POLICY BRIEF

Equitable Access to Primary Care for Adults with Intellectual and Developmental Disabilities in Ontario

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About this document

This policy brief is based on findings from Ontario population-based research on the health status and health services use of adults with intellectual and developmental disabilities in Ontario conducted by the Health Care Access Research and Developmental Disabilities (H-CARDD) program at the Centre for Addiction and Mental Health (CAMH) together with ICES across various research projects since 2011, resulting in key publications and provincial reports including:

Lunsky Y, Klein-Geltink JE, Yates EA, eds. *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario.* Toronto, ON: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health; 2013.

Lin E, Balogh RS, Durbin A, Holder L, Gupta N, Volpe T, Isaacs BJ, Weiss JA, Lunsky Y. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario*. Toronto, ON: ICES; 2019

In addition, this brief has been informed by stakeholder consultations by the College of Family Physicians Canada (CFPC) Developmental Disabilities Member Interest Group and the Developmental Disabilities Primary Care Program (DDPCP) with family physicians, support workers, caregivers and self-advocates about barriers and facilitators to access preventive Health Checks (CFPC MIGs project grant, 2024).

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Background

Ontario is making a historic investment through the 2025 Primary Care Action Plan, committing to connect every person to a comprehensive, team-based primary care model within four years. For adults with intellectual and developmental disabilities (IDD*), who have long faced barriers to care, this presents a rare opportunity to close persistent gaps if their inclusion is made explicit in implementation.

Adults with IDD experience some of the poorest health outcomes in Ontario [1–7]. They are more likely to live with multiple chronic conditions, experience mental health challenges, and face significantly higher rates of emergency department use, avoidable and prolonged (ALC) hospital admissions, and premature death. Unmet needs create serious personal harm for individuals and their caregivers and substantial financial costs for the healthcare system [8].

Extensive Ontario research has documented these disparities for over a decade. The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* (2013, H-CARDD) first quantified these gaps [1]. More recent studies confirm that little progress has been made [9]. Systemic and structural barriers continue to undermine care. Diagnostic overshadowing occurs when physical health problems are mistakenly assumed to be part of a person's disability, leading to missed or delayed diagnoses. Other persistent barriers include communication challenges, fragmented service delivery, limited provider training and confidence, fragmented leadership across ministries, gaps in data, and weak accountability mechanisms [10].

Evidence-based clinical guidelines and practical tools for primary care of adults with IDD are already available, including the *Canadian consensus guidelines on the primary care of adults with intellectual and developmental disabilities* (2018) [11]. These guidelines and practical point of care tools provide clear, actionable recommendations to support proactive, preventive, and coordinated care. However, despite this strong evidence and the availability of well-established guidelines and clinical tools, uptake and consistent implementation remain limited [12].

Broader policy frameworks reinforce Ontario's obligation to act. The Accessibility for Ontarians with Disabilities Act (AODA) mandates accessible health services for people with cognitive and communication disabilities. The Canada Health Act guarantees access, comprehensiveness, and universality. Canada's ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) further commits governments to ensure equal access to health care. These commitments provide a strong foundation but have not yet translated into consistent system-

* *IDD* refers to various lifelong limitations in intellectual functioning and conceptual, social, or practical skills that emerge in persons before the age of 18 years. These limitations differ in severity and type among people with IDD and can vary during a person's lifespan. Intellectual and developmental disabilities encompass intellectual disability, developmental disability, learning disability (as used in the United Kingdom), and autism spectrum disorder. In: Sullivan, W. F. (2018). Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Canadian Family Physician = Médecin de Famille Canadien.*, *64*(4), 254-e166.

wide change for adults with IDD. The Primary Care Action Plan presents a critical window to finally turn policy into practice.

The key priority is to ensure that adults with IDD are connected to comprehensive, team-based primary care through an accessible and equitable process. As Ontario expands team-based models, adults with IDD must be explicitly identified as a priority population for attachment, given their high health needs and long-standing barriers to care. They also require targeted outreach and accessible supports to help navigate and transition into care, such as through Health Care Connect.

But attachment alone is not enough. Primary care teams must be equipped with the tools, training, and system supports needed to provide effective, coordinated care. The following actions outline what's needed now and what will require longer-term structural change:

1) **Actions for early implementation (1–2 years)**
    a) **Fund specialized roles within primary care teams.**
    Invest in dedicated positions to strengthen primary care for people with IDD:
        i) **Care Navigators**: Fund Community Service Workers to coordinate care across developmental services (including DSO, Community Networks of Specialized Care), home care, mental health, and acute care, helping patients and families navigate complex systems.
        ii) **Specialized Nurses**: Fund nurses with expertise in developmental disabilities to support complex care needs such as enteral feeding, epilepsy, cerebral palsy, communication challenges, medication management and behaviours that challenge, working as part of the primary care team.
    b) **Integrate IDD clinical guidelines into EMRs, quality improvement programs, and establish provincial care standards and quality indicators.**
    Embed evidence-based clinical guidelines and point-of-care tools into EMRs and QI processes, while developing formal provincial standards of care and IDD-specific quality indicators to guide consistent care delivery and system accountability.
    c) **Expand clinical education and professional development on IDD care for primary care teams.**
    Broaden access to continuing professional development programs and communities of practice—such as Project ECHO Ontario and the Developmental Disabilities Primary Care Program—to strengthen provider confidence, competence, and capacity in caring for adults with IDD.
    d) **Ensure regional interdisciplinary consultation and outreach teams to support complex IDD care.**
    Invest in interdisciplinary teams providing specialized consultation and shared care support to primary care providers managing complex IDD cases, particularly in underserved and rural areas.
    e) **Integrate co-designed and evidence informed patient-facing tools into EMRs to support proactive care.**

Embed tools such as pre-visit forms, IDD Health Checks, and health passports into EMRs to guide clinical decision-making, improve communication, and support consistent, guideline-based care.

2) **Longer-Term System Reforms (Multi-Year)**
   a) **Ensure consistent identification of IDD within electronic medical records (EMRs).** Standardize IDD identification in EMRs to support population health management, facilitate proactive care planning, and ensure visibility of this population within health system data.
   b) **Include IDD-specific performance and equity indicators in accountability frameworks and public reporting.** Incorporate measures related to IDD attachment rates, preventive care, and health outcomes into quality frameworks and public dashboards to track progress, identify gaps, and ensure system accountability for equity.
   c) **Enable secure, timely data sharing across healthcare and with developmental services.** Strengthen cross-sector data integration to support coordinated care planning, reduce duplication, and enable seamless service transitions for people with IDD.
   d) **Strengthen IDD education in core health professional curricula.** Co-design intellectual and developmental disability (IDD) curriculum with people who have lived experience, including self-advocates and caregivers, and embed it across undergraduate and postgraduate training in medicine, nursing, and allied health professions. Support co-teaching models with people with lived experience to build long-term workforce competence and normalize inclusive care.

Adults with intellectual and developmental disabilities have long been overlooked in health data, system planning, and access to primary care—especially during critical transitions, such as the shift from pediatric to adult care, from hospital to community, and into older age. Achieving true equity requires more than just connecting people to providers; it demands building inclusive, team-based care models that are equipped to meet their complex and evolving needs across the lifespan [13].

Ontario's Primary Care Action Plan represents a bold and timely opportunity to change this. The province has the evidence, clinical guidelines, and policy platform to lead the country in delivering inclusive, coordinated primary care. To make this vision a reality, clear leadership and accountability from the Ministry of Health is essential—alongside strong partnerships with MCCSS and the organizations, providers, and communities who bring expertise in serving adults with IDD. We stand ready to work together to help make this happen.

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