

Getting Older with a Disability

Stories, Tools, and Inspiring Practices from GOLD



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INTRODUCTION



WHAT IS THE GOLD PROJECT?

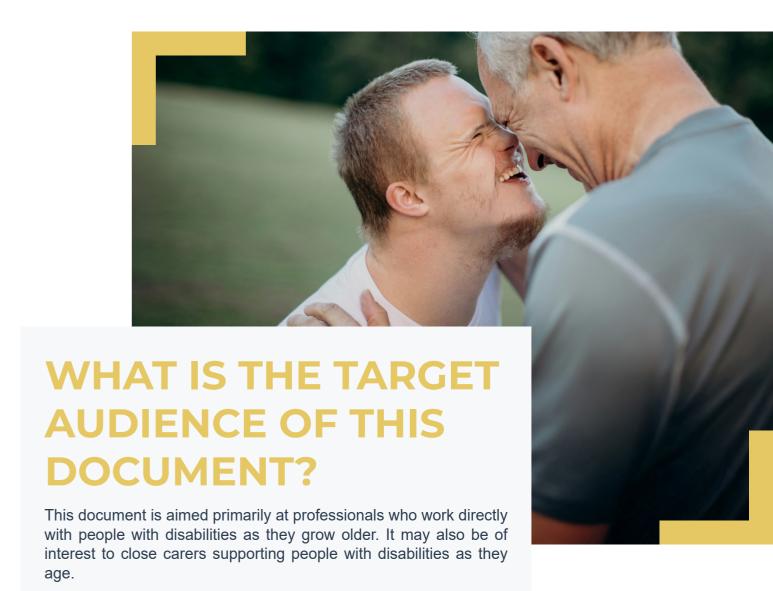
The Erasmus+ GOLD project (2024-2027) brings together partners from Austria, Belgium, France, Italy, Portugal and Romania who focus on improving care for ageing people with disabilities.

The project aims to equip professionals and family carers with essential skills to improve the quality of services and ensure ageing with dignity and in good health. It encourages collaboration between the ageing and disability care sectors at European level to encourage mutual learning between these two sectors and adapt services effectively. Through training, awareness-raising and practical tools, the GOLD project aims to promote inclusion, empowerment and better support for ageing people with disabilities.

The GOLD project has developed three tools for professionals aimed at enhancing their skills in the field of ageing and disability:

- A summary of inspiring stories, experiences and practices
- An online training programme for professionals
- A toolbox to support the adaptation of services and practices
 All these resources are available on the GOLD project website.





WHAT WILL I FIND IN THIS DOCUMENT?

The initial outputs of the GOLD project included the production of a documentary and field research publication. The objective is to provide a contextual framework of the current situation prior to the project, incorporating an analysis of policies and of the situation on the ground. The document also aims to inspire practices and highlight experiences related to the provision of services for people with disabilities as they grow older. The research includes a focus on the situation in Europe and six Member States: Austria, Belgium, France, Italy, Portugal and Romania. The preliminary phase of the research project entailed a thorough examination of the policies and institutional frameworks in place at the European, national and regional levels across the partner countries. Concurrently, the project aimed to identify effective and innovative practices addressing the specific needs of ageing people with disabilities.

In parallel, 45 qualitative interviews were carried out with ageing people with disabilities, professional and family/informal carers. These interviews gave GOLD partners the opportunity to hear directly from the various target groups about the way they perceive ageing and the needs it entails.

This visual and interactive summary document brings together the findings and recommendations from the research report (1), the analysis and summary of qualitative interviews (2), as well as the key concepts related to the project's topic.

Based on the material collected through the research and interviews, GOLD partners were also able to identify examples of tools and practices that can be used by professionals and informal carers supporting ageing people with disabilities in their day-to-day care. These examples are summarized in textboxes.

You will find information on a number of key concepts relating to the ageing of people with disabilities, practical advice, some examples and good practices and testimonials to help you better understand the challenges revolving around the ageing of people with disabilities. In addition, you will have the opportunity to identify inspiring ideas and resources to incorporate into your own practices, both as professional and as informal carers.

WHY IS IT IMPORTANT TO TALK ABOUT DISABILITY AND AGEING?



For the GOLD project, we adopted the definition of "disability" from the United Nations Convention on the Rights of Persons with Disabilities (2006): "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

For the purpose of this project, we define an ageing person with a disability as any person who experienced their disability prior to experiencing the additional effects of ageing.

As shown in the <u>GOLD research report</u>, although limited data is available on the ageing of people with disabilities, it is widely acknowledged that the life expectancy of people with disabilities has increased and that this trend is set to continue.

At the same time, ageing people with disabilities are more likely to lose their independence, as their needs may not be well understood, and are at greater risk of developing co-morbidities due to underlying health problems or unmet healthcare needs.

As they grow older, people with disabilities face multiple and complex forms of discrimination. They often experience double stigmatization because of their disability and their advanced age. This reality exposes them to additional barriers in accessing to healthcare services, housing and employment. Prejudice and stereotypes further marginalize them, thus limiting their participation in society and their access to basic services. In addition, public policies and infrastructures are not always suited to meet their specific needs, exacerbating their social isolation and vulnerability.



Furthermore, professionals and informal carers working with ageing people with disabilities, in some cases, are insufficiently equipped to deal with these complex challenges. In this context, building bridges between the health, disability and elderly sectors is key to ensure that knowledge is shared more effectively, thereby improving the quality of life of life of ageing people with disabilities.

Summary of information on the political and legal framework in the countries covered by the GOLD project

The table below summarizes the main findings of the analysis of the political framework available in the GOLD documentary and field research report.

EU

The EU protects ageing people with disabilities through international and EU legal frameworks promoting equality and human dignity. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was ratified by the EU in 2010 and safeguards rights such as independent living and protection against discrimination. The EU Disability Strategy 2021–2030 promotes independence and access to care services but lacks focus on employment and lifelong learning. The European Pillar of Social Rights supports inclusion and long-term care through key principles. EU law, including the Treaty on the Functioning of the EU and Directive 2000/78/EC, prohibits discrimination based on age and disability. The European Care Strategy calls for accessible, high-quality long-term care and support for carers. Implementation varies across Member States, with the EU supporting coordination via platforms such as AccessibleEU. Initiatives like the European Disability Card and the Rights, Equality and Citizenship Programme enhance mobility and inclusion. Advocacy groups push for a dedicated Age Equality Strategy to address multiple discrimination. Data gaps hinder the effectiveness of policies; better disaggregated data at European level is essential for inclusive EU strategies.

AUSTRIA

In Austria, disability issues are treated as a multi-layered cross-sectional matter between the federal government and the regions. Most disability assistance services are provided by the regional governments and the district or municipal administrations.

<u>Sozialwirtschaft Österreich</u> (Social economy Austria) represents the interests of more than 570 member organisations in the private, social and healthcare sector.

Funding and resources are provided on a national level in the form of family allowance, long-term care allowance and social welfare, and on a regional level in the form of social services and subsistence allowance.

New services for ageing people with disabilities are provided by the **Benefits and Remuneration Regulation of the Styrian Disability Act** (<u>LEVO-StBHG</u>):

- 2024 Day care and support in the context of full-time residential care
- 2025 Mobile assistance for people with disabilities living in nursing homes

BELGIUM

Belgium's support system for ageing people with disabilities is based on a complex, multi-level governance structure. Responsibilities are shared between the federal government and the regions. At federal level, financial measures are in place for compensation for one's loss of independence (income replacement allowance, integration allowance and elderly assistance allowance). The institutions involved are INAMI/RIZIV (National Institute for Health and Disability Insurance), the Belgian Ministry for Social Security, and Fedris (Federal Agency for Occupational Risks).

At regional level:

- Wallonia: AVIQ (Walloon Agency for Quality of Life) covers health, disability and ageing-related services.
- Brussels-Capital: In Brussels, support for ageing people with disabilities is provided jointly by **Phare** (People with Disabilities Seeking Independence) and **Iriscare**, which coordinate and fund tailored services to promote their independence, inclusion and quality of life.

In Belgium, the quality of life of ageing persons with disabilities is hampered by a lack of coordination between the disability and ageing sectors, inadequate care facilities, poor anticipation of life transitions, insufficient training for professionals, and institutional complexity linked to the regionalization of jurisdiction. However, an increasing number of initiatives are being developed to tackle these challenges by building bridges between sectors, supporting families and professionals, and anticipating transitions to nursing homes.

Article 334 of the Walloon Social Action and Health Code establishes the principle that residential or care facilities for the elderly in Wallonia must accommodate people aged 70 and over in at least 90% of their approved capacity. If this threshold is exceeded, a special exemption must be requested. As a result, ageing people with disabilities face unjustified exclusion from nursing homes and unequal access to appropriate facilities.

SAJAs (day care services for adults) and SRNAs (night residential services for adults) face regulatory constraints which limit their ability to adapt to the ageing of people with disabilities. For example, SAJAs must comply with a maximum of 227 days of attendance per year and a minimum attendance requirement, which no longer meets the needs of ageing users, who often exceed this threshold. SRNAs, meanwhile, are hampered by the fact that there is no appropriate regulatory framework for certain essential roles such as care assistants, making it difficult to change practices and care for more dependent users. In Brussels, support for ageing people with disabilities is also hampered by a strict age requirement: The disability must be established before the age of 65 in order to have access to specialised services. This rule excludes people whose disability is identified later in life, even if their needs are comparable.

FRANCE

In France, the rights and support of persons with disabilities are enshrined in legislation and implemented through a structured national and local framework. The legal basis is the **Law of 11 February 2005** on Equal Rights and Opportunities, Participation and Citizenship of People with Disabilities. It provides for a broad definition of disability and strengthens the principles of inclusion, accessibility, and non-discrimination

In France, ageing persons with disabilities are understood as being "Individuals who became disabled earlier in life and are now facing the effects of ageing, which can lead to new health problems, a loss of independence, or an aggravation of existing difficulties». To support them, France has a dedicated system coordinated by the MDPH (County Centre for People with Disabilities), which exists in each county and acts as the main entry point for people with disabilities, assessing their needs and giving access to rights, benefits, and services.

These individuals may be entitled to two main types of financial support: the PCH (Disability Compensation Benefit) and the APA (Custom Autonomy Allowance); when eligible for both, they must choose the most appropriate one depending on their situation. In terms of care, different options exist to help them maintain stability and avoid any major age-related changes: at-home support for them to stay in familiar surroundings, continued assistance within the institutions where they may already be living, or access to specialised residential services adapted to the needs of ageing persons with disabilities. France also acknowledges that ageing can affect not only the individuals themselves, but also their family carers, and it therefore seeks to anticipate changes in care needs to avoid any disruption to people's course of life and ensure the person receives continuous support throughout the course of their life.

ITALY

Law No. 104 of 5 February 1992, also known as the Framework Law for Assistance, Social Integration and the Rights of Persons with Disabilities - a pioneering law for social inclusion and asserting the rights of people with disabilities, aimed at guaranteeing their independence, integration and active participation in social, political and economic life.

Law No. 112 of 22 June 2016, known as the "After Us Law", aims to protect people with severe disabilities who lack adequate family support, guaranteeing them a life in dignity and the highest possible level of independence, even after their parents or carers have passed away.

The National Fund for Non-Self-Sufficiency was established in Italy on through Law No. 296/2006 of 27 December 2006 (Article 1, paragraph 1264) to ensure the implementation of essential levels of assistance services throughout the national territory for non-self-sufficient persons - It finances integrated home care in coordination with health services, independent living projects for people with disabilities, support for families and carers, and assistance and social protection services for older and vulnerable people.

The concept of the personalized "life project" was introduced by Law No. 328 of 8 November 2000 – it aims to enable the implementation of an integrated system of interventions and social services based on a flexible document drafted over time with the involvement of the person with a disability, their family members and a team of various professionals who support and care for that person. The latest step forward in this area is the Disability Reform – L.227/2021 (and the Legislative Decree No. 62/2024), which introduces significant changes in the framework for the acknowledgement and support of persons with disabilities in Italy. Its article 33 introduces the right of the persons with disability, "upon reaching the age of 65, not to be discharged or excluded from services and benefits they already receive and to continue receiving the same support from social welfare."

PORTUGAL

In Portugal, the support system for people with disabilities is guided by the **National Strategy** for the Inclusion of People with Disabilities 2021–2025 (ENIPD), which promotes independence, accessibility, and independent living. However, it does not specifically address their age-related needs. The rights of people with disabilities are legally protected under **Law No. 38/2004 of 18 August**, which defines the general framework for prevention, empowerment, rehabilitation, and participation, ensuring equality and non-discrimination. Services are mainly provided by Private Institutions for Social Solidarity (IPSSs) under agreements with the Social Security Institute, with implementation supported at local level by municipalities and coordinated through Local Social Action Councils (CLAS). Organisations like FENACERCI (National Federation of Cooperatives and Social Solidarity) represent cooperatives that offer specialised services for persons with intellectual and multiple disabilities, including ageing adults, and promote inclusive practices.

Funding comes primarily from the state budget, complemented by the European Social Fund and national programmes such as the *Programa de Alargamento da Rede de Equipamentos Sociais* (PARES). While there is growing recognition of the need for integrated responses, there is no specific legal or policy framework focused on ageing with disability, and there are still many disparities in access to services, especially in rural areas

ROMANIA

In Romania, the national policy and the regulatory framework state that ageing persons with disabilities are entitled to several key rights and services (access to affordable housing with minimum living standards, free of charge use of public transport, and social services).

The government is in responsible for providing specialized rehabilitation centres, medical services, transportation, and access to thermal spas, which include free accommodation for the individual and an accompanying person, and one annual thermal spa treatment voucher prescribed by a medical professional.

Local and regional public institutions play a critical role in providing and coordinating these services. They are responsible for ensuring access to healthcare, social welfare and care services, as well as for training staff, promoting inclusion, providing financial assistance, and assessing the services provided. These institutions are key in creating an integrated support system for elderly people with disabilities.

Romania's framework for people with disabilities aims to ensure the full and effective participation of persons with disabilities in all areas of life, emphasizing freedom of choice within an accessible and resilient environment. Key focus areas include improving accessibility and mobility, ensuring equal legal rights and participation in decision-making, and promoting inclusion in education, employment, health, social protection, independent living, and access to public services. The framework supports the development of inclusive systems that help people with disabilities live independently and participate fully in society.

AGEING WITH A DISABILITY: WHAT DOES IT MEAN?



Giving an objective definition of "ageing" can be challenging since perceptions can vary from one person to another. Statistics on ageing generally classify older people as those who are above a certain age threshold. Indeed, the United Nations noted in its 2019 World Population Ageing report that older people are generally defined as those aged 60 or 65 or more, while the EUROSTAT report titled "Ageing Europe — Looking at the lives of older people in the EU" uses the following terminology:

- Older people those aged 65 years or more
- Very old people those aged 85 years or more

Beyond these general considerations, the ageing of people with disabilities is a multi-faceted process and difficult to identify and define due to the different disability situations.



M. (technical director):

"We see very different realities ... And ageing has very little to do with the age of 65 itself. When we think about ageing, the age question ends up being one of the factors, but it is by far the determining factor."

The effects of ageing generally include reduced functional abilities and an increased frequency of age-related illnesses. People with disabilities may face these usual effects of ageing, which result in a further decline in already impaired functional abilities, but also potentially specific effects linked to each disability.

E.B. (social worker with 20 years of experience in the disability sector):

"It's a change in perspective: the life expectancy of people with disabilities used to be different, and nowadays, the ageing issue is being addressed. There aren't any defined models yet, and they will need to be designed with some flexibility. This process, however, can create fears and uncertainties, particularly when it comes to taking the steps needed to effectively guide these changes."

To hear E.B.'s story, check her full interview on GOLD channel:



¹Ageing Europe — Looking at the lives of older people in the FU European Union 2020

Spotting and supporting early signs of ageing

- Anticipating ideally from the age of 40 or earlier for certain types of disabilities, by:
 - Establishing a reference framework to help monitor changes over time, for example through a tailored assessment of lifestyle habits or functional abilities
 - Encouraging healthy ageing strategies, such as maintaining a balanced lifestyle, taking part in preventive screening programmes, and integrating physical activity into daily routines.
 - Giving people time to acknowledge the ageing process and its potential impact on their life so as to anticipate potential future transitions over the course of their life (end of working life, moving to another place to live).
- Using available methodologies and tools to help spot early signs of ageing (see textbox on Tools)
- Engaging in regular conversations about ageing with the person and about their general well-being in order to identify any signs of ageing, look into any concerns and detect emerging challenges.
- Listening to the person attentively in their day-to-day life and monitoring subtle changes in their routines that may be associated with ageing (e.g. more frequent stumbling may point to a drop in vision)
- Being attentive to what family members have noticed, especially those who live with the person, who can sometimes be the first to identify the emerging charging and/or disorders in the person.

Added to this is the fact that the physiological age of people with disabilities is often higher than their chronological age, due to a pre-existing reduced physiological and/or cognitive reserve, an already-present decline in functional abilities, and sometimes a lower access to health and prevention services. This often leads to **premature ageing among people with disabilities**².



A.T (aged 52, person with degenerative illness):

"We are not ready to grow old yet; it's not on our minds, but it i happening, little by little, it's happening."





Lastly, persons with disabilities have difficulty noticing the effects of ageing or struggle to express them. In the interviews conducted as part of the GOLD project, several professionals referred to the fact that, in some cases, the physical traits of people with disabilities change little with age, making it difficult to identify ageing. This phenomenon is also a challenge for families, who may still see their loved one as a "child", even as they age.



L. (psychologist with 22 years of experience in a social rehabilitation service):

"The challenge is to help ageing persons with disabilities become aware of their own ageing and of the new difficulties this will entail, and to plan engaging rehabilitation activities."



Although ageing does not occur in the same way from one person with a disability to another, some signs are observed more frequently. The interviews conducted as part of the GOLD project helped us identify a number of recurring signs, which are presented below:

A "general slowdown", greater fatigue and, sometimes, a drop in motivation to do daily tasks or take part in proposed activities. This slowdown often goes unnoticed because it happens gradually. It also requires a good knowledge of the person being cared for, acquired over a long period of time.



C. (aged 68, with intellectual disability):

"I've always done housework, and I enjoyed it. I never felt like not doing it, whereas now, I notice I'm getting tired, and I only do the dusting on Sundays. I'm taking it easier, it's less tiring for me."

- Reduced functional and cognitive ability.
- Sometimes ageing results in a further loss of independence. The person needs to assistance for tasks that they could previously do on their own.



W.S (aged 58, multiple sclerosis, full-time assisted living):

"The biggest difference is in my mobility. It has really changed everything. Since I've been in a wheelchair, I am no longer able to do as many things on my own. I need professional help because of my illness. I really need it these days. Whenever I have physical issues, I'd like quick assistance."

To hear W.S.'s story, check his full interview on GOLD channel:



People who are ageing sometimes express the need to "do less", to have moments when they can simply watch and observe, or even to take a break in a quiet place.



F. (trainer specialised on disability and ageing):

"Another challenge is accepting to 'do nothing'. An ageing person may require moments where they should simply sit back and rest. Yet, in an institutional setting where being busy is valued, it can be frowned upon to let a person simply relax and look around. We need to change the way we look at these needs and respect this choice."

- Ageing can lead to the development of **new medical conditions**. Pain can prevent symptoms from becoming apparent and result in behavioural problems. Significant changes in behaviour may warrant looking for a potential medical condition. Similarly, regular check-ups can help detect any developing disease.
- Ageing with a disability also sometimes leads to the development of secondary psychiatric disorders, such as anxiety and mood disorders, or even forms of decompensation. Carers need to pay particular attention to distinguish between what is part of the progression of the initial disability and what is part of a pathological ageing process.

A few tools for spotting signs of ageing:

The NTG-Early Detection Screen for Dementia (NTG-EDSD)

A screening tool to facilitate the early detection of cognitive decline. It has been particularly recommended to facilitate the detection of early signs of dementia for adults with Down syndrome over 40 and other at-risk groups of people. The NTG-EDSD has been implemented successfully in at least two of the countries represented in the GOLD project (Italy and Austria).



BOBE

Developed by the Brux'Aînés working group in Brussels, it is a quick, synthetic visualization, on a human silhouette, of the expression of the support needs for persons with intellectual disability. It can be used to monitor changes to support the needs of these persons (in French).



HANDICONNECT

Leaflets to help assess the profile of an ageing person with a disability (in French).





Inspiring practice - A multidisciplinary approach in France

A number of professionals interviewed as part of the GOLD project mentioned the value in adopting a multidisciplinary approach and in discussing the support given to a particular person among carers. Depending on their role in supporting a person, but also on their sensitivity or their relationship with the person, the way in which the team members perceive changes in a person may differ, with each team member likely to be more attentive or more sensitive than others to certain changes. These discussions can help to compare views and make it easier to identify the impact ageing has on a person, before collectively devising - if necessary - new approaches or proposals to support the ageing person.

If necessary, external expert advice can also be sought to help when decisions need to be made (support or healthcare professionals with in-depth knowledge of the person's condition, the ageing process, etc.).

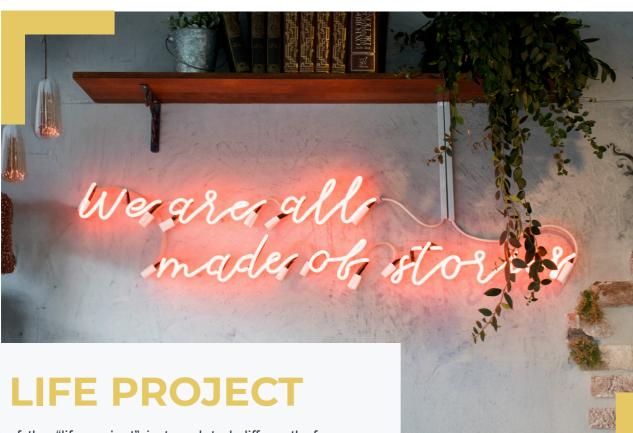
Example of La Maison d'à Côté

La Maison d'à Côté was established in 2019 in Tourcoing (France) by the Association Fraternative. This residential facility has been designed for adults with stabilised psychiatric disorders. It provides a safe and independent living environment for nine residents, supported by a team of professional carers. While the facility's primary focus is on mental health stability, it has developed an adaptive model of care to respond effectively to the ageing of its residents. The support provided at La Maison d'à Côté is tailored to meet the changing needs of its ageing residents. Care plans are regularly reviewed and modified to reflect changes in mobility, cognitive function, and general health. Activities, such as physical exercise and creative workshops, are adjusted to maintain social interaction and cognitive stimulation while preventing social isolation. The facility uses a system of regular assessments in partnership with healthcare professionals to ensure comprehensive medical and psychological monitoring. There are collaborations with external services for ageing people to provide additional support as required. Families are actively involved and supported throughout the ageing process of their relatives, fostering a coordinated and reassuring approach. This collaborative approach enhances the well-being of residents, empowering them to maintain their independence within a secure and predictable environment. Furthermore, it equips families and care staff with the necessary tools and knowledge to navigate the challenges of ageing in the context of psychiatric conditions. The model's emphasis on personalised support, dignified living, and proactive planning makes it transferable to analogous residential settings, provided that interdisciplinary collaboration and staff training are in place.

PUTTING PEOPLE AT THE CORE

The United Nations Convention on the Rights of Persons with Disabilities (Article 19) emphasises the right to self-determination and the need to empower people to plan their lives according to their own wishes and aspirations. It is essential that this right to self-determination is maintained throughout a person's life, including as they age.

Beyond this universal legal framework, the concept of the "life project" was strongly emphasised in the various GOLD research activities, particularly the interviews. This notion covers issues such as independence, the expression and consideration of needs, and having the possibility to choose (for example, when it comes to activities, meals or where to live) for people with disabilities. This chapter looks at these issues with a few theoretical reminders, but above all with practical advice and examples.



THE LIFE PROJECT

The concept of the "life project" is translated differently from one country to another in the European Union, but its philosophy remains the same: It is an essential concept for supporting people with disabilities, making it possible to tailor care and respect individual choices. It has been integrated into various programmes and initiatives at European level to improve the quality of life and social inclusion of people with disabilities.

L. (social worker in a service for adults with disabilities):

"For some people, life is more complicated than for others, so we need to know how to turn their plans into reality. We need to have the skills of a film director and be able to envision new situations. This is part of the code of ethics of some professions, of people who help persons in vulnerable situations."

To hear L.'s story, check her full interview on GOLD channel:



A.M. (social worker who provides at-home support):

In more general terms, the life project is a personal document that reflects the needs, aspirations and wishes of a person with a disability. It is designed to reflect the person's desires and expectations, emphasizing their voice and their choices.

Inspiring practice - Ageing with Quality (Portugal)

[Des] envelhecer com qualidade (Ageing with Quality), was developed by FENACERCI in Portugal in 2013. This project specifically addresses the challenges related to ageing among individuals with intellectual disabilities. The aim of the project is to enhance these individuals' quality of life by providing tailored support, while also empowering families, carers and professionals through tools to promote well-being. This project focuses on creating individualised care plans that are adapted to the progression of the ageing process, addressing not only health requirements but also social participation and emotional well-being. A fundamental aspect of the initiative is its person-centred approach, ensuring that individuals maintain their independence and dignity as they age. The initiative fosters collaboration among families, professionals, and the individuals themselves, thereby enhancing the effectiveness of the care provided. It places significant emphasis on professional development, ensuring that carers are equipped with the right skills to address the evolving needs of ageing individuals with disabilities.

> In the context of ageing, the life project approach supports carers working with people with disabilities to better identify their emerging needs and to consider with them which changes need to be implemented in their environment - including, if necessary, the transition to another living environment that meets their aspirations.

The main aspects of a life project:

- Summary of needs and aspirations: The life project reflects the needs, aspirations and wishes of a person with a disability.
- **Evolving content:** It is important to give people the opportunity to express themselves regularly on their life project so that it can be adjusted, if necessary, over time, reflecting changes in the person's aspirations and
- Personal project: The wishes of the person with a disability must clearly be distinguished from those of their family and friends.

Inspiring practice - Life projects captured on film - Belgian experiences

In Belgium, the Cellule de Référence Handicap et Vieillissement (CHRV) developed a project called Portrait de vie (Life Portrait). The aim of the project is to facilitate the transition of ageing people with disabilities to new living environments, such as nursing homes. The project involves the creation of a personalised video (10-15 minutes) highlighting the person's routines, preferences, skills, and specific needs. The video also features their family and current living environment. This video is used before and during the person's arrival into the new environment, primarily during team meetings, to ensure that care teams, even those without specific expertise in disability, understand the person's needs and preferences. The overarching objectives of the initiative encompass facilitating the seamless integration into the new environment, bolstering confidence in the support services, and cultivating a shared understanding among professionals. The videos have helped improve the quality of the care given by providing essential, tailored information that reassures both families and staff. The project's transferability to other contexts is noteworthy, with minimal resources such as a camera, basic editing tools, and the involvement of families and teams being sufficient. However, it is imperative to emphasise the necessity of observing privacy and consent principles when making use of this tool in diverse settings.

THE IMPORTANCE OF LISTENING

The notion of a "life project" reflects a philosophy of support for people with disabilities which aims to give them the opportunity to play a direct role in organising their own lives, by being receptive to the needs they express.



AT (52 years old, person with a degenerative disease):

"The priority needs are to be able to see a future, even in just a month's time, which is not such a distant future. A future where one has their own "island" and manages it as best as they can within their limits. This island can be their home, it can be their friends, it can be a trip somewhere. Before, people probably had a slightly longer-term outlook, but now they just say, 'Let's see what happens in a month's time'."

To hear L.'s story, check her full interview on GOLD channel:

The person-centred approach makes it possible to develop life outlooks based on the interests, skills and needs of the person. One of the key aspects to this approach is **trust between the carer and the person with disability.** This relationship of trust is built by creating opportunities for listening and sharing. This sometimes means that the carer does not "engage in" any activities with the person with disability, but is simply present and available to listen.

L. (so

L. (social worker):

"We need tools to help us to 'be connected', we need training or relationships are built. [...] and I really believe that relationships are a huge social capital. We need to build a sense of closeness it's something beneficial to all of us."



To hear L.'s story, check her full interview on GOLD channel:

The interviews conducted as part of the GOLD project highlighted the importance of **empathy-based skills**. These can help foster a helping relationship and encourage people to put themselves in the other person's shoes so they can come up with lasting solutions together.

SUPPORTING TRANSITIONS

The ageing of a person with disability can sometimes result in them having to **change their living environment.** There are many reasons why a person may need to move: The infrastructure is no longer suitable, parents are getting older and can no longer provide at-home support, etc. If these changes are not anticipated and prepared for with the person concerned, they can be difficult both for them and those helping them. **Ensuring the smoothest transitions** possible by giving people with disabilities the opportunity to be involved in the decisions that will affect them is key, where necessary and possible.



L. (aged 52, person with multiple disabilities - about their transition to a nursing home):

"We had mapped out a summary of my life in case Dad would no longer be able to take care of me. We said we'd save it for later. And that's what we did.... We brought it out when I moved into the nursing home. My friend, the carer, the nurse and the psychologist were there ... Everyone was there to help us think things through. We discussed it at length before I came here."

Example of tools and practices – Ensuring smooth transitions:

- (Re)define the person's life project by involving them, presenting the various existing solutions that meet their needs.
- Inform the person (and, where applicable, their legal representative and/ or close caregiver) of any steps to be taken and, where necessary, helping them to compile the administrative paperwork.
- Get in touch with the facilities envisaged by the person to determine with them what is offered to get to know a new facility (visits, temporary accommodation, pre-admission periods, etc.).
- Propose a meeting between the main people providing support (previous and new facility).
- Determine which information the person agrees to share with the professionals at the future facility.
- Facilitate the sharing of information between teams, prior to admission into the new service.
- Determine how the teams from the two establishments can work together.
- After the person has left, if possible, maintain ties with the service users/ professionals with whom they wish to remain in contact.

AGE AND RIGHTS

A range of legislation and initiatives at European and national level protect the rights of people with disabilities as they age. These rights aim to guarantee equality, social inclusion and respect for the dignity of people with disabilities, while meeting their specific needs as they age.

As such, it is essential to **ensure that ageing persons are fully aware of their rights -** particularly in relation to emerging issues linked to ageing (work and retirement, social security and access to care, financial assistance, end of life, etc.).

Some examples of fundamental rights:

- Access to healthcare: Ageing people with disabilities must have equitable access to healthcare services adapted to their specific needs.
- Self-determination: They have the right to participate actively in society and to make decisions about their own lives, including their care and support.
- Social inclusion: Policies must guarantee their social inclusion, by encouraging their participation in community life and preventing social isolation.

This means that carers must have the knowledge, resources or, where appropriate, access to external support needed to inform the person about their rights accordingly.

In several European countries/regions, plain-language materials have been produced to make it easier for people with disabilities to learn about their rights.



Inspiring practice - Guides on fighting discrimination against ageing people with disabilities (Italy)

The Federation for Overcoming Handicap (FISH) has led a project entitled Disability: Discrimination does not add up, it multiplies. The project puts in place actions and processes to elaborate, in a participatory and shared way, responses and tools to combat multiple forms of discrimination, focusing on the issue of ageing with disabilities, with the aim of spreading a greater culture of inclusion and equal opportunities, "without distinction of sex, race, language, religion, political opinions, personal and social conditions". The initiative uses a multifaceted advocacy and educational strategy, encompassing the production of awareness-raising kits, a national report, and a stakeholder training course. The initiative's merit lies in its intersectional lens and inclusive methodology, involving persons with disabilities, families and experts in its development. One of the awareness-raising documents specifically targets ageing people with disabilities.

Inspiring practice - End of life care (Belgium)

The Anticipated Life and Care Project (PAVS) and the plain-language leaflets were developed by UNESSA in Belgium in 2024. They aim to support advance care planning, particularly for individuals with comprehension difficulties, such as those with disabilities or cognitive disorders. PAVS records a person's wishes regarding their end-oflife care and treatment preferences should they become unable to communicate. It serves as a vital tool for ensuring that care centres and institutions respect these wishes. Along with this document are plainlanguage leaflets - structured pedagogical "cheat sheets" designed to ease the understanding of complex information regarding topics such as assisted breathing, nutrition, euthanasia, and organ donation. These pedagogical information sheets help facilitate the engagement of persons with disability in the decision-making process related to end-of-life care, including for individuals with intellectual disability. The initiative stands out through its inclusive approach, which ensures that individuals with diverse cognitive abilities can actively engage in the planning of their healthcare. The initiative has been shown to have a significant impact on improving communication between ageing persons with disabilities, families, and healthcare providers, thereby fostering informed decision-making and reducing conflicts at the end of life.

FOSTERING INDEPENDENCE AND ABILITIES

Maintaining the independence and abilities of ageing people with disabilities is crucial to their well-being and quality of life. Preserving their autonomy enables them to continue actively participating in society, to make decisions about their own lives, and to keep a sense of control and dignity. This means adapting environments and services to meet their specific needs, while respecting their choices and preferences. In addition, maintaining physical, cognitive and social abilities helps to prevent their social isolation and the deterioration the health condition of people with disabilities. Initiatives aimed at promoting independence and maintaining abilities play an essential role in creating an inclusive and respectful living environment for ageing people with disabilities.



M. (68, intellectual disability, full-time assisted living):

"I want to be healthy. And have continued good care. And to go on vacation again. And to be able to stay up longer and not always go to bed before the others, but rather stay up late ... And to do a bit of personal development. My greatest wish would be to be able to walk again. And to have peace and quiet in my room."

To hear M's story, check her full interview on GOLD channel:





W.S. (58, multiple sclerosis, full-time assisted living):

"The most important thing in old age is that someone always be there in case I need help. And good, friendly relationships, and that the place I live in has a family-like atmosphere. The place where I live should feel like one big family. I've personally lost my family, so the family atmosphere in the facility is what's most important to me. A place where people help each other and where I can also do my bit, where I am still needed. And plenty of peace and quiet for myself."

To hear W.S's story, check her full interview on GOLD channel:

The interviews conducted as part of the GOLD project showed that the ageing of people with disabilities, when manifested by a loss of ability, can lead professionals to step in more often to "do things for them", or even take on the role of nurses rather than carers. While there is no doubt that the ageing of people with disabilities generates greater needs for support and care, it was also emphasised in the interviews that over-medicalising approaches may accelerate their loss of independence.

Maintaining the independence of people with disabilities can sometimes involve **adapting activities**, **services or infrastructure**. The good practices below illustrate this approach. In general, these adaptations require carers to come up with new solutions using the resources (financial and legal) available to them directly or via local intermediaries.

Inspiring practice - In Romania, a programme to maintain mobility

The Fondul Scaunelor Rulante (The Wheelchair Fund) is an initiative led by Motivation Romania that aims to provide customized mobility equipment to people with locomotor disabilities. The project centres on the provision of wheelchairs and other mobility devices that are customised to suit the specific needs, medical conditions and lifestyle of each individual user. The programme's primary objective is to empower individuals to achieve independent mobility, thereby enhancing their quality of life and facilitating enhanced social integration. The target group of the fund is persons with disabilities, with a specific emphasis on those grappling with mobility challenges and the execution of daily activities. The initiative is unique in Romania as it is the only organisation that assesses and prescribes personalised mobility equipment. The fund offers a wide range of wheelchairs, including manual, electric, and special outdoor models, facilitating navigation of diverse environments. This initiative is founded on the principles of independence and accessibility, with the objective of empowering individuals to engage in social, economic, and professional activities without the constraints imposed by physical or financial limitations. The organisation also provides consultations to assist users in selecting the most suitable equipment based on their individual medical requirements and preferences. The project has a substantial impact on enhancing the independence of people with locomotor disabilities and facilitating their integration into society. By diminishing physical and social impediments, the initiative fosters a more inclusive society.

Inspiring practice - An example of an individualised approach in Austria

In Weiz, Austria, Lebenshilfe Weiz GmbH has developed an individualised approach to support ageing people with disabilities, as exemplified through the case of a 73-year-old man. Previously, he was gainfully employed in a family business and subsequently maintained his independence following the loss of his parents. However, as he grew older and faced health issues such as a heart attack and physical weakness, he came to understand the need for tailored support. Despite not meeting the criteria for full-time assisted living due to a medium level of disability, the organisation developed a personalised plan that enabled him to continue taking part in some activities in the day care service while addressing his physical limitations. The arrangement included additional breaks, creative workshops, and one to two extra days off each week, with support from the housing network. This arrangement helped him to continue engaging in meaningful activities while preserving his health. This case shows the challenges many individuals with disability encounter as they age, particularly in the absence of adequate services. It is imperative to emphasise the need for a flexible, person-centred approach, with services meticulously tailored to an individual's unique requirements. While the approach can be applied in various regional and national contexts, it requires collaboration between residential and day care services, as well as flexible financial structures. This example sheds light on the importance of adapting services to meet the person's needs rather than forcing individuals to fit existing systems.

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ACCESS TO HEALTHCARE

As people age, they may develop additional health problems or medical needs. The interviews carried out as part of the GOLD project showed that care and ergonomic needs increase with age, often making it essential to have larger teams of nurses at facilities hosting ageing people with disabilities to provide care that goes beyond simple hygiene.

Some structures in the disability sector have also opted for more far-reaching institutional changes to provide better care those they support, for example:

- Creating the role of "medical coordinators" to complement that of educational coordinators.
- Setting up specialised living units.
- Purchasing specific equipment, such as cut-out cups and medicine trolleys.

Networking with external healthcare professionals who know how to, or who have experience working with patients with disabilities can also help ensure good medical follow-up. However, this requires that carers have good knowledge of the external support services they can potentially turn to.

Finally, having access to healthcare as close as possible to where one lives, or even exactly where one lives, can make regular, preventive health monitoring much easier.

Inspiring practice - Specialized medical-social facilities in France

The Foyers d'Accueil Médicalisé (FAM) are specialised medicalsocial facilities and were first established in France in 2002. They are designed to provide support to adults with disabilities who require assistance with daily life activities and continuous medical monitoring. A number of these facilities have been specifically adapted to address the evolving needs of ageing residents with disabilities. These facilities offer secure and accessible housing for individuals who are unable to work due to their disabilities. Residents receive daily support with essential activities (hygiene, meals, mobility), along with personalised medical and paramedical care. The operational framework of these facilities is characterised by the integration of multidisciplinary teams comprising medical professionals, including doctors and nurses, as well as therapists, educators, and service staff. Together, these professionals establish tailored care strategies aimed at maintaining or enhancing their residents' health, independence, and social engagement. The programmes encompass therapeutic workshops, adapted physical and cultural activities, and infrastructure modifications such as accessible bathrooms and common living areas. The overarching objective of these initiatives is to foster well-being, reduce social isolation, and maintain functional abilities in the face of ageing or complex disabilities.

WHY AND HOW TO ADAPT SCHEDULES, ACTIVITIES AND THE LIVING ENVIRONMENT?



TIME MANAGEMENT AND RITUALS

All interviews conducted as part of the GOLD project highlighted the importance of adjusting daily schedules for people with disabilities to better reflect the changing needs and slower pace associated with ageing.

As people age, they may require more time for morning routines or meals and often express the need for rest or quiet periods during the day. This sometimes requires a major change in approach for the teams, who were used to schedules with numerous activities aimed at developing skills. Supporting an ageing person can mean maintaining their abilities and overall well-being comes as a priority, rather than focusing solely on progression.



Team in a disability care centre:

"We're not going to have them be too active anymore because it's better for them this way. The question is, what do we do now? Introducing a 'cozying up' activity was destabilizing for the educators because they didn't really know what they are supposed to do. This calls for a true paradigm shift. After having supervised these sessions, we've re-emphasized how important it is to take our time, even when it comes to simply choosing an outfit with the person instead of picking it for them, to have a little chat ... These are things that we need to learn as they're not always intuitively understood."

The importance of rituals

The GOLD project's research activities shows that rituals play a crucial role in the lives of people with disabilities as they age, offering them stability, security and points of reference in their daily routines:

- Reducing anxiety: rituals help to structure the day, which can reduce anxiety and confusion, particularly in people with cognitive impairment. The repetition of daily activities helps to create a predictable and reassuring environment.
- Providing temporal and spatial reference points: regular routines anchor individuals in time and space, supporting emotional and mental stability, which is essential for their well-being.
- Maintaining abilities: repeating familiar activities helps to strengthen skills and maintain certain functional abilities for longer.
- Fostering independence: by integrating rituals into daily activities, people can continue doing certain tasks independently, reinforcing their sense of competence and independence.
- Strengthening social ties: ritualised activities such as having a meal together and leisure activities encourage social interaction and strengthen ties with family, friends and carers.
- Supporting transitions: rituals can help ease transitions between different activities or times of the day, reducing restlessness and confusion.



ADAPTING ACTIVITIES

In addition to a lighter daily schedule, the activities proposed can also be redesigned to take better account of the new needs and abilities of people with disabilities as they age. Continuing to offer activities to ageing people with disabilities is paramount. They support cognitive and physical stimulation, create time for social interactions, are a source pleasure and foster a feeling of well-being.



W.S. (58, multiple sclerosis, full-time assisted living):

"It would be great to have offers for elderly people with disabilities on the topic of digitalization, something like a computer course. I'd be interested in that - there's isn't anything like that yet. More supervised leisure activities would further enhance my care experience. I would like to do more arts and crafts, but I need someone there to guide me. There should be leisure activities tailored to elderly people with disabilities, such as games, craft groups, and so on, with carer supervision."

To hear W.S's story, check her full interview on GOLD channel:

The idea is not necessarily to completely redesign the activities offered, but rather to **focus on what people with disabilities enjoy as a starting point**, while considering the constraints associated with their age in order to work on possible adjustments.



L. (physiotherapist working in a home for people with disabilities):

"My credo is to avoid doing activities just for fun. It's more important to make sure that the activities really meet the person's needs and desires."

In addition, maintaining the person's independence as far as possible in the daily activities that directly concern them (meals, bathing and getting dressed, for example) is essential. These moments are ideal for spotting changes in a person's abilities. What's more, they can mean quality time for the carer and the person being cared for, although they might require more time.

The interviews conducted as part of the GOLD project highlighted the importance of **tackling social isolation among ageing people with disabilities.** This can be done through organising suitable social events where people can actively interact or just watch, depending on their abilities and wishes.



A. (Nurse):

"There's a need for more leisure activities, because they live very isolated lives. When they stop working, they lose touch with society. They don't have any children or grandchildren, and their entire social network has shrunk. Thats why it's important to offer more activities so that they can participate in society and do not self-isolate."



N.Z. (aged 70, person with light intellectual disability):

"I would like to do the things I love doing, like watching TV, talking with my roommate. I would like to do fun things, like going out for a good coffee or an ice cream. I like snacking in the home and talking on the phone with my sisters, they mean a lot to me."



MAINTAINING A HEALTHY LIFESTYLE

As we have seen, staying active is essential to maintain the person's functional abilities, to avoid the risk of becoming overweight (physical activity) and to cultivate a social life. In addition, it is essential to establish the **conditions conducive to people maintaining a healthy lifestyle to limit the risks of pathological ageing.**

This involves, for example:

- A well-balanced diet. As they age, people with disabilities can lose the pleasure of eating, just like any other elderly person. However, a proper diet is one of the keys to healthy ageing. Adjustments can help to make meals more enjoyable, for example, by redesigning the dining area to make it quieter, using technical aids (e.g. nose cut out cups, adapted cutlery) or by adapting the food itself (by chopping it up, for example).
- Good oral hygiene
- Getting enough quality sleep
- Providing basic medical care (vaccinations, screening, regular check-ups)

ADAPTING THE ENVIRONMENT

When the health condition of those being cared for allows it, more targeted adaptations can be devised to improve their everyday life and meet ageing-related needs. The more technical aids a person with a disability has in at their disposal in their old age, the longer they can be independent (standing aids, care beds, good wheelchairs, computers with voice output, special cutlery, drinking cups, support arms, help with dressing, etc.).

The paragraph below summarises some of the ideas that arose from the interviews and research carried out as part of the GOLD project:

- Providing quiet spaces in common areas
- Moving the person's bedroom to the ground floor to avoid them having to climb stairs
- Installing bathroom fittings for easier access to the shower/bathtub



L. (psychologist with 22 years of experience in a social rehabilitation service):

"To start with, we would need suitable facilities and contexts for their needs. The structures should have areas which were designed with particular attention to the colours and the furniture to ensure a tidy atmosphere and uncluttered environment."

Where possible, it is always advisable to involve the person with disability in the organisation and layout of living spaces to best meet their needs.

SUPPORTING AGEING PERSONS WITH DISABILITIES: THE ROLE OF INFORMAL CARERS, PROFESSIONALS AND CARE STRUCTURES



FAMILIES AND CARERS

The role of close caregivers and the issues surrounding their relationship with families were discussed at length in the interviews conducted for the GOLD project.

Where possible, it is important that professionals maintain a relationship of trust and an open dialogue with the family of the person with a disability. This can be particularly useful in identifying signs of ageing in the person. That said, it can be difficult for a close carer to accept that the person they are supporting is ageing, making this conversation more complicated.

Building a relationship of trust between family carers and professionals

Building a relationship of trust with the family of a person with a disability takes a certain level of investment, but will offer many benefits in the long term.

- Professionals should take the time to listen to the family's concerns and needs without interrupting them and plan enough time for this.
- Professionals should be transparent in the information they give. Avoid using technical terms or medical jargon.
- Respect each other's opinions and decisions, even if they differ from your own
- Recognise the expertise and knowledge of the other person.
- Professionals should involve the family in decisions related to care and accommodation. They should work together to find solutions tailored to the needs of the person with a disability.

This relationship can also help to **spot signs of exhaustion in family carers** and, as a result, to help the family in planning ahead for solutions that could ease their daily burden while continuing to meet the new needs of the person with a disability.



L. (aged 52, person with several disabilities):

"My needs haven't changed that much, but Dad was no longer able to carry me or wash me, and Mom had already passed away. So, things just didn't work out."

> The family carers we interviewed as part of the GOLD project highlighted several needs that, if covered, could make their daily lives easier when caring for an ageing person with a disability:

- Teams to support at-home carers, in sufficient numbers and properly trained to deal with the challenges associated with ageing.
- Better interactions between social and healthcare services
- Support groups or forums for carers to break the social isolation they feel
- Regular and accessible psychological support
- Access to practical training on ageing and disability
- Support/tools to identify the most suitable structures if necessary, a transfer from the person's home to an institution.

L. (social worker):

where we can stay together and not become isolated. I hear a lot of parents saying, 'We've been abandoned.'"



To hear L.'s story, check her full interview on GOLD channel:

A. (mother of an ageing person with disability):

"For better support, I think it would be very useful to have some emotional support. Also, I think these institutions should provide us, the carers, with specialized training."

TRAINING NEEDS FOR PROFESSIONALS

The interviews conducted during the GOLD project confirmed the strong need for training professionals in both sectors (older people and people with disabilities) to better understand and integrate into their work the specific issues surrounding the ageing of people with disabilities. It was also recognised that it would be worthwhile for these **training tools to be designed in a crosscutting way to facilitate knowledge sharing between these two sectors** – which, ultimately, experience quite different realities and seldom have opportunities to work together.

The professionals interviewed as part of the GOLD project highlighted the following needs in terms of skills and knowledge:

Knowledge:

- Basic knowledge on the challenges associated with ageing for professionals in the disability sector, and on disability-related issues for professionals in the elderly sector
- Handling and ergonomics
- Knowledge of the local medical-social network to facilitate transitions to other appropriate structures if necessary
- Basic knowledge of the legislative and regulatory framework including the rights of ageing people with disabilities
- Specific training on end-of-life care
- Facilitation techniques to offer activities adapted to ageing people
- Use of technologies and technical aids
- The concept of a «life project» and the tools for implementing it

Skills and know-how:

- Listening and observing
- Understanding the signs of ageing and the person's emerging needs
- Adaptability (being able to reconsider practices)
- Empathy
- Patience
- Ability to establish a relationship of trust with people with disabilities, their families and other professionals in the medical and social sectors who may have to work with them
- Ability to work as part of a team, including a multidisciplinary team



Inspiring practices – Available training programmes

Particip.AGE is an Erasmus+ project that aims to foster social inclusion for ageing individuals with intellectual disabilities by developing e-training for both the professionals who support them and the individuals themselves to foster their social integration.



The **AGID project** provides an international e-learning platform with six modules for professionals working with ageing individuals with intellectual disabilities. Based on the Appreciative Inquiry methodology, the project ensures that the training is grounded in the real needs and aspirations of users, their families and the professionals supporting them.



ANFFAS Trentino has developed a training course made up of five modules, aimed at educational, healthcare and care professionals who work with this target group on a daily basis, with the aim of enhancing specific skills on ageing, comorbidities, dementia and behavioural changes. The course includes aspects on the physiology and pathology of ageing in people with disabilities, the clinical classification of major neurocognitive disorders (DNM), the use of screening and monitoring tools (NTG, AFAST, CDS), evidence-based psychosocial strategies, end-of-life care, as well as support for carers.

SIGNS OF AGEING

Beyond individual professional practice, the ageing of people with disabilities has a broader impact on how care services and facilities operate. The interviews carried out as part of the GOLD project revealed that this topic can be sensitive for teams in both the disability and ageing sectors.

Yet, it is essential that ageing is addressed not only at the individual level, but also at the structural and organisational levels.

Adapting to this reality may involve revisiting how care is coordinated, adjusting daily schedules, revising team structures, redefining job roles, and even reconsidering how spaces are designed. Several interviews conducted as part of the GOLD project also mentioned the benefits of having contact points specialising in ageing in facilities for people with disabilities - and vice versa, contact points specialising in disability in facilities for elderly people.



To support these shifts and engage staff effectively, it can be useful to **organise collective discussion forums** to share findings, identify emerging needs and develop solutions. For example, teams could explore:

- How the ageing of residents affects the organisation's human and material resources
- Developing shared tools and processes to facilitate dialogue and provide targeted support to the person being cared for on issues related to ageing
- Opportunities for local support and collaboration

Finally, there is a clear interest in **establishing local groups with organisations from both sectors** (disability and elderly care). These exchange groups give stakeholders from the different sectors the opportunity to get to know each other better. In doing so, they create a relationship of trust that will help smooth any care handovers or transfer between the sectors.



R. (technical director):

"We don't have to have everything right here (...) Our policy is to see what is also being done out there, in the community, which we can associate with and learn to innovate and become more self-sufficient."

Inspiring practice – A partnership between social workers and nursing homes (Belgium)

A group of social workers wishing to share their day-to-day support experiences and seek answers to the many questions and challenges raised by the ageing of people with intellectual disabilities has been set up in Brussels (BE). The primary objective of this group, called Bruxaînés, is to encourage professionals working with ageing adults with intellectual disabilities to reflect and engage in discussion, with the aim of providing them with the best possible support. The group also works in partnership with nursing and care homes (Maisons de Repos et de Soins) in Brussels likely to cater for ageing people with intellectual disabilities in order to develop a network of trusted partners.





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