





## Autism and Ageing Ethical, Legal and Political aspects

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# **Summary of presentation**



- About AGE Platform Europe
- Intersection of age and autism

- Ethical Questions
- Legal Gaps
- Policy Framework
- Conclusions



### **AGE Platform Europe**



- More than 165 organisations of and for people aged 50+ representing over 30 million older people in Europe
- Mission: To monitor and influence EU policy developments of relevance to older people
- Funding: EU PROGRESS and other funding instruments, and membership fees



### **Guiding Principles**



- Towards a society of all ages: Promote inter- and intra- generational solidariy
- Older people as a resource: take into account the cultural and professional resource represented by older people
- Older people as self-advocates: older people should be able to speak on their own behalf





Older people with autism

**Autism (disability)** 

Age (vulnerability, frailty, dependence)

Multiple discrimination

Lack of access to necessary goods and services

Environment and care not adapted to their needs



Social exclusion and violation of human rights



#### **Ethical Questions**

- Not homogeneous group (age, abilities, socioeconomic status, level of education, comorbities, degree of autism, etc.) → respect for diversity and tailored care
- Person-centered approach
   (support for independent living, improve quality of life, empower for self-determination, involve family) → autonomy
- Human rights do not decrease with age, disability or dependency. → All older persons deserve to be treated with respect and dignity

"What I miss is the freedom to choose when I get up, what to have for lunch, what to wear today"

"I don't like being treated like a piece of furniture. Can't they talk to me instead of discussing between them? I am not dead yet!"



## **Existing legal instruments**

- Charter of Fundamental Rights of the EU (Articles 25 & 26)
- EU anti-discrimination framework (Treaties and directive)
- The UN Convention on the Rights of Persons with Disabilities (UNCRPD)
- The Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)
- European Social Charter (and Revised)
- UN Principles for Older Persons, Madrid International Action Plan on Ageing and Open-ended working group on ageing
- Council of Europe soft instruments and draft recommendation on the rights of older persons

But protection gaps still exist



## Legal gaps and challenges

## Age barriers

- Different protection(ex. FR)
- Not taking into account intersection of age & disability

#### Abuse

- Awareness of rights
- Intentional &
   Unintentional abuse
- Appropriate support

# Access to goods and services

- Discrimination
- Age limits

#### Self-determination

- Consent (bioethics)
- Supported decision-making
- Deprivation of liberty
- End of life situations



## **Policy framework (1)**

- Impact of crisis → limited resources, lack of access to adequate income, benefits and services, risk of poverty and social exclusion
- Adapted environments to age and disability needs → design for all, support for home adaptation, agefriendly environments, accessibility
- Social inclusion → lifelong learning, intergenerational dialogue, employment, involvement in community

"My doctor told me I need hearing aid; I don't have the money to pay for it and my insurance covers only a small part of it, so leave it".

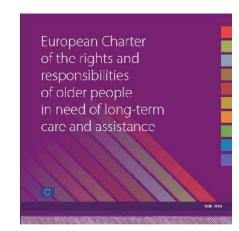
"When my wife died, I felt hopeless and isolated. I did not know how to cook a proper meal and I could not get down the stairs of my building to go to the shops".



## **Policy Framework (2)**

### **Quality of care**

- Support to carers (informal caregivers are ageing)
- Adequate resources & trained professionals
- Tailored care (respect for specific care needs linked with age and autism)
- Assessment of care needs, involving individuals and their families
- Prevent abuse, maltreatment and neglect
- Quality Frameworks
- Improve dignity and wellbeing







#### **Conclusions**

- Human rights approach to ageing and to disability
- Raise awareness of needs and expectations older people with autism and their families
- Improve data gathering to trigger policy change
- Common vision on care → towards a model of dignity and wellbeing
- Break down age barriers → Create a society for all ages





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