



# **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 solidarity**
- **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**



# The intersection of age and autism

## Older people with autism



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, co-morbidities, 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**

## Age barriers

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

## Access to goods and services

- Discrimination
- Age limits

## Abuse

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

## 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, age-friendly 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**



For the Wellbeing and Dignity of Older people

# 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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