BACKGROUNDER

Enabling the IDD Patient Health Home within Ontario's Primary Care Action Plan Implementation

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The IDD Patient Health Home

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Key Messages and Policy Ask

People with intellectual and developmental disabilities (IDD) continue to experience inequitable access to primary care. Ontario's Primary Care Action Plan (PCAP) and the recent Ombudsman's report highlight the need for more connected, proactive care and stronger coordination across sectors. The **IDD Patient Health Home** offers a practical, low-cost way to embed IDD-informed practices within existing primary care expansion.

We are asking Ontario Health to:

1. **Recognize the IDD Patient Health Home** as a preferred model for embedding IDD-informed care within PCAP implementation and reference it in guidance for OHTs and Primary Care Networks (PCNs).
2. **Fund an IDD Nurse and IDD Care Navigator** within primary care team expansion to support attachment, proactive care, and coordinated transitions.
3. **Encourage or require a Lead Developmental Services (DS) partner** in primary care team proposals that identify people with IDD as a focus population.
4. **Support a Provincial Community of Practice** to serve as the implementation backbone, enabling consistent practice, shared tools, and quality improvement.
5. **Embed IDD-specific indicators** within PCAP's performance framework.

These are small, targeted enhancements to existing investments that can significantly improve equity, reduce avoidable hospital use, and advance PCAP's core goals.

1. Introduction

People with intellectual and developmental disabilities (IDD) experience persistent inequities in access to primary care[1]. Many struggle to secure attachment, communicate their health needs, and move smoothly across care settings. These gaps contribute to missed preventive care[2] and poor continuity of care[3].

Recent provincial work has made these inequities visible. Cross-sector working groups have emphasized the need for more equitable access[4], and the recent Ombudsman's report "Lost in Transition" (November 2025) on inappropriate hospitalizations of adults with developmental disabilities demonstrates how weak transitions and limited primary care involvement can leave people with IDD without timely, appropriate care[5]. At the same time, this population has often been overlooked in past primary care reforms.

Ontario's Primary Care Action Plan (PCAP)[6] sets ambitious goals to expand comprehensive, convenient, and connected primary care. The current expansion of interprofessional teams, including OHTs and PCNs, creates a time-limited opportunity to embed IDD-informed enhancements so people with IDD benefit fully from this next phase of reform.

This backgrounder describes an **IDD Patient Health Home** model that builds on Ontario's **Patient Medical Home**[6] and the broader **Medical Neighbourhood**[7]. It incorporates targeted enhancements—an IDD Nurse, an IDD Care Navigator, shared tools for communication and care planning, a Lead Developmental Services partner, and support from a Provincial Community of Practice—to ensure people with IDD are attached to a primary care team, can navigate it, and do not get lost at transition points.

2. The IDD Patient Health Home

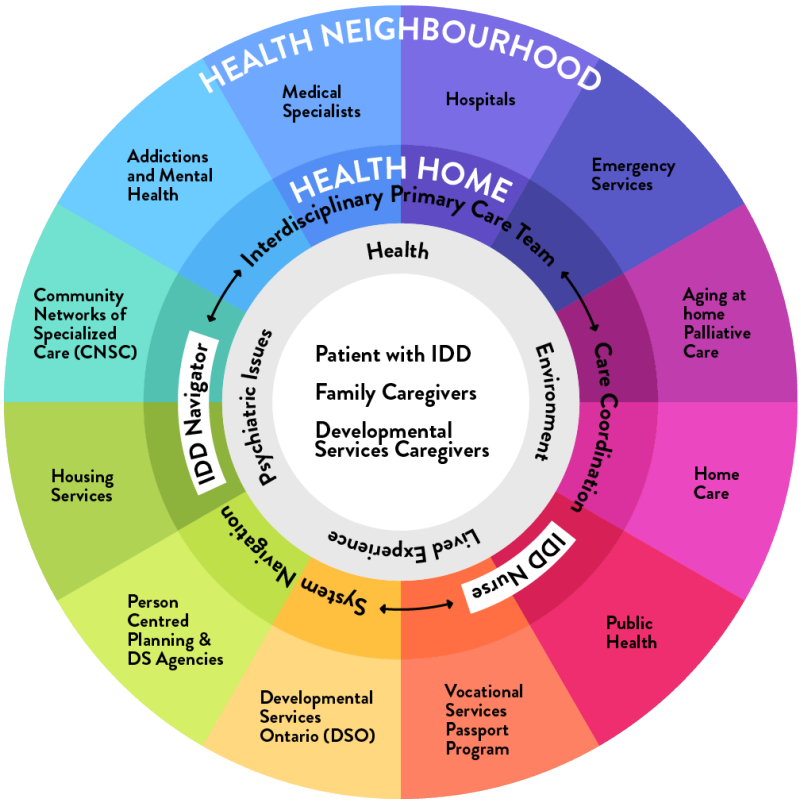

Figure 1: The IDD Patient Health Home including primary care, care coordination, and system navigation

The IDD Patient Health Home strengthens Ontario's existing primary care structures by enhancing the Patient Medical Home (PMH) and Medical Neighbourhood (MN). It adds core functions that improve attachment, navigation, coordination, and continuity for people with IDD, aligning directly with PCAP's goals.

How the Model Builds on the PMH/MN

The PMH provides comprehensive, continuous primary care, supported by a Medical Neighbourhood that includes hospitals, mental health services, home care, public health, rehabilitation, and developmental services (Figure 1).

The IDD Patient Health Home enhances this framework through:

- **An IDD Nurse** to lead IDD-informed preventive care and adapted chronic disease management.
- **An IDD Care Navigator** to strengthen attachment, transitions, communication, and supported decision-making.
- **Shared clinical and communication tools** to support health checks, accessible communication, and care planning.
- **A formal partnership with a Lead Developmental Services (DS) agency** to ensure coordinated pathways and support during transitions, including admission and discharge.

These enhancements allow people with IDD to secure attachment, move smoothly among services, and maintain continuity—especially during major transitions.

Core Roles Supporting the Model

- **IDD Nurse – Clinical Prevention and Health Management**
  A registered nurse with expertise in intellectual and developmental disabilities who adapts preventive and chronic disease management pathways using the HELP framework (Health, Environment, Lived Experience, Psychiatric/Mental Health) outlined in the Canadian guidelines on primary care for adults with IDD.[8] The nurse conducts evidence-informed periodic health checks (OHIP code K133), coordinates screening and immunizations, and supports chronic disease management using accessible communication. Working closely with physicians and nurse practitioners, the nurse adapts clinical pathways to meet the needs of patients with IDD and ensures care remains anchored within the Patient Medical Home, collaborating with the broader Medical Neighbourhood when needed.

- **IDD Care Navigator – Continuity and System Navigation**
  A dedicated coordinator who strengthens attachment and reduces fragmentation. The navigator supports transitions between primary care, hospitals, specialists, home care, and Developmental Services; assists with disability-related documentation; and helps address social determinants. By identifying caregiver stress early and coordinating supports, the navigator reinforces continuity across the care journey.

These roles give primary care teams the capacity to:

- Attach people with IDD who struggle to navigate traditional systems
- Implement proactive IDD health checks and care planning
- Smooth transitions and reduce Alternate Level of Care (ALC) pressures
- Reduce provider administrative burden (e.g., applications for disability specific services like Developmental Services Ontario or caregiver supports)

3. Principles of Care for People with IDD

The IDD Patient Health Home rests on established principles of family medicine and the Patient Medical Home: relationship-based continuity, whole-person assessment guided by the HELP framework, trauma-informed and accessible communication, and proactive, coordinated care.

The **HELP framework**[9], as outlined in the evidence-based Canadian consensus guidelines on the primary care of adults with IDD[8], prompts teams to consider overall **health, environment, lived experience, psychiatric and mental health needs**. This structure reduces risks such as diagnostic overshadowing (attributing symptoms and behaviours to the disability without considering other potential causes) and supports adaptive, preventive care.

Trauma-informed and accessible communication, including plain language, visual supports, extra time, and appropriate caregiver involvement helps create safe, participatory care environments and improves assessment and shared decision-making.

Proactive care and structured transitions reduce avoidable emergencies and prevent fragmented care—fully aligning with PCAP's priorities.

4. Collaboration with Developmental Services

A **Lead Developmental Services (DS) agency** is a core partner in the IDD Patient Health Home. As part of the Medical Neighbourhood, the DS partner supports information sharing, shared care planning, and smoother transitions, including during hospital admission, discharge, and crisis. Their expertise in eligibility, funding pathways, and community supports addresses common navigation challenges within primary care.

The Developmental Services partner contributes:

- Real-time navigation support around eligibility, pathways, funding, and available community services.
- Shared care planning and coordination for people with complex needs, including during ALC, crisis, and major life transitions.
- Joint training and use of common tools[10]—such as *About My Health*, *My Hospital Plan*, and *My Healthcare Visit* —to support accessible communication and consistent IDD-informed practice across sectors.

This embedded Developmental Services role ensures cross-sector collaboration occurs early—not only during crises.

5. Provincial Community of Practice

A provincial Community of Practice (CoP) provides the implementation backbone for the IDD Patient Health Home. Drawing on expertise from Surrey Place's Developmental Disabilities Primary Care Program (DDPCP)[10], CAMH's Adult IDD ECHO, Developmental Services partners, family physicians with training in IDD care, and people with lived experience, a CoP will:

- Support consistent training and practice
- Curate existing tools to reduce duplication
- Provide coaching and case-based learning
- Support common indicators and evaluation aligned with PCAP
- Facilitate shared problem-solving across OHTs and PCNs

By serving as a central implementation resource, the CoP will strengthen conditions for equitable uptake across the province.

6. Alignment with Ontario's Primary Care Action Plan

The IDD Patient Health Home directly advances the priorities of Ontario's Primary Care Action Plan[6]. It improves attachment by helping identify people with IDD who are unattached and supporting them through structured onboarding with the IDD Care Navigator and Developmental Services partner. Within teams, the IDD Nurse strengthens proactive clinical care, chronic disease management, and communication across settings using shared tools that make care more connected and convenient. The model also supports providers by building IDD-specific capacity into the team and offering training and practical tools through the Provincial Community of Practice, reducing provider isolation and increasing confidence in caring for people with complex needs. Together, improved attachment, prevention, and coordinated transitions reduce avoidable emergency visits and inappropriate or prolonged hospital stays, including ALC days, helping ease system pressures and deliver on PCAP's goals[11,12].

7. Policy Levers to Enable the IDD Patient Health Home

Ontario Health can enable this model using mechanisms already in place by:

1. Ensuring that **primary care team funding criteria** identifies the IDD Patient Health Home as the preferred model when people with IDD are identified as a focus population.
2. Providing **guidance for OHTs and PCNs** that outlines what IDD-inclusive primary care looks like in practice: attachment pathways, defined navigation functions, a Lead Developmental Services partner, and shared tools.
3. Including a small number of IDD-specific indicators for this equity deserving population in **PCAP's performance framework** to ensure progress is visible and actionable.

Existing implementation supports, including the Provincial Community of Practice, can help interested teams adopt and adapt the model.

8. Implementation and Scale-Up

Implementation will proceed in three phases: (1) early adopters in high-need communities, (2) spread to interested OHTs and PCNs, and (3) province-wide standardization as part of Primary Care Action Plan (PCAP) implementation.

Early adopter teams will integrate IDD Nurse and Navigator functions, formalize Developmental Services (DS) partnerships, and adopt shared tools. The model is adaptable to local context—teams can configure staffing, choose the Lead DS partner, and integrate tools into existing EMR and care processes. The Provincial Community of Practice (CoP) will provide training, onboarding, and shared problem-solving.

The 2025 primary care team expansion rounds have already generated interest, with several OHTs and PCNs incorporating core features of the IDD Patient Health Home into their proposals. These applicants provide a ready cohort for early implementation and refinement (See appendix A).

A **Learning Health System**[13] approach will guide spread. Early adopters will use local data on performance indications to identify gaps, test changes (e.g., routine IDD health checks, standardized discharge pathways), and measure impact. Lessons will flow through the CoP and into PCAP reporting, allowing guidance and indicators to evolve based on real-world experience.

Over time, these cycles will support province-wide uptake, helping ensure people with IDD experience more coordinated, equitable care while easing system pressures.

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Appendix A: Early Adopters

Proposals Ready to Implement the IDD Patient Health Home

The following proposals for Interprofessional Primary Care Teams (submitted November 2025) represent **ideal early adopters** for Ontario Health's implementation of the **IDD Patient Health Home model**. Each site already demonstrates the core conditions required for success: strong interprofessional teams, formal developmental services (DS) partnerships, accessible and integrated care environments, and a clear equity focus. They are structurally ready to **embed a funded IDD Nurse and IDD Care Navigator**, adopt shared communication and care-planning tools, and implement standardized onboarding and transition pathways.

Crucially, these early adopters are also well positioned to **participate in and help shape a Provincial Community of Practice (CoP)**. With Ontario Health's support, the CoP will provide consistent training, shared tools, implementation coaching, and a learning health system approach for monitoring outcomes. These teams already have the partnerships, leadership, and service models required to benefit from, and contribute meaningfully to, the CoP's provincial implementation infrastructure.

Together, these proposals give Ontario Health a timely opportunity to align PCAP-funded primary care expansion with the IDD Patient Health Home model, generating early evidence on how targeted enhancements can improve attachment, continuity, and health outcomes for adults with intellectual and developmental disabilities across Ontario.

1. West Toronto OHT & Safehaven

West Toronto OHT, in partnership with Safehaven on behalf of the Toronto Developmental Services Alliance (TDSA) and Toronto Service Providers, has submitted two primary care expansion proposals that directly advance the Primary Care Action Plan and address critical gaps in access and coordination for adults with intellectual and developmental disabilities (IDD).

South Parkdale & Liberty Village Expansion

Serving M6K and M6R (65,000 residents; ~11,800 unattached), this proposal establishes a new Primary Care Office in Parkdale with 15 exam rooms, two new physicians, expanded NP and allied health roles, and a full-service laboratory in Liberty Village. The model integrates primary care with trusted community partners (PARC, West Neighbourhood House) to improve attachment, continuity, and navigation for residents, including those with IDD.

Central Etobicoke Community Hub

This proposal creates an accessible, co-located Community Hub that brings together primary care, allied health, mental health, seniors' wellness, and social supports. It expands attachment capacity through new physicians, NPs, PT/OT, dietitians, and case managers. The Hub is explicitly designed to strengthen equitable, coordinated access for adults with IDD and caregivers, supported by formal partnerships with Developmental Services agencies.

Across both submissions, West Toronto OHT demonstrates a clear commitment to addressing longstanding inequities experienced by adults with IDD by:

1. **Embedding strong cross-sector partnerships with Developmental Services agencies**
   Safehaven, TDSA, and Toronto Service Providers are integrated as core partners to support navigation, care planning, and rapid communication between sectors.
2. **Building accessible, integrated care environments**
   Each proposal co-locates primary care with allied health, mental health, and community supports, creating simpler access points and reducing the fragmentation that disproportionately affects people with IDD.
3. **Expanding local capacity to prevent avoidable hospital use**
   New physicians, nurse practitioners, and allied health providers increase access to preventive, team-based care, reducing reliance on emergency departments and improving continuity for individuals with complex needs.
4. **Strengthening navigation and communication pathways**
   Both models formalize connections between primary care teams and Developmental Services partners, enabling earlier intervention, smoother transitions, and more coordinated support for caregivers.
5. **Prioritizing equity by targeting high-need neighbourhoods**
   The proposals are situated in areas with high numbers of unattached residents and identified barriers to care. Each explicitly addresses known access challenges for people with IDD, who often face additional structural and communication barriers.

2. Western York Region OHT, Thornhill Community Health Centre & Reena

Reena, in partnership with Community Health Centre (CHC) Thornhill, submitted a proposal to establish a **fully accessible and inclusive primary care hub** serving the Thornhill L4J community. The model aims to significantly increase attachment for equity-deserving residents, particularly adults with intellectual and developmental disabilities (IDD), neurodiverse individuals, seniors, and newcomers who continue to face barriers in securing consistent, coordinated primary care.

The proposal brings together a strong cross-sector partnership, including Concord Family Health, SE Health, Surrey Place, CAMH's H-CARDD and AIDD ECHO programs, and the Western York Region OHT. Together, these partners will support integrated clinical care, IDD-informed practice, coordinated transitions, and culturally accessible services.

The proposed CHC would provide comprehensive interprofessional primary care, family medicine, nurse practitioner services, allied health, mental health supports, navigation, and health promotion within an intentionally accessible environment. The model aligns directly with the Primary Care Action Plan (PCAP) by advancing four core priorities:

- **Attachment** through expanded interprofessional capacity
- **Equity** by designing accessible services for populations with documented gaps in care
- **Integrated care** via strong partnerships across health, developmental services, and community supports
- **Provider support** through connection to Surrey Place, H-CARDD, and AIDD ECHO for training, shared tools, and consultation

3. Frontenac, Lennox and Addington OHT, Maple Family Health Team & Ongwanada

The FLA OHT Health Home Initiative

The Frontenac, Lennox and Addington Ontario Health Team (FLA OHT) has developed a People-Centred Health Home model to improve primary care attachment, access, and coordination across the region. Co-designed with primary care providers, community members, and system partners, the model positions primary care as the front door to the health system and emphasizes team-based, locally delivered, and equitable care.

Health Homes function as neighbourhood-based primary care hubs where family physicians and nurse practitioners work alongside interprofessional team members and community partners to provide coordinated, continuous care close to where people live. The model is intentionally flexible, enabling practices at different stages of readiness to adopt Health Home principles over time, supported by shared infrastructure, common tools, and a strong regional learning culture.

Early results demonstrate impact. In 2024, FLA OHT partners connected more than 13,000 people to primary care. In the first provincial funding round under Ontario's Primary Care Action Plan, FLA OHT secured $1.49 million to attach an additional 3,500 people by April 2026, further strengthening interprofessional capacity within the Health Home model.

Implementing an IDD Patient Health Home: Readiness and Timing

FLA OHT, in partnership with Maple Family Health Team and Ongwanada as the lead developmental services agency, is well positioned to implement and scale an IDD Patient Health Home and to serve as an early provincial learning site.

Critically, IDD nurse and care navigator roles are being implemented now through the first round of Primary Care Action Plan funding. This creates a timely opportunity to intentionally embed IDD-informed practice from the outset, rather than retrofitting roles later. Maple Family Health provides the primary care infrastructure, governance, and clinical leadership to integrate these roles within team-based care, supporting proactive health assessments, chronic disease management, coordinated care planning, and smoother transitions across settings.

Ongwanada anchors the model in developmental services, bringing deep expertise in supporting people with IDD and their caregivers across the lifespan. As a full partner in the Health Home, Ongwanada supports early identification and attachment, navigation across health, hospital, and community services, proactive planning to prevent crises and avoidable hospital use, and shared communication with caregivers and frontline staff. This formal partnership embeds developmental services as a core component of primary care rather than an external referral.

A Provincial Learning Health System

Together, FLA OHT, Maple Family Health Team, and Ongwanada represent a highly ready site to function as a **learning health system** for the IDD Patient Health Home model. The combination of new role implementation, strong cross-sector governance, and an established co-design culture allows for rapid testing, refinement, and improvement of workflows, tools, and care pathways.

FLA OHT's local data and evaluation capacity enables real-time measurement of attachment, access, care coordination, patient and caregiver experience, and system outcomes. These insights can be systematically shared through a **Provincial Community of Practice**, supporting other Ontario Health Teams and Primary Care Networks to adapt and scale the model using evidence generated in practice.

This positions FLA OHT not only as an early implementer, but as a provincial partner in accelerating consistent, high-quality IDD-informed primary care across Ontario.

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