



Advancing equity for people with intellectual disabilities: Closing the neglected cancer policy gap

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 [1]. 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 [2], they continue to experience significant inequities across the health and social care sphere [3]. 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 distinct cancer profile, experience later-stage cancer diagnosis, and have higher cancer mortality than the general population [3–6], alongside lower participation in screening programmes [7]. 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 [7].

Large-scale studies from the Netherlands [4] and Scotland [6] 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 cancers of the genitourinary system and cancers of unknown primary origin. Equally concerning, evidence indicates reduced access to standard treatment options and overall poorer levels of cancer care for this population [8].

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 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) [9]. 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 [5,10]. 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) [1], 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.

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