

## **AGE Platform Europe**

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# Draft Outline of General Comment on Article 5 Equality & Non-Discrimination Submission by AGE Platform Europe

AGE Platform Europe (AGE), as the largest EU network of organisations of older persons, welcomes the draft outline General Comment (GC) on Article 5 of the UN Convention on the Rights of Persons with Disabilities (CRPD). AGE brings forward the views of the more than 40 million older persons who are directly represented through the organisations involved in our network. The objective of this written submission is to raise awareness of the intersection of ageing and disability and to address the age discrimination faced by *older persons with disabilities*, i.e. adults who are faced with impairments and functional limitations for the first time when they reach old age and by *ageing persons with disabilities*, i.e. people who age with a pre-existing disability.<sup>1</sup>.

#### Introduction

The CRPD 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 Committee<sup>2</sup>, the OHCHR<sup>3</sup>, the Independent Expert on the Enjoyment of all Human Rights by Older Persons<sup>4</sup>, and the UN Secretary General<sup>5</sup> 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.

All too often double standards apply in law and practice, excluding older people from some benefits, applying different eligibility criteria or giving less support when disability occurs in old age. Moreover, when ageism interferes with disability assessments, older people are not offered the same level, quality or ranges of support as younger people with disabilities. Such different treatment reflects a view according to which 'because you are old you are not disabled' or 'you are disabled, but you do not need the same level of support because older people are not so active anymore'. Despite clearly being discriminatory such practices are not only tolerated but often also established by norms.

Under international law age discrimination can be justified based on reasonable and objective

<sup>&</sup>lt;sup>5</sup> UN Secretary General (2011) Follow-up to the Second World Assembly on Ageing, A/66/173, 22 July 2011, §47



<sup>&</sup>lt;sup>1</sup> 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.

<sup>&</sup>lt;sup>2</sup> United Nations Committee on the Rights of Persons with Disabilities (2013) Position statement concerning the CDDH-AGE <sup>3</sup> 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 <sup>4</sup> Independent Expert on the enjoyment of all human rights by older persons (2015) Autonomy and care of Older Persons,

criteria<sup>6</sup>. However, there is lack of clarity as to what a justified limitation to age equality is and whether general exclusions based on age are legitimate. This protection gap renders treaty bodies responsible to rule which situations should be prohibited and which can be allowed. Unfortunately, the CRPD Committee has not yet provided sufficient guidance as to how the rights of older people with disabilities can be applied and claimed, and whether such practices constitute legitimate differential treatment. Furthermore, 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. As long as there is not a clear prohibition of differential treatment on the basis of age, not only are older persons discriminated, but they are also impeded from identifying themselves as persons with disabilities and therefore seeking protection under the CRPD. The GC should adequately address the risk of discrimination at the intersection of age and disability and provide sufficient guidance for duty bearers and rights holders.

## Comments under Heading II Normative Content, article 5(2), Paragraph 7c

AGE members report the fragmentation of policies for people with disabilities of working age and those that are eligible for old age pension <sup>7</sup>. 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. <sup>8</sup> Across the EU we come across laws and policies that enshrine differential treatment for older people imposing age limits in access to disability benefits <sup>9</sup>, mobility allowances <sup>10</sup> or personal assistance <sup>11</sup>. 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 beneficary. Despite a decree according to which the age barrier had to be
  abolished, the distinction between younger and older people with disabilities has been
  retained mainly due to financial reasons in the new law on the adaptation of society to
  ageing<sup>12</sup>
- In Catalonia, Spain, disabled people above the age of 64 are not eligible for the same personal assistance as a younger person<sup>13</sup>;

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<sup>&</sup>lt;sup>6</sup> 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

<sup>&</sup>lt;sup>7</sup> 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.

<sup>&</sup>lt;sup>8</sup> 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: <a href="http://www.andrecontrelasla.be/Atteinte-de-S-L-A-a-71-ans-elle.html">http://www.andrecontrelasla.be/Atteinte-de-S-L-A-a-71-ans-elle.html</a> In Greece, the ombudsman dealt with a relevant case: <a href="http://www.synigoros.gr/resources/perilipsi\_epidoma\_anapirias.pdf">http://www.synigoros.gr/resources/perilipsi\_epidoma\_anapirias.pdf</a>

See for example case dealt by Irish Ombudsman: <a href="https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/governmentdepartments-other-public-bodies/Too-Old-to-be-Equal-/Too-Old-to-be-Equal-pdf">https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/governmentdepartments-other-public-bodies/Too-Old-to-be-Equal-/Too-Old-to-be-Equal-pdf</a>

<sup>&</sup>lt;sup>11</sup> See, ENIL report on personal assistance. Also according to MISSOC, for Slovakia the threshold is set at 65 whereas in Finland "Personal assistant 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".

<sup>&</sup>lt;sup>12</sup> The system of APA, which is different from the one allocated to younger persons with disabilities was retained. See: <a href="http://www.gouvernement.fr/action/l-adaptation-de-la-societe-au-vieillissement">http://www.gouvernement.fr/action/l-adaptation-de-la-societe-au-vieillissement</a>

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

- 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 age<sup>14</sup>.

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 position<sup>15</sup>, 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.

Even where age barriers are extinct, strict definitions of disability or assessments 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 uncovered <sup>16</sup>. 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 life<sup>17</sup>. 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 life affecting multiple functions of the individual<sup>18</sup> - 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

<sup>&</sup>lt;sup>14</sup> 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".

http://cylaw.org/cgi-bin/open.pl?file=apofaseis/aad/meros\_4/2016/4-201601-2005-2012.htm&qstring=%E4%E9%E1%EA%F1%E9%F3%2A%20and%202016

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.

<sup>&</sup>lt;sup>17</sup> 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'

<sup>&</sup>lt;sup>18</sup> The Independent Expert on the Enjoyment of all Human Rights by Older Persons 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)

## treatment<sup>19</sup>.

Older people also face additional barriers in accessing social protection for their long-term support needs. In several EU countries there is little to no right to social protection covering the care needs of older people<sup>20</sup>. Due to gaps in coverage, older people often have to pay out of their pocket for part or all of their needs for long-term assistance. Recent research by the ILO has concluded that wide gaps of social protection coverage in long-term care and infrastructure and unequal treatment of older persons in need of support compared to younger persons with similar needs, such as health care, constitute a form of age-based discrimination<sup>21</sup>. Furthermore, many countries offer only meanstested support that may require older people to sell all assets, including their own homes, before public systems intervene<sup>22</sup>. In addition, based on a comparative project in 6 European countries, sometimes pensions are automatically taken from residents who are only given pocket money, thus losing full control over their finances <sup>23</sup>. This practice puts residents at a disadvantage in comparison to those living in their own homes and is an indirect discrimination on the basis of age insofar as such practices are not common in residential settings for younger people with disabilities. In addition, home care is not a statutory right for older people in all EU countries<sup>24</sup>, which means that they may have access to less support if they decide to live in their own homes. Moreover, in practice sometimes disability allowances that aim to cover loss of capacity to work are bundled together with support for everyday needs, which means that older people receiving state pensions do not have a right to receive a benefit for their support needs. 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'.

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 traps<sup>25</sup>. She has moreover called

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<sup>&</sup>lt;sup>19</sup> 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 care* 

<sup>&</sup>lt;sup>20</sup> Social Protection Committee and European Commission (2014) Adequate social protection for long-term care needs in an ageing society

ageing society

21 Scheil-Adlung, X: LTC protection for older persons: A review of coverage deficits in 46 countries. International Labour Organisation, Geneva 2015 cited in ENNHRI submission to UN OEWG: <a href="https://social.un.org/ageing-working-group/documents/eighth/inputs%20NHRIs/EuropeanNetworkofNationalHumanRightsInstitutions-1">https://social.un.org/ageing-working-group/documents/eighth/inputs%20NHRIs/EuropeanNetworkofNationalHumanRightsInstitutions-1</a> and

group/documents/eighth/Inputs%20NHRIs/EuropeanNetworkofNationalHumanRightsInstitutions-1.pdf

<sup>22</sup> As highlighted in a joint European Commission-OECD study on social protection for long-term care, there is some level of means-test in public support in most countries. Whereas most of them apply limited means-test, some such as the US or England require older persons to use all their income – except from an amount for subsistence – and withdraw any support for those who have assets that they can use to pay for the care they need.

<sup>&</sup>lt;sup>23</sup> ENNHRI project on the human rights of older persons in long-term care: <a href="https://social.un.org/ageing-working-group/documents/eighth/Inputs%20NHRIs/EuropeanNetworkofNationalHumanRightsInstitutions-1.pdf">https://social.un.org/ageing-working-group/documents/eighth/Inputs%20NHRIs/EuropeanNetworkofNationalHumanRightsInstitutions-1.pdf</a>
<sup>24</sup> For example in Ireland home care is not a statutory entitlement and older people with very complex medical and support

For example 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, see <sup>24</sup> 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.

\*\*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.

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for a lifecycle approach in disability assessments. On the other hand, the OHCHR thematic study on non-discrimination has only paid attention to ensuring coverage of disability-related costs when transitioning to retirement<sup>26</sup>, and did not reflect the problems faced by those people with disabilities who are already in retirement when disability occurs. The GC should adequately address the barriers faced both by ageing and older persons with disabilities.

#### **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 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 CRPD 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 ageing and older people with disabilities;
- Raise awareness of the relevance of the CRPD for older persons with disabilities and functional limitations;
- 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 to better reflect the situation of very old persons with disabilities: Without such data it is difficult to evaluate the impact on older people, 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.

## **About AGE**

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 and Dignified Ageing, and former position papers adopted by AGE Council.

<sup>&</sup>lt;sup>26</sup> See paragraph 70 of A/HRC/34/26 available at <a href="https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/406/73/PDF/G1640673.pdf?OpenElement">https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/406/73/PDF/G1640673.pdf?OpenElement</a>

## **Resources**

- AGE Position on Structural Ageism
- AGE response to UN Special Rapporteur on Disability call for submissions on the right of persons with disabilities to social protection
- AGE submission to consultation on article 19
- Older persons' self-advocacy handbook

# **More information**

For more information you may contact Nena Georgantzi, Human Rights Officer, AGE Platform Europe