

AGE Platform Europe a.i.s.b.l. 111 rue Froissart – B-1000 – Tel. +32 2 280 14 70 www.age-platform.eu – @AGE_PlatformEU



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AGE response to OHCHR questionnaire on article 5 of the UNCRPD

In this paper AGE Platform Europe (AGE), as the largest representative organisation of older people at European level brings the views of our members that directly represent more than 40 million older people across the EU. Our response mainly answers to the third question of the questionnaire. It does not refer to a specific country but is illustrative of the discrimination faced by *older people with disabilities*¹, i.e. adults who are faced with impairments and functional limitations for the first time when they reach old age. Although the questionnaire does not mention specifically this form of structural discrimination we argue that the OHCHR study as well as the UNCRPD Committee and State parties to the Convention should address the age discrimination faced by older persons with disabilities and raise awareness of the intersection of ageing and disability.

Introduction

The UNCRPD has enshrined protection for two forms of intersectional discrimination affecting women and children with disabilities. Although the link between older persons and persons with disabilities has been underlined by the UN CRPD Committee², the OHCHR³, the Independent Expert on the Enjoyment of all Human Rights by Older Persons⁴, and the UN Secretary General⁵ among others, no substantive provision acknowledges the situation of older people with disabilities as a type of intersectional discrimination. It thus remains unclear from a legal, policy and advocacy perspective whether old age is just an additional characteristic that compounds the disadvantages linked with disability, or whether there are specific challenges due to the combination of old age and disability, constituting thus a unique vulnerable situation that needs to be recognised as a distinct barrier to the realisation of rights.

Even though age discrimination under international law can be justified, general exclusions based on age are to be avoided unless the age-related limitation is based on reasonable and objective criteria⁶. This absence of clarity as to what is a justified limitation to age equality, renders treaty bodies responsible to rule which situations should be prohibited and which can be allowed. Unfortunately, the CRPD Committee has not yet dealt with such cases and therefore has not provided guidance as to how the rights of older people with disabilities can be applied and claimed in practice. Furthermore,

⁵ UN Secretary General (2011) Follow-up to the Second World Assembly on Ageing, A/66/173, 22 July 2011, §47
⁶ See Committee on Economic, Social and Cultural Rights, general comment No. 20, "Non-discrimination in economic, social and cultural rights" (E/C.12/GC/20, para. 29), Committee on Economic, Social and Cultural Rights, general comment No. 6 "Rights of older persons" and also Human Rights Committee, *Love et al. v. Australia*, Communication No. 983/2001, *Schmitzde-Jong v. The Netherlands*, Communication No. 855/1999, *Solís v. Peru*, Communication No. 1016/2001 and *Althammer et al. v. Austria*, Communication No. 998/2001



¹ The CoE makes a distinction between older and ageing persons with disabilities, see Angela Garabagiu (2009) *Council of Europe actions to promote the rights and full inclusion of ageing people with disabilities*, Int J Integr Care. 2009 Apr-Jun; 9(Suppl): e24.

² United Nations Committee on the Rights of Persons with Disabilities (2013) Position statement concerning the CDDH-AGE Report of the United Nations High Commissioner for Human Rights (2012) E/2012/51, 20 April 2012. See also OHCHR (2012) Normative standards in international human rights law in relation to older persons – Analytical Outcome Paper Independent Expert on the enjoyment of all human rights by older persons (2015) Autonomy and care of Older Persons, A/HRC/30/43





lacking an old age perspective in the CRPD implementation, results in the parallel existence of competing paradigms, such as those resulting from a welfare or medical approach.

Answer to 3rd question of OHCHR questionnaire: Structural discrimination against older people with disabilities

While not all older people are persons with disabilities, the likelihood of acquiring a disability increases with age. In the EU people at the age of 65 are expected to live more than half of their remaining years with a frailty or disability that could affect their ability to manage instrumental and/or self-care activities of daily living⁷.

AGE members report the fragmentation of policies for people with disabilities of working age and those that are eligible for old age pension ⁸. Sometimes 'older' and 'disabled' persons are subject to different administrations, budgets and eligibility criteria that determine the allocation of in kind and cash benefits, without any coordination between the two. ⁹ Across the EU we come across laws and policies that enshrine differential treatment for older people imposing age limits in access to disability benefits ¹⁰, mobility allowances ¹¹ or personal assistance ¹². For example:

- In France there are different schemes depending on whether the disability occurred before
 or after 60 years. The old age scheme provides less generous means-tested care packages
 that unlike the disability benefit cannot be used to remunerate the spouse, cohabitant or
 legal partner of the individual.
- In Catalonia, Spain, disabled people above the age of 64 are not eligible for the same personal assistance as a younger person¹³;
- In Flanders, Belgium, people who become disabled after the age of 65 have no access to any type of support delivered by the Flemish Agency for Disabled Persons;
- In Sweden older people lose some state disability benefits when they reach the age of 65, such as financial support for adjusted cars.
- At least 8 EU countries do not offer personal assistance in old age¹⁴.

¹⁴ See, ENIL report on personal assistance. According to MISSOC, for Slovakia the threshold is set at 65 whereas in Finland "Personal assistance by the Services and Assistance for the Disabled Act is meant for persons whose need of assistance is not mainly caused by illnesses or injuries that have begun, increased or worsened with high age or due to degeneration related to high age".



 $^{^{7}}$ European Commission (2013) *Staff Working document on long-term care,* based on data from 2009 for EU27

See also several policy reports deal separately with long-term care in old age, see for example European
 Commission/Social Protection Committee (2014) Adequate Social Protection for Long-term care needs in an ageing society and OECD/European Commission (2013), A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care.

⁹ In Hungary there are separate services for the elderly and people with disabilities (MISSOC). The 2009 *Barcelona* declaration on bridging knowledge in long-term care and support underlined that: 'bridges across the fields of disabilities and ageing have been limited, and they coexist with significant barriers to communication and information sharing'.

For example in Belgium: http://www.andrecontrelasla.be/Atteinte-de-S-L-A-a-71-ans-elle.html In Greece, the ombudsman dealt with a relevant case: http://www.synigoros.gr/resources/perilipsi_epidoma_anapirias.pdf

¹¹ See for example case dealt by Irish Ombudsman: https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/governmentdepartments-other-public-bodies/Too-Old-to-be-Equal-/Too-Old-to-be-Equal-.pdf
¹² See, ENIL report on personal assistance. Also according to MISSOC, for Slovakia the threshold is set at 65 whereas in

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¹³ http://www.independentliving.org/docs7/Spain-personal-assistance-not-reality.html





Whereas the Cyprus' Supreme Court recently ruled in favour of a claim questioning the age limit for disability benefits that puts older people in a disadvantaged position¹⁵, such age categorisations that perceive disability in old age as a predictable or even inevitable situation persist in various EU countries. These laws sustain the vision of older people as being less deserving of support to live independently or remain included in the community. They also impede older persons from identifying themselves as people with disabilities and therefore seeking protection under the UNCRPD.

Even where age barriers are extinct, strict definitions of disability or assessment based on the type of impairment or degree of incapacity may leave older people who do not suffer from specific or single pathologies, and those with complex high-support needs, completely or partially uncovered¹⁶. In Ireland home care is not a statutory entitlement and older people with very complex medical and support needs, find themselves with practically no choice to live in the community and end up in acute hospital departments.¹⁷ In some countries, including the Netherlands, Belgium and Finland, a certain type of medical diagnosis is needed to benefit from disability allowances, reasonable accommodation in employment or make a disability-related claim. These restrictions create additional difficulties for older people to receive equal treatment, as old age disabilities are not necessarily linked to a specific condition, while medical professionals tend to attribute some of the difficulties encountered 'just to old age'.

Moreover, our members report cases where support is medicalised; or conversely, only focuses on cleaning and grooming, excluding assistance aimed towards improving health and quality of life or preventing further disabilities. Many older persons lack access to preventive healthcare and affordable rehabilitation services, which take into account their specific needs. This is often linked to the fact that disability policies focus on preventing disabilities in working life¹⁸. For example, in Finland, the scheme for medical rehabilitation was reformed in 2016 and is no longer available to people over the age of 65.

In addition, frailty, chronic illness and mental decline can accumulate and gradually aggravate in later

¹⁷ Irish Equality Authority (2001) Implementing Equality for Older People, p. 50-51, Cahill, O'Shea and Pierce (2012) Creating excellence in dementia care: a research review of Ireland's national dementia strategy. See also ENNHRI (2015) Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care: The Application of International Human Rights Standards to Older Persons in Long-Term Care, arguing that there is no automatic right to receive long-term care services, nor to choose the provider or care setting. Recipients of long-term care are not automatically entitled to immediate treatment or healthcare if they require it - they only have the right to the same equal access to available services, which may mean being placed on a waiting list.

18 For example, according to the EU Disability Strategy the EU aims to support policies that reduce the risk of developing disabilities during working life -to date- it has paid limited attention to preventing and tackling disability in old age. Moreover, according to the thematic study of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (A/HRC/18/37), older people are faced with 'several specific concerns, including the lack of adequate prevention and management of chronic illnesses and disability among older persons. Overall, age-based discrimination is cited as a significant barrier to accessing health care that compromises meaningful communication between patients and medical personnel, with consequences for the accuracy of diagnosis and quality of treatment'



¹⁵ http://cylaw.org/cgi-bin/open.pl?file=apofaseis/aad/meros 4/2016/4-201601-2005-2012.htm&gstring=%F4%F9%F1%FA%F1%F9%F3%2A%20and%202016

^{2012.}htm&qstring=%E4%E9%E1%EA%F1%E9%F3%2A%20and%202016

16 Also in Greece invalidity levels are calculated on account of certain illnesses (MISSOC). In addition, the Irish Disability Act defines disability as a substantial restriction, which results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes.





life affecting multiple functions of the individual¹⁹ - a process not always reflected in disability scales or national policies. Furthermore, ageist attitudes lead to lower quality or less options of services, different levels of support and abusive practices, such as delayed, refused, inadequate or undignified treatment²⁰.

The Special Rapporteur on the human rights of persons with disabilities has highlighted some of the structural inequalities faced by older people that lead into poverty traps²¹. Old-age pension schemes are not conceived to cover for disability-related needs, but for the loss of work-related income; without adequate compensation for their support needs, older people have to choose between paying for long-term care and covering other basic needs, including housing, food and medication. According to the EC/SPC report on social protection for long-term care, 'just two hours care every day can cost more than many people's pension, while institutional care could cost a multiple of the average pension'.

Conclusions and Recommendations

Only limited attention was given to the overt and covert discrimination faced by older people with disabilities in national and EU disability strategies as well as in UN CRPD Committee conclusions. This permits the continuation of these policies and practices that treat older people with disabilities unfavourably. Focusing on the intersection of old age and disability will ensure that disability rights are equally effective for all persons with disabilities regardless of the age when disability occurs.

The OHCHR and the UNCRPD Committee should:

- Recognise the systemic, multifaceted, structural discrimination faced by older people with functional limitations;
- Prevent discrimination against older people with disabilities as well as promote affirmative action to tackle the structural disadvantages faced by this group;
- Construct disability in a manner that does not justify the exclusion of older people;
- Encourage Member States to systematically report on the barriers faced by older people with disabilities;
- Raise awareness of the relevance of the UNCRPD in old age;
- Systematically include older people's organisations in consultations and monitoring mechanisms;
- Request the collection of data for all age groups, without age limits and with additional age bands: Without such data it is difficult to evaluate the impact on older people and to eliminate unlawful age discrimination and promote age equality;
- Provide legal clarity and policy guidance for duty bearers, human rights practitioners and self advocates on the specific human rights challenges in the intersection of old age and disability, including through a General Comment on the rights of older persons with disabilities.

http://www.un.org/en/ga/search/view_doc.asp?symbol=A/70/297



¹⁹ The Independent Expert states that 'Older persons have different patterns of disease presentation than younger adults, they respond to treatments and therapies in different ways, and they frequently have complex social needs that are related to their chronic medical conditions.' (paragraph 85)

²⁰ See WHO (2011) European report on preventing elder maltreatment, Equality and Human Rights Commission (2011). See also, Equality and Human Rights Commission (2011) Close to home-An inquiry into older people and human rights in home





About AGE Platform Europe

AGE Platform Europe (AGE), is the EU largest network of organisations of and for older persons. Funded by the European Commission DG Justice, we aim at voicing and promoting the rights and interests of the 190 million inhabitants aged 50+ in the European Union. Through our membership we represent directly more than 40 million older persons across the EU. AGE is a holder of ECOSOC status and also has a consultative status with the Council of Europe.

AGE's positions are developed in close consultation with its member organisations, which are mainly older people (self-advocacy groups) and some services providers providing support to older persons. AGE governing bodies and task forces are open to all older persons nominated by AGE member organisations and our activities are organised to include older persons with disabilities. AGE submission is informed by the input of AGE task forces on Human Rights, Healthy Ageing, Dignified Ageing and Accessibility and former position papers adopted by AGE Council.

Resources:

- AGE Platform Europe (2016) Position on article 19 of the UNCRPD: http://age-platform.eu/images/stories/Publications/papers/AGE input CRPD Art19.pdf
- AGE Platform Europe (2016) Position on Structural Ageism: http://age-platform.eu/images/stories/Publications/papers/AGE Intergenerational Solidarity Position on Structural Ageism.pdf
- AGE Platform Europe (2015) response to UN Special Rapporteur on Disability call for submissions on the right of persons with disabilities to social protection: http://age-platform.eu/images/AGE response Special Rapporteur Disability social protection FINAL.
 pdf
- European Charter on the rights and responsibilities of older people in need of long-term care and assistance (2010): http://age-platform.eu/images/stories/22204 AGE charte europeenne EN v4.pdf
- WeDo project (2012) European Quality Framework for long-term care services: http://wedo.tttp.eu/european-quality-framework-long-term-care-services.

More information

- Anne-Sophie Parent, Secretary General: <u>annesophie.parent@age-platform.eu</u>
- Nena Georgantzi, Policy Officer on Human Rights and Non-Discrimination: nena.georgantzi@age-platform.eu

