

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

Advancing Hospice & Palliative Care Worldwide

1 September 2022

Statement on agenda item 5: The WHO European framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030.

The International Association for Hospice and Palliative Care and co-signatories welcome this opportunity to respond to the Framework for Action. We note that the document aligns with <u>European Programme of Work</u>, 2020–2022, which includes palliative care as part of the continuum. The IAHPC stresses the importance of developing palliative care services for persons with physical and intellectual disabilities, including the dementias.

We commend the Framework for recognising that persons with disabilities are more likely to experience delayed access to healthcare, have unmet health care needs and poorer health outcomes, leading to unnecessarily high health care costs. We also agree with Objective One's Strategic priority to strengthen health systems, as set out in paragraph 14(c), and request that the list of services be expanded to include palliative care.

We are happy to see the Life Course approach that includes all age groups and remind member states that they approved Human Rights Council Resolution 48/3 in 2021 on Older Persons that explicitly includes a right to palliative care as a component of the right to the highest attainable standard of health for older persons. Key to best practice end of life care is the actualization of human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are variably afforded these rights at the end of life.

The IAHPC shares concerns noted in paragraph 4 that "persons with disabilities may be less likely to receive needed life-saving treatment and that they may be disproportionately affected by the measures taken to control the pandemic" and we suggest that they may also less likely to receive palliative care.

Finally, the IAHPC offers our expertise in palliative care to the development of reliable, disability-disaggregated datasets regarding health outcomes and health care access and utilization and call for the inclusion of availability of palliative care services in the Region in midterm (2026) and final (2030) monitoring reports.



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We invite RC member states and the Secretariat to review the following relevant documents on palliative care for persons with intellectual disabilities in the EURO Region.

- The Human Rights of Older People with Mental Health Conditions and Psychosocial Disability to a Good Death and Dying Well
- Consensus Norms for Palliative Care of people with Intellectual Disabilities in Europe: EAPC White Paper
- The challenges and triumphs of developing a survey on palliative care for people with intellectual disabilities around the world

This statement is endorsed by

European Society for Medical Oncology International Federation on Ageing World Organization of Family Doctors International Federation of medical Students' Associations







