



## Questionnaire on the rights of older persons with disabilities

### Contribution AGE Platform Europe

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

AGE's positions are developed in close consultation with our member organisations, which are mainly older people (self-advocacy groups) and some providers of support services for older persons. AGE governing bodies and task forces are open to all older persons with disabilities.

Although AGE as an organisation represents older people with varying degrees of abilities and needs, the probability of facing a disability such as mobility problems, dementia and other functional limitations increases with age. In reality older people with age-related disabilities are rarely recognized and supported in a similar way as younger people with disabilities. Bringing the voice of older people in such consultation is thus critical.

**1. Please provide information on the legislative and policy framework in place in your country to ensure the realization of the rights of older persons with disabilities, including both persons with disabilities who are ageing and older persons who acquire a disability later in life.**

Both at national and European level, laws are often based on single grounds of discrimination, which makes multiple discrimination claims challenging. While the CRPD is supposedly covering all persons with disabilities, this lack of attention to the specific situations of older persons with disabilities is the result of the fragmentation of policies for persons with disabilities of working age and older persons. In many countries, old age and disability fall under separate administrations, without coordination between them and this is also true at EU level where "disability" is covered by Directorate General "Employment and Social Affairs and Inclusion" and "age" discrimination is covered by Directorate General "Justice and Consumers".



**European Union instruments:**

- European Charter of Fundamental Rights (18 December 2000)<sup>1</sup>, art. 21 is covering all discrimination grounds, art. 25 is considering more specifically older persons and art. 26 deal with persons with disabilities.
- Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation<sup>2</sup>: this directive is limited to non-discrimination on the grounds of disability, age, religion and belief, and sexual orientation. It only access to employment and occupational training.
- Equal treatment directive<sup>3</sup>: tabled by the European Commission more than 10 years (2008), this Directive is still under discussion and so far no agreement has been found in the Council of the European Union to adopt this instruments which would provide a equal protection against discrimination across all grounds and domains within the EU<sup>4</sup>.
- The European Disability Strategy (2010-2020)<sup>5</sup> does not address per the intersectionality between age and disability, still it shows in its introduction how widely the two areas crosscut. For some of its objectives, there is clear reference to older persons (e.g. Participation with the issue of the transition from institutional to community-based care or Equality) while it misses some key elements such as lifelong learning, employment of older disabled workers as well as social protection schemes which addresses differently the needs of older persons with disabilities in comparison to younger people with disabilities.

**Council of Europe (CoE) also has instruments to address the multiple discrimination of older people with disabilities thanks to:**

- the Council of Europe: Committee of Ministers, *Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of human rights of older persons*, 19 February 2014, CM/Rec(2014)2, available at: <https://www.refworld.org/docid/53fdc73e4.html>
- the Council of Europe: Committee of Ministers, *Recommendation CM/Rec(2009)6 of the Committee of Ministers to member states on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society*, 8 July 2009, CM/Rec(2009)6, available at:

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<sup>1</sup> European Charter of Fundamental Rights, full text: [http://www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf)

<sup>2</sup> <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:en:HTML>

<sup>3</sup> Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation {SEC(2008) 2180}/\*COM/2008/0426 final - CNS 2008/0140 \*/ (July 2008): <https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:52008PC0426>

<sup>4</sup> <https://www.age-platform.eu/policy-work/news/draft-eu-horizontal-non-discrimination-directive-ten-years-and-sadly-nothing-show>

<sup>5</sup> <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>



<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016806992fc>

However, these instruments are non-binding for Member States.

## **2. Please provide information on discrimination against older persons with disabilities in law and practice.**

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 older age. Moreover, ageism – i.e. stereotyping, prejudice and discrimination on the basis of age – interferes frequently with disability assessments, and as result older people are not offered the same level, quality or ranges of support as younger people with disabilities.

Persons with disabilities who are ageing and older persons who acquire disabilities in older age, may face common but also distinct challenges. For example, some services are not available to individuals who acquire disability for the first time in older age, whereas they continue to be available for those who acquired a disability before retirement age.

Age-based biases create unique challenges to older persons with disabilities. For example, older people may have access to fewer services or opportunities because they are seen as no longer playing role in society.

### **In law:**

#### **Age limits in access to disability benefits**

Across the EU we come across laws and policies that enshrine differential treatment for older people imposing age limits in access to disability benefits, mobility allowances or personal assistance<sup>6</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 providing informal care to the persons with disabilities.
- In Catalonia, Spain, disabled people above the age of 64 are not eligible for the same personal assistance as younger person;

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<sup>6</sup> 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](http://www.synigoros.gr/resources/perilipsi_epidoma_anapirias.pdf)

Case dealt by Irish Ombudsman:

<https://www.ombudsman.gov.ie/en/Publications/InvestigationReports/governmentdepartments-other-public-bodies/Too-Old-to-be-Equal-/Too-Old-to-be-Equal-.pdf>

ENIL report on personal assistance: “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”. <http://www.independentliving.org/docs7/Spain-personal-assistance-not-reality.html>”



- In Flanders, Belgium, people who become disabled after the age of 65 have no access to the 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<sup>7</sup>.
- At least 8 EU countries do not offer personal assistance in old age<sup>8</sup>.
- 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>9</sup>.

### **Legal capacities and guardianship:**

Recently, an issue was raised by a number of CSOs in relation to the Convention on Human Rights and Biomedicine, better known as the Oviedo Convention, which is adopted by the Council of Europe. A draft Additional Protocol<sup>10</sup> concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment has been elaborated but it runs against human rights standards, in particular the provisions of the UN Convention on the Rights of Persons with Disabilities, with regard to non-discrimination, legal capacity, liberty and health<sup>11</sup>.

Similarly, at EU level there are ongoing discussions on the protection of adults which tend to refer to the so-called Den Haag Convention on the International protection of adults<sup>12</sup> instead of the UN CRPD. The latter is higher up in terms of human rights standards and has now been adopted and ratified by the EU and all its Member States and should be the first and main reference.

### **In practice:**

#### **- State administration's organisation:**

State policies, services and administration often separate older persons from persons with disabilities leading to diverging levels of protection of the rights of the two populations, but also diverse procedures for accessing entitlements. Even where age barriers are extinct, strict definitions of disability or assessment based on the type of impairment or degree of

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<sup>7</sup> ENIL Input to the 9<sup>th</sup> session of the OEWG: <https://enil.eu/news/enil-submission-on-older-people-and-independent-living/>

<sup>8</sup> ENIL Input to the 9<sup>th</sup> session of the OEWG: <https://enil.eu/news/enil-submission-on-older-people-and-independent-living/> and ENIL Personal Assistance's Table: <https://enil.eu/independent-living/personal-assistance/>

<sup>9</sup> 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)

<sup>10</sup> <https://rm.coe.int/inf-2018-7-psy-draft-prot-e/16808c58a3>

<sup>11</sup> <https://age-platform.eu/policy-work/news/age-objects-adoption-protocol-forced-treatment-people-mental-disorders>

<sup>12</sup> <https://assets.hcch.net/docs/c2b94b6b-c54e-4886-ae9f-c5bbef93b8f3.pdf>



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>13</sup>:

- 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<sup>14</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'.

- **Structural ageism:**

- Preventive healthcare and rehabilitation services tend to focus on preventing disabilities in working life<sup>15</sup>. There are reports of states that link funding to care and support services for older people to the level of care needs of individuals, which in practice acts as a disincentive to offer rehabilitation and prevention.
- Ageist attitudes: lower quality or less options of services, high risk of institutionalisation, different levels of support and abusive practices, such as delayed, refused, inadequate or undignified treatment<sup>16,17</sup>.
- Senior workers may lack a right to reasonable accommodation and adapted work settings and be required to retire on the basis of assumptions around their ability to work beyond retirement age<sup>18</sup>.

- **Predominant medical model** in the way ageing is approached while for the disability sector the change of mindset towards a human rights-based approach is more advanced. Therefore, older persons with disabilities tend to be considered as

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<sup>13</sup> 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>14</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*.

<sup>15</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.'

<sup>16</sup> See WHO (2011) *European report on preventing elder maltreatment*, Equality and Human Rights Commission (2011). Also ENNHRI (2015) *Human Rights of Older Persons and Long-Term Care Project*.

<sup>17</sup> ENIL Input to the 9<sup>th</sup> session of the OEWG: <https://enil.eu/news/enil-submission-on-older-people-and-independent-living/>

<sup>18</sup> The EU Employment Framework Directive gives a right to reasonable accommodation only on the basis of disability. In addition, see *Joined Cases C-159/10 and C-160/10, Gerhard Fuchs and Peter Kohler v Land Hessen*, where the ECJ suggested it is legitimate to retire older workers to encourage the promotion of a younger workforce and prevent disputes concerning employees' fitness to work beyond a certain age



patients only, with a paternalistic approach denying their rights to decision and to consent<sup>1920</sup>.

**3. Please provide information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the realization of the rights of older persons with disabilities in general, as well as with particular focus in the following areas:**

Statistical data are missing in this area. While the 2018 Report of the Fundamental Rights Agency reports that “in the EU-28, it is estimated 49% of people aged 65 years and over reported long-standing limitations in usual activities due to health condition (figures for 2016)”. It acknowledges that this number is a proxy for older people in need of some sort of support<sup>21</sup>.

When it comes to ageing, there is a critical lack of disaggregated data, not only between ageing and disabilities but also for ageing and gender, and simply within the wide age group of 65+.

A number of resources are available through the web portal of the Academic Network of European Disability Experts (ANED): <https://www.disability-europe.net/theme/statistical-indicators>

The FRA has developed a matrix of indicators in relation to art. 19 of the CRPD where age is considered as a criteria in some cases - <https://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>

**4. Please provide information on the existence of long-term care services in your country and describe to what extent they promote the autonomy and independence of older persons with disabilities.**

In the European Union, there is no common legally binding definition of long-term care (LTC); however, there are EU policies that contain definitions, such an EU report<sup>22</sup> that defines it as a range of services encompassing care for both self-care<sup>23</sup> and for activities related to independent living<sup>24</sup>. Such definition focuses on social care and overlooks the

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<sup>19</sup> <https://ageing-equal.org/rethinking-care-for-older-people-through-the-lens-of-disability-policies/>

<sup>20</sup> <http://www.equalitiesinhealth.org/Publications%20From%20Media%20Downloads/Human%20Rights%20Issues%20in%20Later%20Life.pdf>

<sup>21</sup> <https://fra.europa.eu/en/publications-and-resources/publications/annual-reports/fundamental-rights-2018>

<sup>22</sup> [Adequate social protection for LTC needs in an ageing society. Report prepared jointly by the Social Protection Committee and the European Commission](#), 2014

<sup>23</sup>Self-care or Activities of Daily Living in the report include “bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions”.

<sup>24</sup>Activities related to independent living or Instrumental Activities of Daily Living include “preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone”.



support that older people with care needs might need to effectively live independently and autonomously, including through participation in the cultural, economic and social life.

- The European Pillar of Social Rights<sup>25</sup> includes a right to affordable and quality LTC, especially home care and community care; however, this is a non-binding instrument.
- Council of Europe CM(2014)2<sup>26</sup> recommendation calls on member states to ensure older people's access to quality, affordable and coordinated care, with a stress on community care, but this is a non-binding instrument.
- ILO recommendation R202 lays down principles for universal access to social protection that should apply also to developing access to LTC<sup>27</sup>; however, references to such instrument are scarce across Europe.

#### Issues:

- Lack of access, unaffordability and low quality of LTC are issues consistently reported across European Union countries.
- An estimated 30% of older persons lack access to LTC in the region<sup>28</sup>, with substantial gaps in access in all countries<sup>29</sup> for all levels of care and support needs.
- Affordability issues are due to the relatively weak social protection for LTC in the EU (1.7% of GDP on average), which is most often a highly means-tested safety net and not a universal entitlement. When social protection is available, hours of care covered are often insufficient<sup>30</sup>.
- Because of the scarcity of resources, difficult working conditions and care services that overlook the dignity of care recipients, quality is a concern, with cases of violence, abuse and neglect reported across the spectrum of care services<sup>31</sup>. Reforms aiming to contain costs have aggravated the situation<sup>32</sup>.

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<sup>25</sup> [https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles\\_en](https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en)

<sup>26</sup> See above

<sup>27</sup> Scheil-Adlung, X.: "[LTC protection for older persons: A review of coverage deficits in 46 countries](#)", *Extension of Social Security*, Working Paper No. 50, International Labor Organization, 2015

<sup>28</sup> Idem

<sup>29</sup> [Adequate social protection for LTC needs in an ageing society](#). For instance, 20.6% of those between 65 and 74, and 32.6% of those over 75 report limitations in daily activities in Sweden, but only 16.3% of those over 65 receive LTC. This gap is bigger in most countries, up to 73.4%-88.9% of older persons reporting limitations in Slovakia, where only 3.2% of them are receiving care.

<sup>30</sup> [This joint European Commission-OECD report](#) analyses social protection for LTC in several EU countries and shows gaps in protection.

<sup>31</sup> WHO: [European Report on preventing elder maltreatment](#), 2011

<sup>32</sup> These include, for instance, the underfunding of the law of personal autonomy in Spain; the abolition of the LTC insurance in the Netherlands; the reform of social care in the United Kingdom that has put a reportedly unsustainable financial burden on local authorities; the closing of residential care in Portugal or Belgium without home or community-based alternatives.



- Relatives and other informal carers (friends, neighbours), mostly women, remain the main providers of care (around 80%)<sup>33</sup>; in most countries they are legally responsible for providing and/or covering the costs of care that the older person her/himself cannot afford<sup>34</sup>.

Consequently, the ability of older persons to live autonomously and independently, as well as free from violence, abuse and neglect, is seriously at risk, and is even higher for older persons with disabilities.

**5. Please describe how is access to justice guaranteed for older persons with disabilities. Please provide information on jurisprudence, complaints or investigations in relation to violence, abuse and neglect against older persons with disabilities.**

Compared to other forms of violence, relatively few studies focus specifically on the forms and prevalence of violence, abuse and neglect experienced by older people, and even fewer refer to older persons with disabilities. Despite some notable exceptions, such as the 2011 World Health Organization (WHO) European report on elder maltreatment and some European projects, overall cross-national studies on older persons with disabilities are largely missing, whereas national data are not always readily available. When data are available, the underreporting is also made clear and the more older persons are in vulnerable situation, the higher they do not report since they are afraid to be completely left aside. Some studies on gender-based violence may indirectly address elder abuse, but methodological issues and age limits in data collection do not always allow capturing violence at the intersection of ageing, disability and gender. For example, the largest EU survey on violence against women had an age limit at the age of 74, did not include women in residential settings and mainly targeted inter-partner violence, failing to capture cases of institutional abuse and neglect in care services for older people or financial abuse.

At European Union level there is no law that explicitly addresses abuse, violence and neglect against older persons. There are some broad provisions in instruments of EU law, such as the Charter of Fundamental Rights of the European Union, which enshrines the right to the integrity of the person and the prohibition of torture and inhuman or degrading treatment.

An EU Directive of 2012 established minimum standards on the protection of victims of crime. Abuse, violence and maltreatment of older persons are not explicitly mentioned; however, the directive binds EU member states to ensure that all victims, regardless of their condition, can access information regarding support and prosecution. It also binds states to offer special protection measures to victims of all kinds of abuse and violence in close relationships – including “economic violence” – which might be seen to include abuse and violence against older persons. However, there has been little action in promoting these rights among older persons and in exploring how they can apply to older persons at risk of

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<sup>33</sup> [Data provided by Eurocarers](#), European network of informal carers.

<sup>34</sup> This also has consequences on the gender pension gap and the poverty risk among older women, including older women with disabilities.



abuse and violence; the full effect of this instrument depends on the recognition of abuse, neglect and violence that target specifically older people as a crime in the legislations of EU Member States, which is not the case in most of them.

Further, the 2014 Council of Europe Recommendation on the promotion of human rights of older persons addressed violence and abuse by recommending States to improve the prevention of abuse and protect older persons who are at risk of abuse and violence; however, this is a non-binding instrument.

**6. Please describe to what extent and how are older persons with disabilities involved in the design, planning, implementation and evaluation of policies related to ageing and/or disability.**

From what we can witness at EU level, the consultation of older persons in policies related to disability is still weak. There are different reasons which can explain this situation, including the widespread difficulty to acknowledge the disability identity<sup>35</sup>, the quasi-absence of consultation of older persons living in residential care settings as well as the lesser access of older persons to new technologies through which a number of consultations is conducted at EU level, considering that with help and support to get acquainted with the technological tool some of them would be able to get on board.

There is also a clear lack of information and a gap to be closed when it comes to a “human rights culture” in the ageing sector: a survey among AGE members revealed that across the EU there are still organisations of and for older persons who are not aware of the relevance of the UNCRPD and disability law and policy for older persons, while the majority has not been involved in the monitoring and the implementation of the UNCRPD in their country. The fact that the UNCRPD was developed without the active and meaningful participation of older people is often seen as a partial reason why there is still little ownership of this instrument by older people.

The experiences of the disability and ageing movements have been rather different and the two constituencies do not necessarily overlap although de facto the majority of people with significant impairments are over retirement age<sup>36</sup>.

The lack of involvement is also linked to the fact that most of older persons with disabilities are mostly defined as older and not as disabled<sup>37</sup>, which inevitably conducts to an exclusion of older persons with disabilities from the policies and programmes developed for persons with disabilities, not only in terms of benefits and rights they might provide, but also from the starting point of the design of these policies and programmes.

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<sup>35</sup> <https://ageing-equal.org/shared-stigma-separate-silos/>

<sup>36</sup> Mark Priestley & Parvaneh Rabiee (2002) Same Difference? Older people's Organisations and Disability Issues, *Disability & Society*, 17:6, 597-611, <https://www.tandfonline.com/doi/abs/10.1080/0968759022000010399>

<sup>37</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0890406508000819>



**7. Please provide information on any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of older persons with disabilities and identify lessons learned from these.**

In March 2019, the European Association of Service Providers for Persons with Disabilities (EASPD) conveyed a conference entitled “Ageing and disability” which showcased interesting examples<sup>38</sup>:

- Fundació Ramon Noguera (Spain) which address more and more the question of ageing among people with intellectual disabilities and how to address their needs. (<https://grupfrn.cat/en/>).
- Jugend am Werk (Austria) which offers housing services for older persons with intellectual disabilities (<https://www.jaw.at/de/dienstleistungen/wohnen/121/Wohnangebote-fuer-aeltere-Menschen>).

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<sup>38</sup> Press Release: <https://www.easpd.eu/fr/content/ageing-and-disability-shaping-agenda-tomorrow> - Agenda of the event: [https://www.easpd.eu/sites/default/files/sites/default/files/programme\\_21-22.3.19\\_7\\_0.pdf](https://www.easpd.eu/sites/default/files/sites/default/files/programme_21-22.3.19_7_0.pdf)