

Title: Advancing Equity for People with Intellectual Disabilities: Closing the Neglected Cancer Policy Gap

Authors: Martin Mc Mahon martin.mcmahon@tcd.ie; Suzanne Denieffe suzanne.denieffe@setu.ie; Kate Sykes kate.sykes@northumbria.ac.uk; Peter Knapp peter.knapp@york.ac.uk; Maarten Cuypers maarten.cuypers@radboudumc.nl; Pinar Soylar psoylar@gmail.com; Adela Elena Popa adela.popa@ulbsibiu.ro; Dalia Ismail Ibrahim daliaismail07@gmail.com; Bahar Aksoy baharaksoy6161@gmail.com; Seda Cansu Yeniğün Akbulut seda.cansu.yenigun@gmail.com; Katerina Flora katerinaflora@hotmail.com; Soner Dogan soner.dogan@yeditepe.edu.tr; Bilge Güvenç Tuna bilge.tuna@yeditepe.edu.tr; Ayşegül Ilgaz ailgaz@akdeniz.edu.tr; Gunilla Kulla gunilla.kulla@hvl.no; Jasmin Mušanović jasmin.m.gene@gmail.com; Rebecca Hansford hansford.rebecca@queensu.ca; Amina Banda amina.banda@radboudumc.nl; Derya Özalp Ünal derya.ozalpunal@tarimorman.gov.tr; Özge İşeri ozgepekiniseri@gmail.com; Eda Sahin edabasustaoglu@gmail.com; Fatoş Uncu funcu@firat.edu.tr; Dragana Milutinović dragana.milutinovic@mf.uns.ac.rs; Damla Altın altin@sakarya.edu.tr; Merve Sena Topkaya dytmervesena@gmail.com; Edanur Tar Bolacali edanurtar.1107@gmail.com; Eilish A. Burke eburke7@tcd.ie; Şebnem Özdemir sebnemozdemirtr@gmail.com; Burcu Akciğer burcuakcigr@gmail.com; Serghei Sprincean sprinceans@yahoo.com; Kálya Yasmine Lima limaky@tcd.ie; Dušanka dusanka.tadic@assb.edu.rs; Fatima Kassymbekova f.kassymbekova@gmail.com; Eleonora Passeri drpas84ele@gmail.com; Terezia Kisková-Šimková terezia.kiskova@upjs.sk; Emel Bahadır Yılmaz ebahadiryilmaz@yahoo.com; Mairead O'Connor mairead.o'connor@screeningservice.ie; Lau Caspar Thygesen lct@sdu.dk; Trine Allerslev Horsbøl tria@sdu.dk; Vladimir Vukovic vladimir.dr.vukovic@gmail.com

Corresponding Author: Dr Martin McMahon martin.mcmahon@tcd.ie

Main text

Cancer is one of the leading causes of morbidity and mortality worldwide. This public health concern not only extends to the general population but also more urgently, to underserved and marginalised populations (Vukovic et al., 2023). These populations include people with intellectual and developmental disabilities (defined by significant limitations in adaptive functioning and learning skills originating in the developmental period) who represent a particularly high-risk and underserved group across the cancer care continuum. Although life expectancy for people with intellectual and developmental disabilities has increased substantially in recent decades (Hirvikoski et al., 2021), they continue to experience significant inequities across the health and social care sphere (Chapman et al., 2024). Despite increased recognition of these inequities, inclusion in cancer policy across Europe and globally remains markedly absent for this population.

Emerging evidence consistently highlights that people with intellectual disabilities are uniquely exposed to social determinants of health associated with cancer development, have a unique cancer profile, experience later stage cancer diagnosis, and have higher cancer mortality than the general population (Chapman et al., 2024; Cuypers, 2025; Mahar et al., 2023; Ward et al., 2024), alongside lower participation in screening programmes (Chan et al., 2022). Indeed, participation in breast, bowel, and cervical screening programmes is consistently lower among people with intellectual and developmental disabilities, pointing to systemic barriers in access and accommodation (Chan et al., 2022).

Large-scale studies from the Netherlands (Cuypers, 2025) and Scotland (Ward et al., 2024) suggest that while overall incidence of cancer may be lower in adults with

intellectual and developmental disabilities, there are higher rates of specific cancers, particularly of genitourinary system cancers and of unknown primary origin. Equally concerning, evidence indicates reduced access to standard treatment options and overall poorer levels of cancer care for this population (Boonman et al., 2022)

Without inclusive targeted actions across the full cancer prevention and care continuum, inequities will continue to persist, resulting in poorer outcomes and preventable deaths. This constitutes a profound injustice. The inclusion of reasonable adjustments and accommodations in policy and practice statements to meet the needs of people with intellectual disabilities is essential. Europe's Beating Cancer Plan, one of the most comprehensive cancer strategies globally, calls out that there should be no "first- and second-class cancer patients in the EU" (p.3) (Commission., 2021). While a commendable assertion to reduce inequities and inequalities, people with intellectual and developmental disabilities remain underserved and internationally reported outcomes across the cancer continuum remain remarkably poor (Hansford et al., 2024; Mahar et al., 2023). To be clear, policy inclusion creates the impetus to bring sustained change. It acts as an enabler that provides visibility, establishes an environment of accountability, improves opportunities for advocacy and enables systems to plan and develop. Nonetheless, ongoing policy and research reviews through the CUPID COST Action (CUPID: Cancer - Understanding Prevention in Intellectual Disabilities) (Vukovic et al., 2023), which seeks to establish a research agenda and knowledge base to improve cancer prevention in the European Union and beyond, have found little to no inclusion of people with intellectual and developmental disabilities in national cancer prevention strategies or screening policies across 47 European countries. Only rare examples exist, such as the European Commission Initiative on Breast Cancer recommendation for tailored screening invitations for

women with intellectual and developmental disabilities. Still, there is a need to explore the extent to which cancer screening and cancer prevention policies are inclusive, accessible, and implemented for people with intellectual and developmental disabilities.

That this population remains unseen and unheard is a particular concern given the incidence and impact of cancer, and the legal and ethical commitments made by signatories to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on issues such as accessibility and healthcare. The implication of this exclusion is clear. People with intellectual and developmental disabilities due to their disability will continue to receive substandard services and they may die with and from cancers that are diagnosed at a late stage or even not at all.

Therefore, there is an urgent need for cancer policies to explicitly include people with intellectual and developmental disabilities, ensuring accessible prevention strategies, equitable screening opportunities, and equal access to treatment and care. These are fundamental human rights that demand immediate and sustained action from policymakers and health systems alike.

Declaration of interest

The authors declare no conflicts of interest relevant to this correspondence. The work was conducted independently and without financial, commercial, or personal relationships that could be perceived to influence the content of the manuscript. All authors are members of the COST Action CA21123 (CUPID), which is funded by the European Cooperation in Science and Technology (COST). This funding supported networking activities only and had no role in the preparation, analysis, or writing of this correspondence.

Final Accepted Version - 28th November 2025

References

- Boonman, A. J., Cuypers, M., Leusink, G. L., Naaldenberg, J., & Bloemendal, H. J. (2022). Cancer treatment and decision making in individuals with intellectual disabilities: a scoping literature review. *Lancet Oncol*, 23(4), e174-e183.
[https://doi.org/10.1016/s1470-2045\(21\)00694-x](https://doi.org/10.1016/s1470-2045(21)00694-x)
- Chan, D. N. S., Law, B. M. H., Au, D. W. H., So, W. K. W., & Fan, N. (2022). A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities. *Cancer Epidemiol*, 76, 102084.
<https://doi.org/10.1016/j.canep.2021.102084>
- Chapman, H. M., McMahon, M., Kaley, A., Mafuba, K., & Donovan, M.-A. (2024). The Case for More Action and More Research into Health Care Provision and Health Inequalities for People with Intellectual Disabilities.
- Commission., E. (2021). *Europe's Beating Cancer Plan (COM(2021) 44 final)*. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52021DC0044>
- Cuypers, M., Naaldenberg, J., Banda, A., Oost, L., Bloemendal, H., & Leusink, G. (2025). Cancer incidence and diagnostic characteristics in people with intellectual disabilities in the Netherlands: A national registry-based cohort study. *BMJ Oncology* 2025;4:e000686. <https://doi.org/https://doi.org/10.1136/bmjopc-2024-000686>
- Hansford, R., Ouellette-Kuntz, H., Bourque, M. A., Decker, K., Derksen, S., Hallet, J., Dawe, D. E., Cobigo, V., Shooshtari, S., Stirling, M., Kelly, C., Brownell, M., Turner, D., & Mahar, A. L. (2024). Investigating inequalities in cancer staging and survival for adults with intellectual or developmental disabilities and cancer: A population-based study in Manitoba, Canada. *Cancer Epidemiol*, 88, 102500.
<https://doi.org/10.1016/j.canep.2023.102500>
- Hirvikoski, T., Boman, M., Tideman, M., Lichtenstein, P., & Butwicki, A. (2021). Association of Intellectual Disability With All-Cause and Cause-Specific Mortality in Sweden. *JAMA Network Open*, 4(6), e2113014-e2113014.
<https://doi.org/10.1001/jamanetworkopen.2021.13014>
- Mahar, A. L., Biggs, K., Hansford, R. L., Derksen, S., Griffiths, R., Enns, J. E., Dawe, D. E., Hallet, J., Kristjanson, M., Decker, K., Cobigo, V., Shooshtari, S., Stirling, M., Kelly, C., Brownell, M., Turner, D., & Ouellette-Kuntz, H. (2023). Stage IV breast, colorectal, and lung cancer at diagnosis in adults living with intellectual or developmental disabilities: A population-based cross-sectional study. *Cancer*, 130(5), 740-749.
<https://doi.org/10.1002/cncr.35068>
- Vukovic, V., Banda, A., Carneiro, L., Dogan, S., Knapp, P., McMahon, M., Milutinovic, D., Soylar, P., Sykes, K., & Tosun, B. (2023). The importance of cancer prevention policies to inform and guide preventative and screening measures for people with intellectual disabilities: The COST project "Cancer-Understanding Prevention in Intellectual Disabilities". *Journal of Intellectual Disabilities*, 17446295231213752.
- Ward, L. M., Cooper, S. A., Sosenko, F., Morrison, D., Fleming, M., McCowan, C., Robb, K., Hanna, C. R., Hughes-McCormack, L., Dunn, K., Conway, D., Henderson, A., Smith, G., Truesdale, M., & Cairns, D. (2024). Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland: a retrospective cohort study with record linkage. *BMJ Open*, 14(8), e084421.
<https://doi.org/10.1136/bmjopen-2024-084421>