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Submission to the Independent Expert on the Enjoyment of All Human Rights by Older Persons
Human Rights, Cognitive Impairment and Ageing: Strengthening Autonomy, Participation, Dignity and Social Inclusion of Older Persons in Slovenia, South-Eastern Europe and Eastern Europe

Submitted by:
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Introduction
The Centre for Cognitive Impairments at the Department of Neurology, University Medical Centre Ljubljana, welcomes the opportunity to contribute to the report of the Independent Expert on the enjoyment of all human rights by older persons concerning cognitive impairment, autonomy, participation, recognition and dignity.
Population ageing is transforming societies across Slovenia, South-Eastern Europe and Eastern Europe. As cognitive impairment and dementia become more prevalent, it is increasingly important to recognize that these conditions are not only medical and social care issues but also human rights issues.
Older persons living with cognitive impairment often face social exclusion, reduced participation in decision-making, diminished recognition of their identities and capacities, and assumptions that equate cognitive decline with loss of personhood. Such experiences can undermine dignity, autonomy and inclusion even in the absence of overt rights violations.
A human rights-based approach requires recognition of the continuing personhood, values, relationships, capabilities and social contributions of people living with cognitive impairment.

Fear of Dementia, Stigma and Social Exclusion
Across the region, dementia remains strongly associated with dependency, institutionalization and loss of self. These perceptions contribute to delayed diagnosis, social withdrawal, discrimination and reduced expectations regarding participation in family and community life.
People living with cognitive impairment are frequently spoken about rather than spoken with, and may gradually lose meaningful social roles. Public awareness initiatives should therefore promote dementia literacy and emphasize that cognitive impairment does not

eliminate emotional life, personal values, cultural identity, relationships or the ability to express preferences.
National strategies should actively combat stigma, ageism and assumptions of incompetence while promoting inclusion and continued participation.

Autonomy and Supported Participation
Autonomy should not be viewed as an all-or-nothing concept. Decision-making abilities often fluctuate and can be supported through appropriate communication, environmental adaptations and trusted relationships.
Many older persons with cognitive impairment retain the ability to express preferences, values and wishes when given adequate support. Consequently, healthcare, social care and legal systems should prioritize supported decision-making wherever possible.
Key measures include:

- development of supported decision-making frameworks;
- communication-support strategies;
- recognition of advance care preferences;
- involvement of trusted supporters while preserving the individual's voice;
- person-centred and relationship-centred care approaches;
- recognition of relational and context-dependent autonomy.

The Role of Neurology and Healthcare Professionals
Neurological services and memory clinics have an important role not only in diagnosis and treatment but also in protecting human rights and supporting social participation.
Healthcare professionals are often among the first to identify cognitive decline and therefore influence how individuals and families understand dementia. Clinical encounters should promote agency, participation, communication and future planning.
Healthcare institutions can contribute through:

- early diagnosis accompanied by rights-based counselling;
- education of patients and families;
- promotion of advance care planning and supported decision-making;
- collaboration with community organizations and civil society;
- participation in public awareness activities;
- support for community programmes that maintain social engagement.

Healthcare professionals should receive education in communication, ethics, human rights and person-centred care in addition to clinical training.

Intergenerational Solidarity as a Regional Strength
Family relationships, intergenerational connections and local cultural traditions remain important strengths throughout Slovenia and many countries of South-Eastern and Eastern Europe.
Older persons should be recognized as holders of valuable cultural, historical and experiential knowledge. Their contributions include local history, traditional crafts, language preservation, cultural customs, environmental knowledge and community memory.
Governments and communities should support programmes that enable older persons to share knowledge through:

- storytelling and oral history initiatives;
- cultural heritage projects;

- traditional skills workshops;
- local history activities;
- community gardening and environmental programmes;
- participation in schools, cultural institutions and community centres.

Intergenerational exchange should also operate in the opposite direction. Younger generations can support older persons in acquiring digital skills and accessing modern communication technologies.
Such reciprocal relationships strengthen autonomy, social inclusion, community participation and mutual understanding while reducing age-related stereotypes.

Community Services and Social Inclusion
Governments should strengthen community-based and person-centred support systems that enable people with cognitive impairment to remain active members of society.
Priority actions include:

- development of dementia-friendly communities;
- integration of health and social care services;
- expansion of home-based support;
- establishment of community resource centres;
- age-friendly and dementia-inclusive public environments;
- support for family caregivers;
- inclusion of people living with cognitive impairment in policy development and service evaluation.

Particular attention should be given to rural and underserved areas where access to specialized services remains limited.

Education and Capacity Building
Long-term progress requires sustained investment in education.
Priority educational areas include:
Healthcare Professionals

- dementia literacy;
- communication skills;
- supported decision-making;
- human rights and ethics;
- person-centred care.

Social Care Professionals

- dignity-preserving care;
- participation support;
- social inclusion.

Legal Professionals

- legal capacity;
- supported decision-making;
- rights-based approaches.

Educational Institutions and the Public

- intergenerational learning;
- positive ageing;
- reduction of stigma;
- awareness of autonomy and participation.

Equitable Access to Emerging Disease-Modifying Therapies

Recent advances in Alzheimer's disease research have led to the development of disease-modifying therapies targeting amyloid pathology. While these therapies represent important scientific progress, they also raise questions regarding equity, accessibility and human rights.

Current anti-amyloid therapies are available only to carefully selected individuals with biomarker-confirmed early Alzheimer's disease and require specialized diagnostic pathways, advanced imaging, multidisciplinary expertise and substantial healthcare resources. Consequently, only a minority of people living with dementia are currently eligible.

There is a risk that public attention and healthcare resources become disproportionately focused on those eligible for innovative therapies while the broader population of people living with dementia remains underserved.

From a human rights perspective, dignity, autonomy, participation and access to quality care must never depend on eligibility for a particular treatment.

Most individuals living with dementia today either have conditions other than Alzheimer's disease, present at later stages of disease, have contraindications, or lack access to specialized diagnostic services. Nevertheless, they retain the same rights to recognition, participation, inclusion and support.

Healthcare systems should therefore avoid creating a two-tier model of dementia care. The emergence of disease-modifying therapies should strengthen, rather than narrow, the overall dementia care pathway.

Investment priorities should include:

- equitable access to diagnosis and specialist consultation;
- timely post-diagnostic support;
- psychosocial interventions;
- cognitive rehabilitation and stimulation programmes;
- caregiver support and education;
- community-based services;
- dementia-friendly environments;
- supported communication and decision-making;
- programmes promoting autonomy, participation and quality of life.

Healthcare professionals should communicate realistic expectations regarding emerging therapies while emphasizing that every person living with dementia deserves respect, support and dignity regardless of treatment eligibility.

Scientific innovation and social justice must progress together.

Recommendations

The Centre for Cognitive Impairments recommends that States:

1. Adopt rights-based dementia and cognitive impairment strategies.
2. Promote supported decision-making and strengthen safeguards for autonomy.
3. Implement national anti-stigma initiatives addressing fear of dementia.
4. Invest in dementia-friendly and age-friendly communities.
5. Expand community-based services that support ageing in place.
6. Strengthen interdisciplinary education on cognitive impairment, communication and human rights.

7. Ensure meaningful involvement of persons living with cognitive impairment in policy and service design.
8. Promote intergenerational programmes that support reciprocal exchange of knowledge and skills.
9. Recognize older persons as contributors to cultural continuity, social cohesion and sustainable development.
10. Encourage active involvement of neurological services, memory clinics and healthcare institutions in community engagement and human rights promotion.

Conclusion

Cognitive impairment does not negate personhood, dignity, identity or human rights. Older persons living with cognitive impairment remain valued members of families, communities and societies whose voices, experiences and preferences deserve recognition and respect. The future of ageing societies will depend not only on healthcare and social services but also on the ability of societies to value older persons as active participants, knowledge holders and rights bearers.

The success of future dementia policies should not be measured solely by the number of individuals receiving novel disease-modifying therapies, but equally by the extent to which all persons living with cognitive impairment remain visible, heard, respected and meaningfully included in society.

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