

Particip.AGE Project

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

Collection of Case Studies on the support
for social inclusion of Ageing People with
Intellectual Disabilities



Particip.AGE

Institutions participating in the project:



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



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Abstract

The report shows a summary of fifteen (15) 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. These case studies aim at maintaining the social inclusion of ageing persons with intellectual disabilities and a questionnaire in three main areas, such as: more inclusive policies, accessibility and more effective training. The case studies are provided by project's partnership organizations from 7 different European countries: Austria (Chance B), Belgium (EPR), Germany (Mariaberg e.V.), Greece (Panagia Eleousa), Ireland (University of Galway), Italy (Medea Academy) and Spain (Fundación INTRAS, Fundación Rey Ardid) in order to identify and collect good practices in social services from the North, Centre, South, East and West of Europe to have a clearer understanding and need-based analysis of ageing persons with intellectual disabilities all around Europe.

The case studies were collected by the project's partners on the basis of conducted interviews and direct observations of patients receiving social services in partner's institutions. The studies respect strong confidentiality of the persons described, that is why no names referred and no photographs included to the following cases. Each case describes a personal story of a patient (ageing person with intellectual disabilities) and answers the questions related to the condition and services a target person receives.

Introduction

The main objective of Particip.AGE project is establishing enhanced community and ensuring social inclusion of ageing persons with intellectual disabilities where their rights are fully protected. For this to be achieved, the project involves the major stakeholders and 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. Consequently, expected actions to be taken to achieve the main objective are:

- 1) upskilling competences and developing innovative tools to support work, activities, and practices of beneficiaries and other service providers, that is going to support the collaboration among the sectors of social service provision and community care services);
- 2) strengthening transnational relationships among partners and across different sectors (i.e. service provision, including community-based services);
- 3) responding to the specific needs of the context and supporting education that promotes inclusion;
- 4) innovating the project partners' educational tools on the one hand and transforming operational approaches on the other which will impact the individual, organizational and sectoral level of the partnership and beyond.

For achieving the project's objective, it is important to pay an additional attention on the priorities of the project which are the following:

- inclusion and diversity in all fields of education, training, youth, and sport;
- addressing digital transformation through development of digital readiness, resilience and capacity;
- improving the availability of high-quality learning opportunities for adults (namely ageing people);
- improving the competences of educators and other adult education staff.

According to the 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-centered and affordable, community- and family-based services comprising personal assistance, medical care and interventions by social workers. More precisely, the UN CRPD Art. 5² refers to the right to equality and non-discrimination of people with disabilities, with the support of Art. 19 of the Convention³ referring to the right of persons with disabilities to live independently and be included in the community and Art. 25 (b)⁴ referring to the provision of health services needed by persons with disabilities specifically because of their disabilities including services designed 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 2021-2030⁵ 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 this issue is the European Pillar of Social Rights (Principle 17) that 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 needs⁶” 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 services⁷”.

However, none of these legal documents address this particular target group with double vulnerability – ageing persons with intellectual disabilities. Despite of some efforts being made at policy levels, the goals are far from being achieved.

¹ [UN Convention on the Rights of Persons with Disabilities](#)

² Ibid.

³ Ibid.

⁴ Ibid.

⁵ [Strategy for the rights of persons with disabilities 2021-2030](#)

⁶ [The European Pillar of Social Rights \(EPSR\)](#)

⁷ Ibid.

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 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 disabilities⁸". Therefore, health, functional, and psychosocial changes not only impact the individual but the family as well, adding emotional and financial stress. Same applies to persons 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 aging 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 disabilities. This further element feeds a negative spiral that exposes the target group to a further worsening of

⁸ [The RRTC on Ageing with a Disability approach to the research program](#)

their quality of life and health.

Key messages, aims and challenges

Due to a substantial inefficacy of the legislation and policies that can assure the protection of rights of ageing persons with intellectual disabilities (so called group with a double vulnerability), they face a lot of challenges and barriers on their way to social inclusion and community participation.

According to the analysis conducted from the research undertaken, 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 this target group are lacking, meaning, for example, that the real needs of stakeholders are not taken into consideration by policy-makers and legislators. 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 changes in the legislative framework. For instance, although the *European Commission’s Strategy for the Rights of Persons with Disabilities 2021-2030*⁹ mentions the risks older persons with disabilities face and acknowledges the diversity of disability spectrum, it does not address the specific group of ageing persons with intellectual disabilities, making it harder to find effective solutions for social inclusion of this particular target group. It also emphasizes on a gap that exists in EU law in ensuring the equal treatment of persons with disabilities outside the field of employment, such as social protection, healthcare, education as well as an access to goods and services, including housing, underlining the need for further progress in EU legislation. Therefore, existing regulations are considered to be not effective enough and incapable of supporting the rights of ageing persons with intellectual disabilities in particular.

As a particularly vulnerable group, ageing persons with intellectual disabilities have unique and differing characteristics that must be handled by highly specialized personnel which raises another barrier for inclusivity of ageing persons with intellectual

⁹ [Strategy for the rights of persons with disabilities 2021-2030](#)

disabilities – inadequate competences of service providers’ staff to support this vulnerable group. The context analysis has shown clear shortcomings in this sense, including:

- staff training is not specific enough (preparing them to work only with persons with intellectual disabilities or only with ageing people, but not with ageing persons with intellectual disabilities);
- service provision is structured in silos: services for ageing people and services for people with disabilities are usually different, with different staff which prevents communication, exchange of competences, reciprocal support etc.;
- staff providing different services, working with people with double vulnerabilities without having the adequate competences and tools, is often unmotivated and exposed to a higher risk of burn-out;
- service providers in this sector often do not have the ability to attract young staff, thus the average age of the staff is advanced (that usually may lead to an issue of staff being not very competent in using the digital tools which, in its turn, may represent more an obstacle, than a resource);
- the staff training is often not really up-to-date and does not include recently developed topics, such as digital skills;
- assistive technology is nowadays a fundamental resource for improving the lives of vulnerable people, including their participation in society, although the relevant staff is often either not aware of them, don't have access to these tools or don't know how to use them properly;
- the target’s group input, needs and knowledge are often not properly considered and not integrated into the training pathways of the relevant staff;
- staff training is mostly focused on working on their clients with scarce attention being paid to the role of communities and the paramount importance of working on / with them.

Moreover, the target group has such characteristics that social inclusion and participation in their community is much more difficult than that of the mainstream population. In particular due to the following factors:

- the interpersonal network (family, friends, relatives, etc.) that often bridges the

rest of society, 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 centre that 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;
- other existing approaches and tools for social inclusion of ageing persons with intellectual disabilities are often not exploited much in daily practice.

The context analysis has shown that the isolation of ageing persons with intellectual disabilities largely depends on the attitude of the community, local or digital, in which these people live. In particular with the relation to:

- communities often being completely unaware of the presence of ageing persons with intellectual disabilities (especially surrounding institutions of the territorial communities);
- communities often being not very attentive to the minorities in general (especially the online community);
- presence of a strong and widespread stereotype towards persons with intellectual disabilities and ageing people that leads to an even greater stereotype towards target group with double-vulnerability – ageing persons with intellectual disabilities which generates various reactions, such as fear and avoidance, infantilization and pietistic attitudes, passivation of the target group etc.;
- inability of the relevant staff to work actively in support of the social inclusion of the ageing persons with intellectual disabilities and the objective difficulties

that the target group may face.

In order to eliminate these barriers, the following measures are recommended to be taken:

- increase awareness of the staff about their active role in supporting social inclusion of ageing persons with intellectual disabilities;
- develop a positive attitude of the staff aiming at working actively in support of the social inclusion of ageing persons with intellectual disabilities and the objective difficulties of the target group;
- advocate the use of assistive technology in daily life of ageing persons with intellectual disabilities with the aim of connecting with friends, families and communities;
- encourage participation of ageing persons with intellectual disabilities in the informal exchange sessions within the community and in the multiplier events at national level as well as other relevant events;
- encourage participation of ageing persons with intellectual disabilities in project-related activities in order to get their input and analyse their needs better;
- break existing stereotypes about ageing persons with intellectual disabilities by providing more information and educating the staff;
- research and collect the relevant data on the specificities of ageing persons with intellectual disabilities;
- develop impactful policy recommendations targeting all relevant stakeholders on the basis of which a respective legislation shall be drafted.

Methodology

The provision of effective training modules to promote social inclusion for both staff/carers and ageing persons with intellectual disabilities requires collecting 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 case studies on service provision (15) were collected. The collected contents (interviews and direct observations) were thoroughly analysed and will be resulted in the material for the policy recommendations. In addition to, all the mentioned activities will be incorporated into the study “Ageing People with Intellectual disabilities. A pathway to their social inclusion”.

A case study is a direct observation of the target group that has investigating role, containing interviews and other qualitative elements that cannot be shown through the documentation and is a subject to strong confidentiality (no names are mentioned and no photographs are included) and involve the specific specialists/professionals such as: psychiatrists, psychologists, social workers, occupational therapists, physiotherapists, speech therapists. In the following case, the studies included an observation in type of story-telling containing the background information of a target person (user) and a questionnaire with replies relevant to the case (i.e. user’s main features, his communication skills, level of autonomy, some information on the living environment, family members and the access to the social services).

Overview of findings

The case studies provided by the partners showed 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.

Moreover, case studies 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. Among other barriers participants

tend to face are often the following:

- therapy dependency;
- need of professional aid;
- inpatient care necessity;
- lack of family ties;
- absence of persons (supporters) being able to look after them;
- lack of financial support;
- anxiety, depression and lack of communication;
- fear of unfamiliar environments;
- other concerns resulting from health conditions.

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. For instance, this can be done with help of such elements as:

- user's localization (geographical situation) in a small town (makes it easier to intervene if needed);
- support of condominium (living area community);
- engagement of user's family members or close persons to the participant in the common activities conducted between the user and the service provider.

The case studies have showed the 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.

Conclusions

Summarizing the following case studies, it is worth mentioning the 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.