



AGE Platform Europe

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Public consultation: Feedback Disability Rights Strategy 2021-2030

Contribution from 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 welcomes the EC roadmap for the post-2020 European Disability Strategy. We particularly welcome the reference to the correlation between age and disability in the Roadmap. However, we regret that the intersection between old age and disability is not further reflected in the priorities and activities foreseen in the Roadmap. For example, the Roadmap fails to acknowledge that disability is a strong risk factor for abuse among older persons,¹ and only refers to the risk of violence faced by women and children with disabilities. This illustrates that despite the high prevalence of disability among older persons, the challenges they face are poorly understood and often left unaddressed. Underpinning the exclusion of older persons with disabilities is the problem of insufficient age-disaggregated data on disability. Against this background, we suggest that the upcoming Disability Strategy should have a stronger focus on older persons with disabilities, by systematically addressing the intersection of ableism and ageism. As a cross-cutting obligation we believe that more data and evidence on older persons with disabilities is urgently needed. Older people's organisations and older persons with disabilities themselves, must have a key role in improving the application of disability rights across the lifecycle.

As recommended by the UN Special Rapporteur on the rights of persons with disabilities, **the mainstreaming of the rights of older persons with disabilities into all disability and ageing-related policies and programmes is key to ensure that the concerns and needs of older persons with disabilities are adequately addressed**². The renewal of the Disability Strategy for the next decade, 2020-2030, is a unique opportunity to make it concrete.

¹ World Health Organization, "Risk factors for elder abuse", Violence Info. Available at <http://apps.who.int/violence-info/studies/?area=elder-abuse&aspect=risk-factors&risk-factorlevel=Individual&risk-factor-sub-levels=Victim>

² Report of the Special Rapporteur on the rights of persons with disabilities (theme: older persons with disabilities), 2019, https://www.un.org/ga/search/view_doc.asp?symbol=A/74/186

In our supporting document, we suggest how the EU can address the distinct challenges faced by older persons with disabilities in the frame of its 2020-2030 Disability Rights Strategy to ensure the equal treatment, full participation and inclusion of persons with disabilities of all ages, focusing on key areas:

- Equality and non-discrimination
- Health, care and support
- Participation
- Evidence and data collection

Equality and non-discrimination

Existing disability programmes tend to focus on children or people of working age. Functional limitations are often considered as a normal part of ageing. Policies and services therefore tend to ignore the experience of disability that is acquired in old age and older persons themselves may not self-identify as having a disability. This form of institutionalized and internalized ageism compounds discrimination and exclusion on the basis of disability.

As demonstrated during the COVID-19 pandemic, health systems may ration health care and deny medical services to older persons with disabilities. Because older persons are perceived as unproductive, useless and undeserving they are more likely to be excluded from programmes that aim to increase independence, mobility and empowerment. It is not uncommon that disability benefits are capped at a certain age. Those who acquire a disability for the first time in older age may therefore never have a right to access personal assistance and mobility allowance, among others.³

These multiple and intersecting forms of discrimination are not adequately addressed by EU and national law and policy. Differential treatment on the basis of age and disability is often considered permissible. For example, EU law allows mandatory retirement ages based on the assumption that older workers may become disabled and unable to work.⁴

Without equal access to support, older persons with disabilities are more likely to face further human rights violations, such as lack of opportunities for participation, violence, neglect and abuse, denial of legal capacity, breach of the right to live independently and increased risk of poverty, because they have to make more out of pocket payments for disability-related costs.⁵

³www.age-platform.eu/sites/default/files/AGE_contribution_on_rights_of_older_persons_with_disabilities-April2019.pdf

⁴ Gerhard Fuchs (C-159/10), Peter Köhler (C-160/10) v. Land Hessen; Gorka Salaberria Sorondo v Academia Vasca de Policía y Emergencias (C-258/15).

⁵ Report of the Special Rapporteur on the rights of persons with disabilities (theme: older persons with disabilities), 2019, https://www.un.org/ga/search/view_doc.asp?symbol=A/74/186

It is therefore crucial that the next Disability Strategy addresses the intersectionality between disability and ageing, as well as that of ageism and ableism, across different domains, such as. accessibility, participation, equality, employment, education and training, social protection, health and external action.

- The EU needs to continue efforts for the adoption of a horizontal non-discrimination directive covering discrimination on the basis of age and disability – among other grounds – beyond the field of employment. Multiple and intersecting forms of discrimination must be included in the remit of this directive.
- The implementation of the EU employment framework directive needs to pay particular attention to the situation of older workers with disabilities, who are likely to suffer from double bias and also be adversely affected by measures taken as a protection from COVID-19.
- Combating ageism (alongside ableism) and raising awareness of older persons as rights holders is key to any strategy targeting persons with disabilities. This involves the elimination of stereotypes, awareness-raising of older people's capabilities and contributions and empowering older persons with disabilities to claim their rights.
- While it is important to mainstreaming disability in all existing and upcoming EU strategies, including the Gender Equality Strategy, Strategy on Victims' Rights, EU Framework on Roma Equality and Inclusion Strategies, Asylum and Migration Pact, Strategy on Children rights, LGBTI+ Equality Strategy, additional efforts are necessary to adequately address the intersection of ageing and disability is taken into account, bearing in mind that there is currently no EU initiative focusing on older persons/age discrimination.
- Dedicate a chapter of the 'Green Paper on Ageing' to the rights of older persons, including older persons with disabilities, with a particular focus on granting older persons autonomy and full participation in society, as mentioned in the recent Council Conclusions.⁶

Health, care and support

Older persons with disabilities are more likely to be subject to guardianship, institutionalization, home confinement and involuntary treatment than those without disabilities.⁷ Central to these problems is the lack of quality support services within the community, including personal assistance, home support and rehabilitation for older persons. Older persons with disabilities, in particular those with dementia, face a high risk of neglect and abuse at home and in congregated settings. COVID-19 exposed in sharp ways some of the enduring failures of the long-term care sector in Europe, which have led -in some cases- to isolation, neglect, denial of autonomy, degrading treatment or even death of

⁶ <https://data.consilium.europa.eu/doc/document/ST-11717-2020-REV-2/en/pdf>

⁷ Report of the Special Rapporteur on the rights of persons with disabilities (theme: older persons with disabilities), 2019, https://www.un.org/ga/search/view_doc.asp?symbol=A/74/186

older people with disabilities. Older people in institutional care account for half of all COVID-19-related deaths in Europe, according to the World Health Organization. Overprotection and paternalistic models of care beyond the pandemic may cause more older persons with disabilities to be isolated at home or in institutions for their 'safety'. Lack of community services also entails an over-reliance on informal carers, who continue to provide the bulk of care across the EU. Many informal carers, predominantly women, have to reduce or stop employment to be able to fulfil this responsibility.

The next EU Disability Strategy must help member states' reforms to ensure that sustainable, adequate, accessible and person-centred care and support services will be available for people with disabilities of all ages across the EU.

- EU funding programmes must prioritise care and support services in the community for all people with disabilities, including older persons. These instruments should include support for professional long-term care services and informal carers alike. They should also seek to develop and improve the coordination and integration of health and social care services at national level, the lack of which has been one of the major obstacles in properly managing the COVID-19 pandemic.
- Ensure that there are no silos in care and support policies for young and older persons with disabilities. Principle 18 of the European Pillar of Social Rights, which covers long-term care has been interpreted narrowly to target only older persons. Likewise, the implementation of Principle 17 on the inclusion of persons with disabilities focuses on people of working age. Read alone, principle 18 focuses on the means, i.e. the services needed to support older persons while failing to describe the objective these serve, which could become the basis for the application of protectionist and medical approaches on long-term care for older people. The ultimate aim of long-term care and support services in old age remains inclusion and full participation in society as mentioned in principle 17. The two principles must be read together in order to adequately cover older persons with disabilities. The upcoming Disability Strategy has a key role to ensure that the implementation of the European Pillar takes due account of the intersection of ageing and disability in order to guarantee access to quality community-based services, including palliative care, recognition of care work and improved working conditions in services as well as support for informal carers, such as day-care, respite care and training.
- The new EU Disability Strategy should address the full range of barriers that older persons with disabilities face in accessing good-quality health-care services, limitations (such as age limits) on health insurance and legal, institutional and attitudinal barriers and stigma concerning persons with disabilities and older persons within the health care system.

Participation

Older persons with disabilities are not just recipients of care and support, but also important members of their communities. The Disability Strategy must recognize this reality. As UN Secretary General António Guterres [said](#): “Listen to older people’s voices, suggestions and ideas to build more inclusive and age-friendly societies”.

Older persons with disabilities, including those who acquire disabilities for the first time in old age, must be equally consulted, through their representative organisations, in the development of disability policies and programmes and the implementation of the UNCRPD at EU and national levels.

In addition, the Strategy must address the following:

- Young people and older people are more vulnerable to losing their jobs as a result of the looming economic crisis. Older people with disabilities who find themselves in unemployment will have fewer chances to re-enter the labour market. Employment services and skills-building must not only focus on young people, but also on those older persons whose job prospects are affected, including many older persons with disabilities.
- Digital skills will be crucial in the post COVID-19 era, both in terms of employment and social inclusion, so older persons with disabilities, who typically lag behind in terms of digital literacy and inclusion must remain a key priority for the EU in this field.

Evidence and data collection

Statistical data are missing to better monitor the intersectionality between age and disability. National statistics often use age limits and lack granulation by age.⁸ Surveys and research on disability tend to use indicators relevant to people in working life, omitting later life issues. Likewise, many national surveys do not cover older persons with disabilities living in institutions. Compared to other forms of violence, few studies focus on the forms and prevalence of violence, abuse and neglect experienced by older people, and even fewer refer to older persons with disabilities. 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 conducted by the FRA 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.

⁸ Report of the UN Independent Expert on the rights of older persons: Human rights of older persons: The Data Gap Conundrum, 2020: <https://undocs.org/A/HRC/45/14>



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To support the intersectional approach and facilitate its implementation, it is crucial to improve statistics and data collection on ageing and disability.

- As part of the Disability Strategy the Fundamental Rights Agency should improve understanding of the particular challenges faced by older persons with disabilities, as existing FRA studies have very small samples from this age group and do not adequately reflect issues faced by individuals who experience disability for the first time in old age.

For more information:

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