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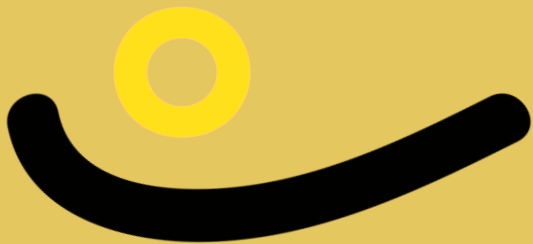
# Ageing with a disability: what does it mean?

Introduction to the summary document

*Fina Kanam, UNESSA (Belgium)*

**GOLD**

GETTING OLDER  
WITH A DISABILITY



G.A. N° 2024-1-FR01-KA220-ADU-00024495

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# WP 2 - Summary of inspiring stories, experiences and practices: Quick overview

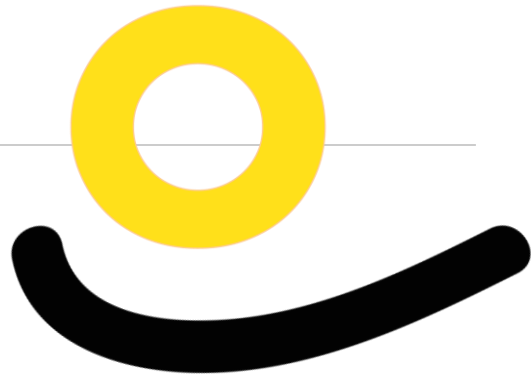
Summary of testimonials, experiences  
and inspiring practices

- Literature and field research
- Collection of inspiring practices
- Qualitative interviews
- Competency framework



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## Getting Older with a Disability

Stories, Tools, and Inspiring Practices from GOLD



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### SIGNS OF AGEING

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 , 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'Alnés 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).



##### HANDCONNECT

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



# Purpose of the document

- An accessible introduction to the topic, this document is aimed primarily at professionals who work directly with people with disabilities as they grow older. It may also be of interest to close carers supporting people with disabilities as they age.
- A practical, concise document of around twenty pages, easy to read and tailored to professionals

Inspiring practices relating to the ageing of people with disabilities.

Testimonials from interviews

Identifying training needs for professionals in the disability and elderly care sectors



# Overall approach

Structure of the document:

1. An introductory chapter (definitions + overview of the legal framework in different countries)
2. What does ageing mean for a person with a disability?
3. Putting the person at the centre / Independence and life plans
4. What tools should be put in place to support the ageing of people with disabilities?
5. Needs of professionals (training, structural requirements)

Working method:

Phase 1: Data collection

Phase 2: Analysis

Phase 3: Synthesis and production of the document



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# Phase 1: Data collection



- **Field and literature review:** conducted between January and March 2025 by the partners, focusing on providing a contextual framework of the current situation prior to the project, incorporating an analysis of policies and of the situation on the ground.
- **Interviews and testimonials:** • 45 qualitative interviews carried out with ageing people with disabilities, professional and family/informal carers
- Inspiring practices



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# Phase 2: Analysis



- Cross-referencing data
- Identification of issues
- European vision
- Reports & recommendations



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# Phase 3: Synthesis and production of the document



- Visual format
- Accessible
- Varied content
  - *Context (political / legal)*
  - *Key theoretical concepts*
  - *Testimonials (quotes)*
  - *Inspiring practices*
  - *Tools / resources*
  - *QR codes → additional content (videos)*



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# Participatory approach

All partners have set up a local 'stakeholder committee' comprising key players in the field of ageing people with disabilities.

- **Role of stakeholders:**

Provide feedback on deliverables

Verifying relevance in the field

Co-developing the tools

Support the dissemination and promotion of outputs and various activities



# Adaptation & accessibility

- Document available in all project languages
- Easy to read and understand version

## **Objective:**

To make the content accessible to people with disabilities

## ***Target sections:***

*Introduction*

*Ageing (signs, impacts)*

*Life plan*

*Rights*

*Health*



# Link to the next section

The document is not an end in itself, but serves as a basis for:

- Competency framework
- E-learning training modules
- Toolkit





# Thank YOU



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