A Call to Action For Fundamental Cross-Sectoral Change

Advancing access, equity and improved health outcomes for persons living with intellectual and developmental disabilities

A Position Paper from the Health Strategy & Engagement Working Group of the Provincial Network on Developmental Services

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Introduction

People living with Intellectual and Developmental Disabilities (IDD) are **poorly understood** by the healthcare system.

Improved Understanding

Invent in the future

Experience has shown that **government-prioritized investments** into sector-driven, strategic quality improvement initiatives at the intersection of Developmental Services (DS) and Health result in **significantly improved and sustained health outcomes for people with IDD.**

Persons with IDD live with **inferior health, wellness and safety supports**, and experience **higher rates of morbidity and mortality** due to systematic barriers and inequities.

Identify Barriers

Make Improvements

Recent **successes, critical success factors and calls to action** to improve health outcomes for persons with IDD are summarized in this presentation.

Health System Improvements for People with IDD

Current Issues and Challenges

Health Disparities

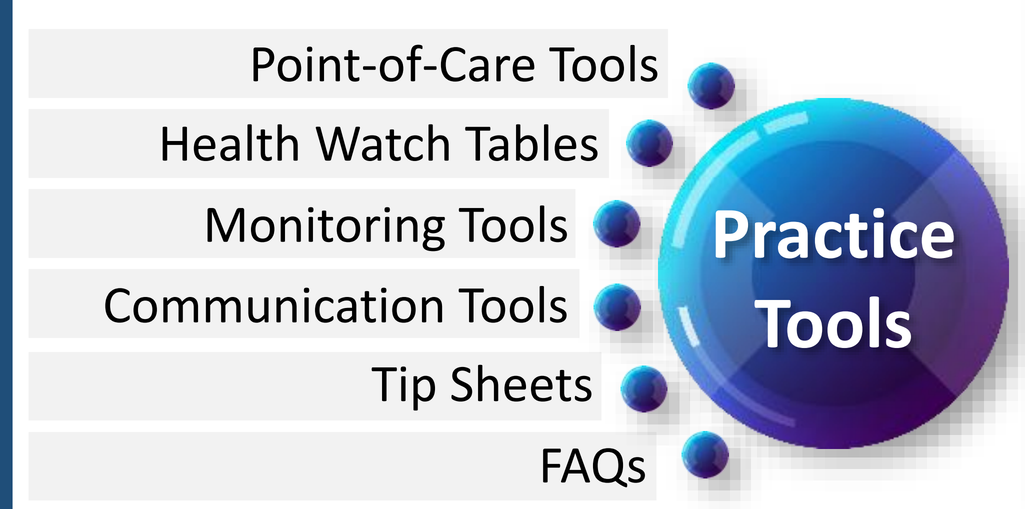
Disparities in health status (chronic diseases, aging, co-morbidity, mental health diagnoses).

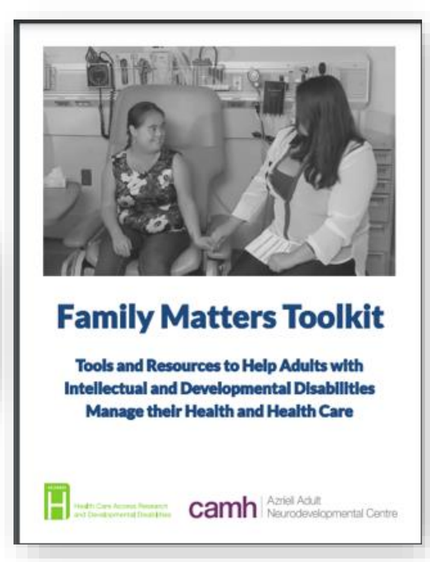
Overuse of health services (return Emergency Department visits, hospital visits, Alternate Level of Care).

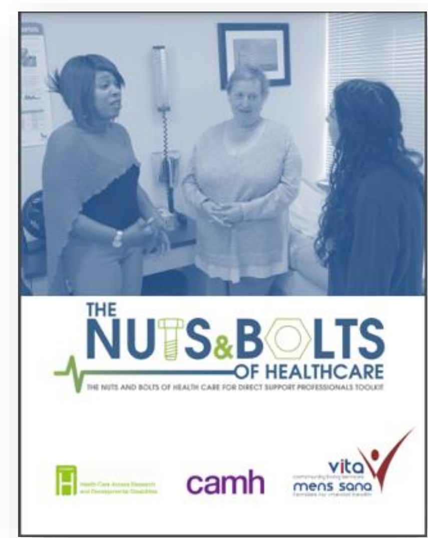
Over-prescribing of medications and antipsychotic medications, putting people at risk for adverse reactions and death.

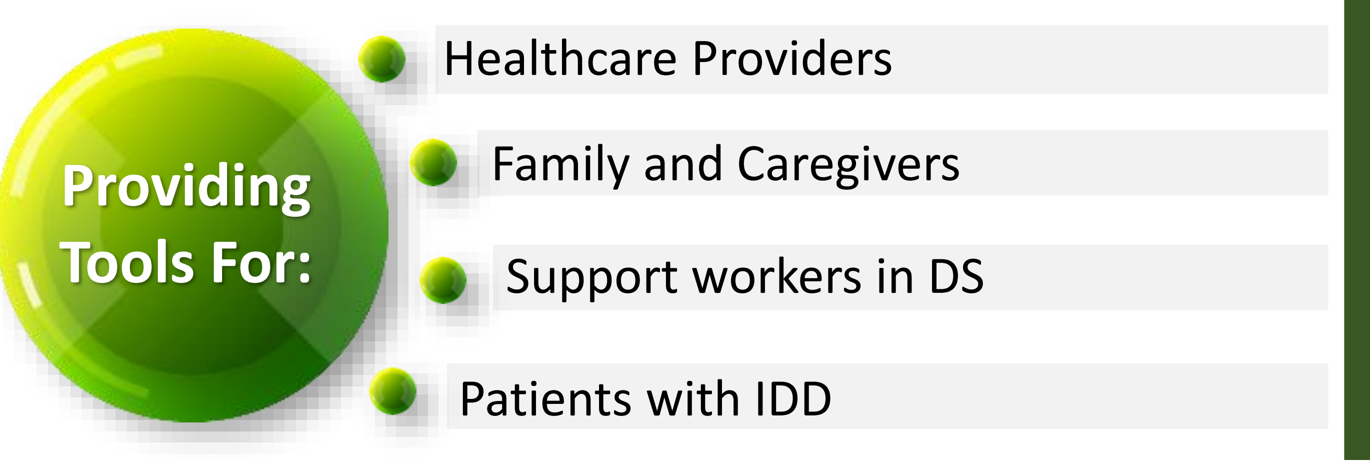
High-cost healthcare users.

Health System Improvements









Health System Improvements

Barriers to uptake of best practice

Lack of awareness of Canadian **guidelines and tools** for the primary care of adults with IDD.

Lack of **knowledge and skills** of healthcare providers in IDD health.

Lack of awareness with patients and caregivers about their **rights to reasonable adjustments** in care.

Lack of integration of existing clinical tools in a modern **e-health environment**.

Lack of implementation studies and **quality of care indicators**.

Health System Improvements

Recent Successes - Addressing The Barriers

Toolkit for IDD Health Care with **new mental health toolkit** released March 2024. Available at Surrey Place's Developmental Disabilities Primary Care Program.

Availability of **IDD Health Check tool** in a leading Ontario Electronic Medical Record (EMR) system, Telus PS Suite.

Increased understanding of barriers and facilitators through implementation research

McNeil, K., et al. (2024) *Towards developing an intervention to support periodic health checks for adults with intellectual and developmental disabilities: Striving for health equity.* Journal of Applied Research in Intellectual Disabilities, 37(1), e13169.

New Ontario billing code – K133 for the IDD Health Check (periodic health visit).

Health System Improvements

Call To Action – Sectoral Improvements

Increase awareness of guidelines and tools through dissemination efforts.

Develop standards of care against which quality can be measured.

Technology Integration

Integration of clinical tools into all main EMR systems.

Ensure future **AODA Health Care** standards are in compliance through mandated consultation with DS.

Preparation

Implementation studies to **understand change**.

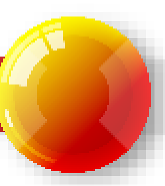
Reimagine prevention and reduction strategies, processes and pathways to improve health outcomes, working together with all stakeholders (providers, caregivers, patients).

Alternate Level of Care (ALC)

Cost

Transitions from Hospital ALC to Developmental Services (DS) Group Living		
PERSON	**ALC LENGTH OF STAY**	2022 studies estimate the cost of a Hospital ALC stay to be in the range of $700,000 - $800,000 per year.
Josh	2 Years	
Pam	3 Years	
Mark	11 Years	
TOTAL	**16 Years**	**Estimated healthcare system costs of $12 million over 16 years in ALC**

Hospital/ALC costs



DS Group Living costs

Individuals with IDD who have transitioned out of Hospital ALC stays can typically be supported in DS Group Living for up to 50% less than costs incurred while in Hospital.

Alternate Level of Care (ALC)

Adverse Health Impacts

Extended hospital stays may result in various dimensions of health decomposition for persons living with IDD, including:

- **Prevalence of infectious diseases** – Antibiotic-Resistant Organisms and other infectious diseases such as COVID-19, Influenza, Respiratory syncytial virus (RSV)
- **Mental health issues** – Social isolation, depression
- **Other concerns -**
    - Communication barriers
    - Loss of ambulation
    - Aging and dementia
    - Nutritional deficiencies
    - Overmedication, etc.

Alternate Level of Care (ALC)

Dual Diagnosis – Case Studies

Individuals with a dual diagnosis face a **higher risk of being designated as ALC**:

- Adverse impacts to the ALC patient
- Delays for other patients in need of hospital resources

Amanda's Story

"It took more than a year for Amanda to finally move into her apartment. The barriers we faced included insufficient expertise in developmental disabilities within the hospital staff, lack of a centralized process to find housing, and delays getting the budget approved."

– Sarah, Amanda's stepmom

Peter's Story

"Transition is key...There shouldn't be a timeline. It should be very flexible so that you can do it according to what the person needs and what staffing needs."

– Peter's community services supervisor

John's Story

"Until you are in that situation, you don't realize there is not much out there and you can't plan for it. John being in a home was not part of our parents' plan, or the route we wanted to take but you have to be open to change your mind. We all wanted what was best for John to lead a self-fulfilling life."

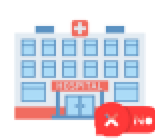
– Isabelle, John's sister

Chin, M., Coriolan, B., Hasan, S., Lunsky, Y., Morris, S., Selick, A., Volpe, T. (2024) *Dual Diagnosis Alternate Level of Care Vignettes Series.* The Health Care Access Research and Developmental Disabilities Program (H-CARDD) and the Centre for Addiction and Mental Health (CAMH). Available: https://www.camh.ca/-/media/files/professionals/hcardd/dual-diagnosis-alternate-level-care-vignettes2024-pdf.pdf. Accessed March 3, 2024.

Alternate Level of Care (ALC)

Helping People With Developmental Disabilities To Move From Hospital To Home

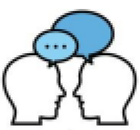
A hospital is not a person's home.



Everyone should live in a home that is right for them with the right kind of help to meet their needs.

People with disabilities have the same rights as all other people, to be treated with dignity and respect.

Everyone needs to work together to come up with a good plan to leave the hospital.



"Hello, my name is...... My role is....."

"Here is my own copy of my Transition Plan!"

"Let's use pictures to show what we are talking about."

Lunsky, Y., Morris, S., Selick, A., Volpe, T. (2023). *Supporting alternate level of care (ALC) patients with a dual diagnosis to transition from hospital to home: Practice guidance.* The Health Care Access Research and Developmental Disabilities Program (H-CARDD) and the Centre for Addiction and Mental Health (CAMH). Available: https://www.camh.ca/-/media/files/professionals/hcardd/easy-reads/hcardd-easyread-alc-report-things-help-people-leave-hospital2023-pdf.pdf. Accessed March 4, 2024.

Alternate Level of Care (ALC)

Primary Benefits - Transition To Developmental Services

Tailored DS supports, **peer socialization, inclusion and belonging**.

Recognizing that persons with IDD are an **equity-deserving population**.

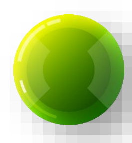
Availability of hospital & other health resources

Best use of public funds with care/support costs being lower in DS vs. Health sector.

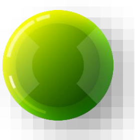
Alternate Level of Care (ALC)

Health / DS Cross- Sectoral Improvement Opportunities

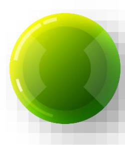
ALC best practice guidelines and discharge pathway for persons living with IDD.



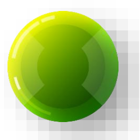
Strengthen DS-embedded **specialized clinical services**.



Health system representation at DS priority placement and system planning tables.



Strengthen resources (tools, staffing) Developmental Services Ontario (DSO) offices.



Digital information sharing – Health, hospitals, DS & Community.

Dual Diagnosis – need for specific processes and pathways.

Home and Community Care (HCC)

Recent Successes

Nurse Support

HCC Direct Support Nurse specializing in IDD – facilitates discharge planning from hospitals back into the community.

Valuable Respite

DS Community Respite works with Hospitals and HCC – ER avoidance, reduce hospital stays and enable seamless transitions to home.

Specialized Teams

Special Team in HCC – multi-disciplinary team with a range of specialization and experience in working with people with IDD, takes the lead no matter which setting the individual lives in.

Strong partnership across sectors leads to improved health outcomes for persons with IDD and families to remain in community longer.

Critical Success Factors

Collaboration between HCC, Hospitals and DS.

HCC staff having **specialized experience and training** in supporting persons with IDD to provide an individualized, person-centred approach.

Mutual understanding of each other's roles and responsibilities facilitates improved health outcomes.

Agreements with Public Health agencies to deliver supports to this priority population.

Home and Community Care (HCC)

Primary Benefits

Home and Community Care supports **tailored to the unique needs** of persons with IDD, better ensuring positive health outcomes.

Recognizing that persons with disabilities are an **equity-deserving population**.

Reduce reliance on and use of health system resources due to preventative care, reducing ER visits and inappropriate/premature LTC placement.

Home and Community Care (HCC)

Calls To Action – Sectoral Improvements

Sustained partnership between HCC and DS across all local communities to increase access and adaptable support models in the delivery of Home & Community Care to persons with IDD.

Implement and scale evidence-based best practices that have been developed in local HCC support.

Infection Prevention & Control (IPAC)

Recent Successes

- Person-centered COVID-19 pandemic precautions.
- Vaccine prioritization for persons with IDD and caregivers.
- Essential role of DS direct support staff.

COVID-19 Vaccination Clinics - operated, coordinated and/or facilitated through DS collaborative partnerships.

DS IPAC Champions – in-house expertise, understanding of persons with IDD.

Persons with IDD experienced disproportionately negative outcomes during the COVID-19 pandemic.

Infection Prevention & Control (IPAC)

Barriers For Advancing IPAC In DS Sector

Crisis of Expertise

Organizations do not have in-house IPAC **expertise or regulated health professionals**.

Requires Resources

Community-based DS congregate living settings **require dedicated resources** for protecting vulnerable clients.

Absent Viable Plan

No comprehensive plan to enable sustainable IPAC practices to continue in DS settings.

Lack of **coordination, collaboration and accountability** between Health Ministries, Ontario Health, Public Health Ontario & MCCSS.

Infection Prevention & Control (IPAC)

Primary Benefits

IPAC precautions, practices and resources dedicated to the **unique needs** of persons with IDD.

Recognizing that persons with disabilities are an **equity-deserving population**.

Reduce reliance on and use of Health system resources.

Strengthens knowledge and skill with DS sector subject matter experts.

Infection Prevention & Control (IPAC)

Calls To Action – Sectoral Improvements

Support and sustain IPAC expertise in the DS sector through annualized funding.

Reinstate funded IPAC Champion model for MCCSS organizations.

Dedicated Programming

Recognition of DS Sector uniqueness with **dedicated IPAC programming**.

Updates to DS Sector Quality Assurance Measures framework to incorporate **mandatory IPAC standards, education and training** with regional supports.

Data Improvements

Recent Successes

System-level Success:

Legislation change will permit ICES to **receive and link data** from other Ministries.

Linked data at ICES led to:

- **Documentation** of higher risks of COVID to people with developmental disabilities.
- Informed **prioritization** for vaccines and Paxlovid.
- ICES Dashboard allowed for regional real time vaccination **monitoring** for our population.

Funding success from CIHR to study team-based primary care in the province

Builds on prior work using **administrative data** to study primary care.

Data Improvements

Primary Benefits

Recognizing that persons with disabilities are an **equity-deserving** population.

Implications for other disability groups.

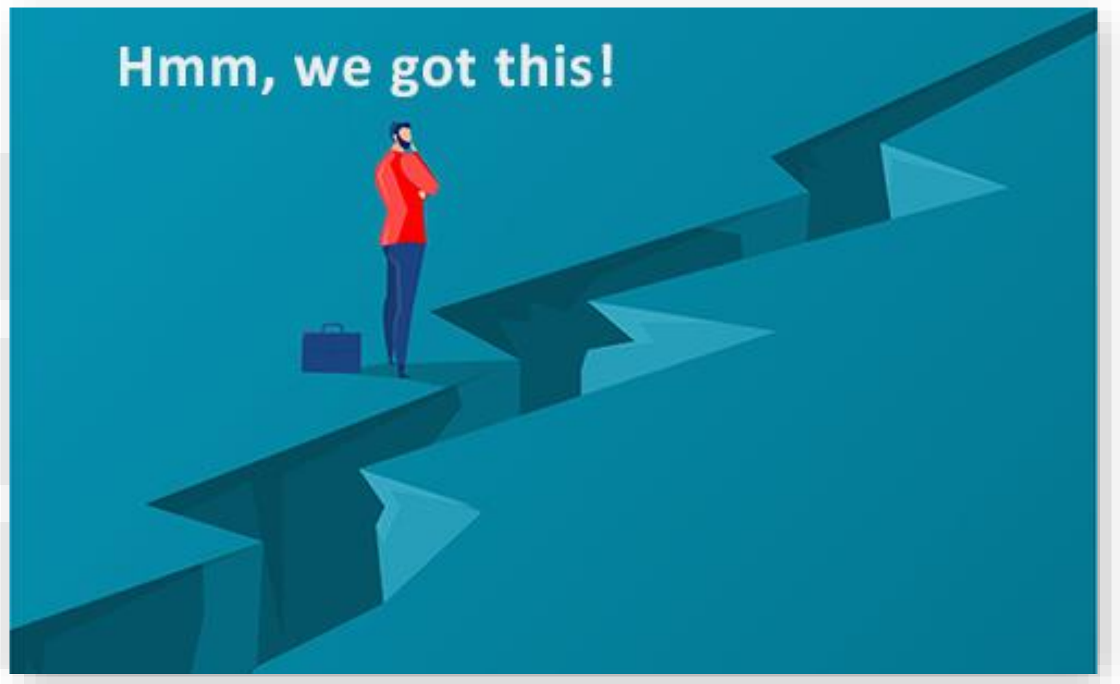
Data Dependent

Need for **data to inform** our decisions.

Useful to **inform** health care guidelines and to **measure progress** with health (e.g., new initiatives like new billing code).

Data Improvements

Barriers For Advancing Data Improvements



- DSCIS is **not regularly updated** and not linked to other provincial health data held at ICES.
- Information/Data on people receiving DS services **not readily available** (e.g., residential support type).
- Top level databases **don't have information** on who receives DS supports.
- Despite attention to EDI in healthcare, **little attention paid** to disability and accessibility.
- **No mandatory regular monitoring** of health outcomes for people with DD.
- **Limited required reporting** of health outcomes at DS agency level.
- **No funding** specific to health research and DD at a provincial or national level.

Data Improvements

Calls To Action – Sectoral Improvements

Define Indicators

Develop **standards of care** for persons with IDD and define key quality indicators.

Establish Processes

Governmental commitment of resources and mandate to establish data-driven, evidence-based processes and solutions.

Funding Removes Barriers

Dedicated **annualized funding** to facilitate data quality improvement and remove barriers to access.

Take Action

Fully enact the **six recommendations** from the 2016 paper "Summary of Proceedings: Making the Invisible Visible".

Data Dependent

Ombudsman report mentioned **need for data**.

"Advancing Access, Equity and Improved Health Outcomes for Persons Living with Intellectual and Developmental Disabilities"

Overall, key themes for cross-sectoral quality improvement that have emerged are:

I. Structural integration of pathways between the Health and DS sectors
II. Investment into research, data and systems spanning the Health and DS sectors
III. Retention, sustainability and growth of DS linkages to the Health sector, and embedded specialized clinical services, knowledge, expertise and tools within the DS sector

To view the paper in full, please visit the Provincial Network website.