

Policy Brief: Equitable Access to Primary Care for Adults with Intellectual and Developmental Disabilities in Ontario – SUMMARY

The Opportunity: Ontario's 2025 Primary Care Action Plan presents a rare, time-sensitive opportunity to close long-standing gaps for adults with intellectual and developmental disabilities (IDD), a population that has historically faced significant barriers to accessing comprehensive, team-based primary care. This system transformation can set a national standard for inclusive primary care — if deliberate steps are taken to ensure adults with IDD are explicitly included in implementation.

The Challenge: Adults with IDD experience some of the poorest health outcomes in Ontario. They have significant unmet preventive care needs and experience higher rates of polypharmacy, repeated emergency visits, preventable hospitalizations, alternate level of care (ALC) days, and premature, avoidable mortality compared to the general population. These disparities have been documented for over a decade through Ontario-based research (H-CARDD) and persist due to well-known systemic barriers including diagnostic overshadowing, fragmented services, limited provider training, poor data visibility, and lack of coordinated leadership.

Solutions Exist: Ontario already has a strong foundation of evidence, including the *2018 Canadian Consensus Guidelines on Primary Care for Adults with Developmental Disabilities*, established practice tools, and decades of expertise across healthcare, developmental services, research, and advocacy. The Primary Care Action Plan provides a critical window to embed these solutions into system-wide practice.

Policy Alignment: Existing legislation such as the Accessibility for Ontarians with Disabilities Act, The Canada Health Act and the Convention on the Rights of Persons with Disabilities (ratified by Canada in 2010) reinforce Ontario's obligation to ensure accessible, comprehensive, equitable care for adults with IDD. The Primary Care Action Plan offers a platform to translate these commitments into practice.

Recommendations: *The key priority is to ensure adults with IDD are attached to comprehensive, team-based care through an accessible, equitable process.* Ensuring quality care for these newly attached patients and addressing the challenges providers face will require both immediate and longer-term actions.

Actions Ready for Early Implementation (1–2 Years):

- Embed IDD care navigators and specialized IDD nurses in primary care (e.g., in OHT Health homes).
- Embed existing clinical guidelines and key Ontario specific resources into EMRs and establish IDD care standards at the practice level.
- Expand IDD-specific professional development (e.g., CME, onboarding, clinical training).
- Ensure interdisciplinary outreach supports for adults with complex care needs.
- Integrate co-designed and evidence informed patient-facing tools for people with IDD (e.g., health checks, care passports) into provider workflows.

System-Building Actions Requiring Structural Change (Multi-Year):

- Standardize IDD identification in EMRs to support population health management.
- Include IDD-specific performance indicators in accountability frameworks.
- Strengthen cross-sector data sharing between health and developmental services.
- Fully embed IDD content in core health professions education and curricula.

Call to Action: The leadership, evidence, and policy foundations are in place. What's needed now is clear leadership and accountability from the Ministry of Health, working together with developmental and social services, lived experience advisors, and scientists, to ensure adults with intellectual and developmental disabilities are fully included in Ontario's Primary Care Action Plan. We stand ready to collaborate.