participated in the project. This structural and organisational shortfall has a detrimental impact on the quality of care and services extended to ageing persons with intellectual disabilities. In addition, staff members grapple with financial constraints, particularly in terms of limited support for social inclusion activities. This financial constraint is further compounded by the increasing demand for services and a simultaneous reduction in financial support, creating a challenging environment for staff to provide optimal care. This highlights the need for addressing these barriers by not solely focusing on staff training but by providing them with additional support and resources. Furthermore, a moderate barrier identified by staff is the absence of specific legislation designed to protect the rights of ageing persons with intellectual disabilities with respect to social inclusion. On the facilitator side, a few key elements shine through in supporting staff members as they endeavour to overcome these barriers. Teamwork emerges as a significant asset, promoting collaborative efforts and shared responsibilities among staff. Interdisciplinary training (e.g., from a mental health professional) also plays a vital role, equipping staff with a broader skill set that allows them to better address the diverse needs of ageing persons with intellectual disabilities. Proactive planning for activities further enhances the capabilities of staff members, ensuring a well-structured and inclusive approach to social inclusion initiatives. The collective experiences of staff, as revealed in this survey, underscore the importance of addressing these barriers to ensure that ageing persons with intellectual disabilities receive the care and support necessary for leading inclusive and fulfilling lives. Furthermore, the findings highlight that staff member's experiences differ significantly across organisations, and the individual experiences of staff significantly contribute to the successful social inclusion of ageing persons with intellectual disabilities. Recognising and leveraging these differences can be instrumental in tailoring support and resources to enhance the quality of care provided by staff.



Policy and practice recommendations

Key policy and practice recommendations have been drawn from the analysis of these reports ?. While developing these policy and practice recommendations, all project findings were taken into account.

Among the policy and practice recommendations are: legislative proposals, guidelines and trainings, pathways and approaches developments. Each proposal is directed specifically towards its target audience including users (ageing persons with intellectual disabilities), staff (service providers) and policy-makers (EU institutions, national, regional and local authorities).

The key policy and practice recommendations that have been drawn from this report are the following:

1. **FOLLOWING HOLISTIC APPROACH WHILE TAKING DECISIONS CONCERNING AGEING PERSONS WITH INTELLECTUAL DISABILITIES**

The results reveal a common challenge in which ageing person's with intellectual disabilities values and preferences are oftentimes disregarded, highlighting a lack of personal agency and recognition of their individual choices and needs. This, in turn, hampers their opportunities for developing fulfilling friendships, significantly affecting their quality of life.

Solution: Develop policies and procedures designed specifically for ageing persons with intellectual disabilities and not only, in general, for persons with disabilities. For this purpose, existing good practices and case studies shall be taken into consideration and serve as a foundation among professionals and policy makers. They shall be disseminated at local and regional level through learning materials, workshops and trainings as well as up-skilling and re-skilling programmes.

Addressed to: EU INSTITUTIONS, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

2. INCREASE AWARENESS ABOUT THE PRESENCE OF AGEING PERSONS WITH INTELLECTUAL DISABILITIES AND FACILITATE THEIR COMMUNITY PARTICIPATION

The report has shown that communities are often being completely unaware of the presence of ageing persons with intellectual disabilities (especially surrounding institutions of the territorial communities) that leads to their marginalization and isolation which, in its turn, creates obstacles for inclusive society and give birth to various bias and stigma around this group of society.

Solution: Increase awareness of staff and user's families about their active role in supporting social inclusion of ageing persons with intellectual disabilities and develop a positive attitude aiming at working actively in support of the social inclusion of ageing persons with intellectual disabilities and elimination of difficulties of this target group through participatory flagship initiatives, mutual time-spending, outdoor activities, awareness-raising campaigns and effective communication programmes. Additionally, increase the feeling of responsibility for inclusion of ageing persons with intellectual disabilities into the community facilitated by specific respective legislation.

Addressed to: PUBLIC AUTHORITIES, HEALTHCARE SERVICES AND INSTITUTIONS, COMPETENT AUTHORITIES, COMMUNITIES, EU

INSTITUTIONS, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

3. FACILITATE THE USE OF ASSISTIVE TECHNOLOGIES

Ageing persons with disabilities experience a high rate of medical, functional, and psychosocial complications and/or changes about 20-25 years sooner compared to aging individuals without disabilities. The findings have shown the need to take into consideration the interest of the "non-included" group – users with severe disabilities who cannot communicate their needs and wishes verbally and for whom the assistive technology is a necessity to be able to express their wishes in a most clear way, so their interests are taking into consideration.

Solution: advocate and have an access to adequate funding possibilities for the use of assistive technology in daily life of ageing persons with intellectual disabilities with the aim of connecting with friends, families and communities and being able to participate in everyday life activities and treatments.

Addressed to: HEALTHCARE SERVICES AND INSTITUTIONS, COMPETENT AUTHORITIES, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

4. PROMOTE UP-SKILLING AND RE-SKILLING TRAINING PROGRAMS FOR SERVICE PROVIDERS

The findings highlight that staff member’s experiences differ significantly across organisations in terms of qualifications and skills. There appears to be a lack of appropriate training programmes to address the complexities of ageing in people with ID which result in training programmes developed without soliciting input as usually the staff is trained for the work with persons with intellectual disabilities, not with ageing persons with intellectual disabilities specifically.

Solution: Research focusing on staff who support ageing persons with intellectual disabilities has highlighted the need for proactive planning, individualised care, and teamwork in providing the best possible care in services. That is why, the collaborative efforts between family, client and healthcare professionals are essential for providing quality care. Furthermore, it is recommended that staff adopt a leading role in this collaboration and planning of care, as it allows for the implementation of professional, individualised care through the development of realistic, proactive and responsive strategies. Therefore, a specific training programmes targeting the individualised care shall be developed.

Addressed to: STAFF (SERVICE PROVIDERS), HEALTHCARE SERVICES AND INSTITUTIONS, COMPETENT AUTHORITIES, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

5. MORE SPECIFIC DATA COLLECTION

The research has shown a limited attention to the concept of age and ageing and therefore, the gaps in existent data on ageing persons with intellectual disabilities that result in the absence of sufficient studies on this specific target group, on their need, the challenges and barriers they face, etc. Even if these studies are available, they do not consider the fundamental elements, such as, for example, the impact of the digital transition on their support services and their lives, as well as their relationship with the community (the territorial one as well as the digital one). This leads to the paradox of having very inadequate answers to the need of a doubly vulnerable group that, more than others, would need specific and effective support.

Solution: All these shortcomings consequently have a devastating impact on one of the fundamental aspects of human's life: social inclusion and participation in the community. Taking part in community activities is regarded to be crucial for the wellbeing of every person, although, in fact, it is very difficult, if not impossible, for the specific group of ageing persons with disabilities. This further element feeds a negative spiral that exposes the target group to a further worsening of their quality of life and health. Therefore, the collection of specific data would help to gather more information on the interests and needs of this specific target group and, consequently, make their transition into community participation smoother and less challenging.

Addressed to: EU INSTITUTIONS, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

6. INCREASE OF FUNDING IN THE SECTOR

The findings highlighted that staff usually faces the barriers like understaffing and financial constraints, emphasizing the importance of support and resources. This includes limited support for inclusion activities, further complicate matters. Furthermore, high staff competency and knowledge emphasize the need for additional support and resources rather than just training.

Solution: Allocation of specific budget and funding possibilities in support of training programmes for ageing persons with intellectual disabilities beneficial for both the users and the staff.

Addressed to: EU INSTITUTIONS, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

7. STAFF WORK-LIFE BALANCE ASSURANCE

One prevailing issue identified by the report is the widespread problem of understaffing, a concern pervasive across all organisations. This structural and organisational shortfall has a detrimental impact on the quality of care and services extended to ageing persons with intellectual disabilities. In addition, staff members grapple with financial constraints, particularly in terms of limited support for social inclusion activities. That leads to not enough support from staff as a result of understaffing and burn outs, therefore no clear distinction between work and private life.

Solution: Work schedules reflecting better time-management, more teamwork and multi-disciplinary trainings (also together with psychologists), development of friendly relationships with users with the support of different activities.

Addressed to: STAFF (SERVICE PROVIDERS), HEALTHCARE SERVICES AND INSTITUTIONS, COMPETENT AUTHORITIES, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

8. INCREASE OF COMPETENCES FOR SERVICE PROVIDERS IN MAINTAINING AGEING PERSONS’ WITH INTELLECTUAL DISABILITIES CARE

The report has shown that recent developments in national laws across project partner's countries provide changes aiming at de-institualisation of the care and re-consideration of social assistance granted for users. This leads to clear disparities between counties and significant differentiations in the assistance provided.

Solution: In order to eliminate disparities and to guarantee the support of ageing person's with intellectual disabilities decent life, specific legislation designed to protect the rights of ageing persons with intellectual disabilities with respect to social inclusion shall be guaranteed. Service providers play a crucial role in maintaining care and assure decent quality life conditions of ageing persons with intellectual disabilities, therefore they shall be entitled to having a right to design the living guidelines for this target group and to represent their rights.

Addressed to: EU INSTITUTIONS, NATIONAL, REGIONAL AND LOCAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR.

Conclusions

The study reveals diverse challenges and opportunities in promoting social inclusion for ageing persons with intellectual disabilities across different organisations and countries. It is crucial that both a general and specific perspective is taken into account, there are both similarities and differences that are shared across locations, but also disparities. A dual perspective which takes account of the lived experiences of ageing persons with intellectual disabilities and the staff who support this population is essential when addressing social inclusion.

Summarizing the findings, it is worth mentioning the importance of creating a specific legislation designed to protect the rights of ageing persons with intellectual disabilities as a separate target group, with respect to social inclusion that has to be addressed in twofold way – both from the user's and from the service provider's perspective. A dual perspective is indispensable in the endeavour to foster social inclusion for ageing persons with intellectual disabilities. The narrative analysis of ageing persons with intellectual disabilities and staff viewpoints elucidates the barriers and facilitators present in their respective experiences. Ageing persons with intellectual disabilities face challenges such as active exclusion from the community and the neglect of their values, emphasizing the need for a more inclusive society.

Conversely, staff members encounter barriers like understaffing and financial constraints, emphasizing the importance of support and resources. Notably, trust in staff, emotional support, and enhanced staff connections are essential facilitators. The synthesis of these dual perspectives highlights the need for a holistic and collaborative approach to advance social inclusion effectively and compassionately for all.

Consequently, fostering a sense of belonging and trust within the community, coupled with promoting emotional well-being, can significantly contribute to enhancing social inclusion for ageing persons with intellectual disabilities.