



Access to Health as a Foundation for Active Citizenship

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European Disability Forum

- Umbrella organisation of persons with disabilities
- Ensure full inclusion in society of persons with disabilities in Europe
- Nothing about us without us!





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Workshop aims

Explore health and active citizenship

Understand barriers and rights-based solutions

Align with EU policies

Explore innovative solutions

Foster peer learning



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Active and inclusive citizenship

Persons with disabilities are recognised as equal members of society with the **same rights, opportunities, and ability to participate fully in community life.**





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Through a rights-based lens

The Convention on the Rights of Persons with Disabilities sets out the full architecture of what active citizenship means for persons with disabilities.

- **Article 19 on independent living and inclusion in the community**
- **Article 27 on employment**
- **Article 24 on education**
- **Article 25 on health**



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Core premise

The rights to person centred health is not only a healthcare issue - it is a **precondition for participation, independence, and inclusion in society.**





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Sessions

- Barriers and rights-based solutions
- Beyond clinical care
- Sustaining access, fostering inclusion and long-term impact





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Session 1

Barriers and rights-based solutions





Setting the scene

Persons with disabilities have higher unmet medical needs, poorer health outcomes and higher mortality than persons without disabilities.

- In 2024, 5% of persons with disabilities reported an unmet medical need compared to 1,6% of persons without disabilities.
- 17% of persons with disabilities report depressive symptoms compared to 3,4% of persons without disabilities. 31,8% of persons with severe disabilities report depressive symptoms.
- Persons with disabilities are more than twice as likely to die from COVID-19 and have higher mortality rates related to cancer





Health study – Overview

- **Desk and field research** to understand the barriers facing persons with disabilities in the EU, Norway and Iceland
 - 72 interviews across 25 countries
- **Survey on access to cancer care**, feeding into the European Cancer Inequalities Registry
 - 1.816 survey responses including 232 from the ETR version
- **Guidelines** to Member States on how to improve access and overcome barriers to healthcare for persons with disabilities
 - Active consultation with over 8 OPDs





Barriers identified

- Discrimination
- Data
- Affordability and inclusive financing
- Disability leadership
- Autonomy and legal capacity
- Accessibility
- Availability
- Healthcare professionals' awareness and skills
- Complexity of services
- Institutionalisation





Guidelines – Introduction

A set of **17 system-level actions** that aim to address the barriers identified in the research.

The guidelines are:

- **Specific:** They detail how the situation of persons with disabilities can be improved.
- **Measurable:** They include ways to measure improvements from the baseline to realistic future milestones.
- **Achievable:** They are based on available resources at the EU, national, or sectoral level. Various scenarios provided.
- **Realistic:** They are feasible regarding their scope, approach and cost.
- **Targeted:** They specify the targeted audience.





Guidelines – Informed consent (1/2)



Action 6: Adopt national **legislation prohibiting involuntary treatment**, including monitoring mechanisms

- Enact and enforce comprehensive national legislation that:
 - prohibits involuntary treatment and ensures informed consent through the provision of accessible information
 - abolishes exceptions for persons with disabilities
 - promotes approaches that reduce coercion in mental health services
- Establish systematic and publicly available complaint or reporting procedures for documenting cases of involuntary treatment.



Guidelines – Informed consent (2/2)



Action 7: Realise the transition from substitute to **supported decision-making**

- Enact and enforce national legislation that prohibits substituted decision-making
- Enact and enforce national legislation that establishes supported decision-making programmes and practices





Guidelines – Integration of services

(1/2)



Action 15: Adopt a person-centred and holistic care approach, supported by **multidisciplinary teams (MDTs) and liaison officers** to assist patients in navigating healthcare services

- Establish MDT in public healthcare facilities to organise and ensure continuity of the patient journey.
- Establish liaison officers to manage the interaction between healthcare and social services and the transition from paediatric to adult services.





Guidelines – Integration of services (2/2)



Action 16: Promote the use of **telemedicine and telepharmacy** to enhance access to healthcare for persons with disabilities, but not replace in person care

- Ensure accessibility of telemedicine and telepharmacy services.
- Train healthcare professionals on the provision of accessible telemedicine and telepharmacy.





Guidelines – Deinstitutionalisation



Action 17: Promote full **deinstitutionalisation and independent living** in community through a range of solutions ensuring freedom of choice.

- Reduce the ratio of persons with disabilities residing in institutions.
- Adoption and gradual expansion of personal assistance and healthcare provided at home and in the community.





Summary

- Persons with disabilities face many barriers to healthcare.
- These barriers result in gross health inequities for persons with disabilities.
- The EU wanted to study the issue to give guidance to Member States on how to improve the situation.
- The guidelines provide human rights-based recommendations for system level changes.





Thank you!

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