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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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Executive Summary

People living with Intellectual and Developmental Disabilities (IDD) are poorly understood by the healthcare system (Health), with their unique health and support needs being unnecessarily overlooked. As a result, 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.

Some examples of cross-sectoral, person-centred, evidence-based solutions to healthcare barriers and inequities for persons with IDD do exist. Maintaining, strengthening and embedding the commitment to cross-sector collaboration, investment and accountability is critical to advancing sustainable solutions, and enabling access and equity to ensure improved health outcomes for persons with IDD.

During the COVID-19 pandemic, persons with IDD benefited from singular Health/Developmental Services (DS) engagements that included initiatives led by DS service providers and the Ministry of Children, Community & Social Services (MCCSS), and effective DS representation at Health tables. This diverse and inclusive representation balanced perspectives and helped to inform issues and solutions for persons with IDD through a policy, experience and service provider lens. Further, through this heightened engagement we saw firsthand the introduction of proactive approaches that helped build capacity in the health system while promoting greater health interventions for all Ontarians.

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

The identified *Calls to Action* contained within this paper must ignite immediate collaboration, engagement, investment, accountability, inclusion and a commitment to action between the Developmental Services sector and the Health sector.

Calls to Action: Key Themes

The Calls to Action within this position paper have been developed by leaders in the DS sector in partnership with Health/DS data subject matter experts all of whom have extensive experience with the many healthcare system barriers and inequities encountered by persons with IDD.

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.**

Introduction

Advancing health equity ensures improved access and health outcomes for persons living with IDD. People with IDD often have complex healthcare needs that require unique supports, necessitating early interventions and evidence-based treatments. Inadequate healthcare supports for persons with IDD having common, avoidable, and/or treatable conditions as well as complex clinical needs has a costly toll on their health and well-being and contributes to ongoing pressures within an already stressed healthcare system.

Driven by longstanding health system challenges, the *Provincial Network on Developmental Services (PNDS)* formed a *Health Strategy & Engagement Working Group (Working Group)*. The Working Group is comprised of organizational leaders from Developmental Services (DS) service providers across the province who have in-depth experience working with health system partners/Health and includes data/systems experts in Health whose work regularly intersects with the DS sector.

The Working Group was formed to: *Provide advice and recommend strategies that assist the PNDS in its mandate to: inform MCCSS about the interests and concerns related to healthcare delivery, health policy, specialized clinical services, infection prevention and control, research and education; support system change in light of OHTs, and identify broader inter-ministerial opportunities to improve health outcomes for persons living with IDD.*

Through an assessment of currently identified challenges, pressures and opportunities experienced by persons with IDD, their families and DS organizations supporting these individuals, the Working Group established targeted sub-committees to focus on the following key areas:

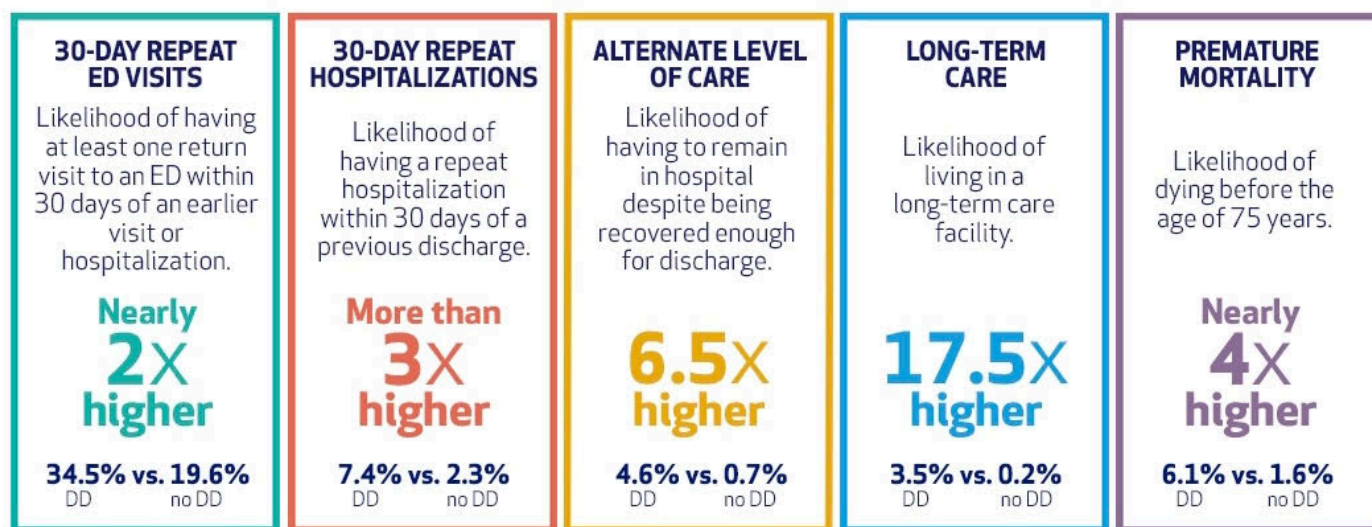
- *Health System Improvements (including but not limited to Primary Care)*
- *Alternate Level of Care (ALC)*
- *Improvements to Home and Community Care*
- *Infection Prevention and Control*
- *Data Improvements.*

A commitment to **collaboration, engagement, investment, accountability and inclusion** by and between both DS and Health is essential to drive strategies and actions to produce consistent and sustained improved outcomes for persons living with IDD.

Health Equity is a Right

Ensuring a person-centred and family-centred approach to support the needs and rights of persons with IDD is essential throughout and will not only result in improved health outcomes for this vulnerable population but also improved and sustained systemic collaboration and efficiencies across sectors.

In 2019, the Institute for Clinical Evaluative Sciences (ICES) released a report highlighting some of the key health system areas where people with IDD fared far worse than those without a disability. Data from a six-year period (2010-2016) was reviewed and highlighted the following experience:



Lin E et al. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario*. ICES; 2019.

ICES Data. Discovery. Better Health.
ices.on.ca

H ICARDD
Health Care Access Research
and Developmental Disabilities

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mental health is health

These outcomes are unacceptable and inequitable to persons living with IDD, and in stark contrast to a society committed to accessibility.

Ontario Health (OH) is a Crown agency established by the government to execute the government's strategy and oversee Ontario's healthcare and long-term care delivery. OH's mandate is to connect, coordinate and modernize our province's health care system to ensure that the people of Ontario receive the best possible patient-centered care, when and where they need it.

To date, Developmental Services is neither an invited nor recognized expert at OH planning tables and advisory groups, contributing to the healthcare needs of persons with IDD remaining inequitable, and fraught with barriers to care and extremely poor outcomes. Without recognition, engagement, consultation and collaboration at healthcare planning tables and collaboratives, OH is not meeting its mandate with the DS population, failing to consider the needs of persons with IDD.

Persons with IDD must have Equity of Access to:

- Early intervention and treatment;
- Appropriate and AODA-compliant healthcare response, treatment and supports at Emergency Rooms (ER), while in hospital and within primary care;
- Alternate Level of Care (ALC) prevention and timely, person-centred resolution;
- An informed approach to Home and Community Care Support Services;

- Appropriately supported ER experiences, hospital stays and related healthcare services as outlined in the Accessibility for Ontarians with Disabilities Act (AODA);
- Primary Care with an improved understanding of the clinical, social, physical, communication and emotional support needs of persons with IDD.

The DS sector must have:

- Engagement and evidence-based decision-making at Health planning tables regarding health service design to meet the unique and complex needs of the DS population;
- Data-informed and data-supported decision-making;
- Access to data across Health, Developmental Services Ontario (DSO), and MCCSS platforms, with tools and expertise to analyze and understand said data for outcome-focused system planning and collaborative quality improvements across Health and DS sectors;
- OH planning, processes and integrated system infrastructure that mandates the inclusion of the healthcare needs of persons with IDD.

“*Journey to Belonging: Choice and Inclusion*”, the sector transformation initiative announced by MCCSS in 2021 recognizes that current systems do not consistently provide a framework/mechanism that consider, anticipate or plans for people with IDD. Journey to Belonging highlights the need for improved system equity and the Ministry’s role in supporting initiatives to promote health, well-being and safety with improved outcomes.

To support the intent of the anticipated reforms, it is essential that MCCSS both advocate for and facilitate required barrier-free voting DS representation at OH planning tables and collaboratives, including but not limited to Ontario Health Teams. Ontario Health Teams (OHTs) are groups of providers and organizations that are clinically and fiscally accountable for delivering a full and coordinated continuum of care to a defined geographic population. This action will help ensure informed health system planning and the fulfillment of the MCCSS commitment to “act now to plan for the future and look at how to better serve the people who depend on developmental services”¹.

In order to realize this cross-sector commitment to change, two principal recommendations surfaced through the development of this position paper.

Principal Calls to Action

1. Establish a Health/DS inter-ministerial position or entity/secretariat, with authority to embed collaboration between sectors.
2. Mandated barrier-free DS voting representation at all OHTs.

Recognizing that longstanding systems and support models are entrenched in both Health and DS, the Health Strategy and Engagement Working Group, through its sub-committees, has identified key systemic barriers inhibiting change and innovative opportunities where impactful, scalable and sustainable improvements can be achieved.

Following are highlights from each of these sub-committees.

1. Health System Improvements, including but not limited to Primary Care

The Health Systems Improvement sub-committee is working to improve access to, and provision of appropriate healthcare services by identifying systemic issues and barriers and developing evidence-based and experience-based collaborative solutions. Greater access, equity, service quality and outcomes of healthcare for persons with IDD will result.

Sustainable improvements to accessing and delivering effective health services require a deeper understanding by primary care providers, hospitals and other health service providers of the clinical, social, communication and emotional support needs of persons living with IDD. This can only be achieved through an ongoing commitment to Health/DS collaboration and engagement.

SYSTEMIC BARRIERS

- The representation and participation of DS at OHT's across the province is inconsistent, ineffective where DS does not have voting member status, and remains non-existent in many communities. Exclusion from Health planning tables and prohibitive OHT (voting) membership fees, where they exist are significant barriers to effective DS representation and involvement;
- Poor integration of existing clinical practice tools and resources in the eHealth environment to facilitate uptake of Canadian best practice guidelines for the healthcare of adults with IDD;
- Patient-oriented tools require integration with the Electronic Medical Record (EMR) system, i.e. pre-health visit questionnaires. Involvement of e-Health expertise and leadership is key;
- Existing evidence-based IDD resources and tools for use by healthcare providers, planning tables, decision-making and governing entities are not broadly known, supported, disseminated, or maintained;
- Lack of inter-ministerial collaboration in healthcare improvement efforts for persons with IDD;
- Primary care providers lack both awareness and knowledge of the DS system and a clear/identifiable referral path to appropriate DS sector and community supports and services for people with IDD; a coordinated and integrated referral system is absent;
- Instances occur regularly where the unique medical, support or emotional needs of persons with IDD are not accommodated by hospitals (including ERs); this is a conspicuous breach of the rights of persons with disabilities under the Accessibility for Ontarians with Disabilities Act (AODA);
- Data definitions, systems infrastructure and data collection practices are inadequate to inform collaborative Health/DS quality improvements and facilitate cross-sector research and innovation.

Calls to Action

- 1) Reimagine prevention and reduction strategies, processes and pathways to improve health outcomes for persons with IDD.
- 2) Mandated consultation with DS to ensure AODA Healthcare Standards compliance.

- 3) National and international jurisdictional review of systems, best practices and models addressing health access inequities.
- 4) Integrating patient-oriented tools with EMR systems.
- 5) Development and ongoing maintenance of existing evidence-based IDD resources and tools for use by Health.

2. Alternate Levels of Care

The ALC Sub-Committee is working to understand and strategize how the DS sector can become better engaged as a collaborative system partner, to help identify, develop and realize solutions for ALC challenges involving people with IDD.

On March 27, 2023, the Ontario Ombudsman announced an investigation into the “plight of adults with developmental disabilities who are inappropriately housed in hospital due to a lack of supports and services in the community”. This investigation is a follow-up to the 2016 Ombudsman’s Report, Nowhere to Turn, which made five recommendations to improve outcomes for those experiencing ‘inappropriate hospitalization’. Unfortunately, no improvements have been realized in any of the five areas to date.

Though ALC status is an important indicator, it is essential that Health also considers and addresses persons with IDD who are inappropriately placed in Long-Term Care, living in forensic units or inappropriately housed/stranded in long-term mental health programs, particularly as a quick, easy solution to address acute care needs and system pressures. Solutions to the ALC challenge for persons with IDD will naturally translate to opportunities for improvement for these other equally inappropriate placement situations.

Currently, it is estimated that at least 140 people living with IDD are currently in ALC status in hospitals across Ontario. It is understood and accepted that this estimate is understated due to data capture issues at time of hospital intake and systemic challenges with gaining a consolidated provincial view of such data.

Systemic Barriers

- The perception that Health views the current Ombudsman investigation as an MCCSS issue, rather than a systemic problem requiring Health/DS co-ownership and co-leadership;
- Hospital admission processes, forms and systems are complicated and impede the timely capture of data indicating that a person (patient) has, or is suspected of having, an IDD. Thus, hospital intake data and processes are inconsistent and regularly lack the information needed to trigger engagement with or a referral to DS during hospitalization;

- No formalized inter-ministerial committee, position or secretariat exists to identify and address issues that span Health and DS sectors;
- DS engagement with hospitals and OHTs, where it currently exists, is often initiated by DS or else it relies on informal, inconsistent reach outs by health service providers during times of crisis or system pressures (ALC). No formalized, structured, consistent framework exists to ensure that health service providers and planning entities regularly engage with DS;
- Health is not at local DS prioritization placement tables (“Service Solutions” table for adults; “Service Resolution” table for children) to support and inform prioritization efforts for persons with IDD in ALC;
- Limited regional consistencies between OHTs is impacting provincial-scope initiatives; often, a local community of DS organizations may deliver services across multiple OHTs, each having different identified priority populations with inconsistent strategies for delivering a full and coordinated continuum of care – thus creating barriers to standardized processes, systems and communications pathways;
- Limited DS sector capacity and resources available to help Health address the ALC challenge for persons with IDD;
 - The extremely limited pockets of specialized clinical services embedded in the DS sector are key contributors to enabling and supporting successful transitions out of ALC and are underfunded, under-resourced and inconsistent in their availability across communities;
 - The supply/availability of intensive behavioural support resources (treatment and ongoing support) for persons with IDD within the DS sector are scarce, lagging well behind the growing demand for this expertise which is also often required to support successful transitions from ALC;
 - Current DS group home registry/waitlist demand far exceeds capacity across all communities, thus vacant supported/group home living spots are never immediately available to help ease ALC pressures for persons with IDD;
- Human Resource pressures impact both sectors in their capacity to support initiatives;
- MCCSS has not recognized persons with IDD in ALC as a priority, therefore sustained funding, resources and strategic initiatives are not allocated to support the Ministry’s role in addressing the ALC challenge for persons with IDD.

Calls to Action

- 1) Develop ALC best practice guidelines and framework for a designated ALC discharge pathway for persons with IDD.
- 2) Health must be represented at DS priority placement and system planning tables.
- 3) Enable digital information sharing between healthcare, hospitals, DS and related community agencies.
- 4) Annualized funding from MCCSS, Health Ministries and/or Ontario Health must be designated to sustain and grow sector-embedded specialized services in DS.

- 5) Develop systems, processes and pathways to ensure early engagement of DS in ALC situations involving persons with IDD.
- 6) Strengthen tools and systems, formalized process pathways and staff resourcing at provincial DSO's.
- 7) Resource and implement process improvement recommendations gained from the Dual Diagnosis ALC committee.

3. Improving Home and Community Care

The Improving Home and Community Care (HCC) Sub-Committee has been working to identify the best ways to ensure people with IDD have access to and are benefitting from, coordinated community-based health supports which also consider the unique support needs of persons with IDD.

The sub-committee has been focused on the following:

- Identifying impacts due to a lack of service or insufficient and/or inappropriate services;
 - e.g. increased ER visits, higher hospital admissions, morbidity/mortality rates versus a person not living with IDD;
- Misunderstandings about the accountability, role and responsibility for certain supports between Health and MCCSS;
- Potential areas for system collaboration and partnership.

Systemic Barriers

- Financial resources to support service solutions that are making a difference, i.e. DS leads supporting outbreaks, thus minimizing the demand on Public Health. The resulting efficiencies and cost savings in Health are not being used to support and sustain these DS-driven solutions;
- Lack of recognized accountability structure to enforce mandated system changes;
 - i.e. Human Rights case that determined persons with IDD have the right to full access to Home and Community Care (HCC) supports has yet to be fully addressed;
- Health system lack of knowledge and ability to provide home and community supports to persons with IDD to meet their unique support needs, resulting in inappropriate and ineffective health supports leading to poor outcomes for the persons supported;
- No coordinated staff position(s) dedicated to problem-solving and facilitating solutions between Health-funded and DS-funded services;
- Lack of mandated DS representation voting presence at OHT tables impacts the ability to effectively advocate for the health needs of persons with IDD;

- There is no established process or forum in place to inform and educate the DS sector about local, new successful models and established best practices.

Calls to Action

- 1) Increase access and adaptable support models in the delivery of Home and Community Care through a sustained partnership between HCC and DS across all local communities.
- 2) Implement and scale evidence-based best practices that have been developed in local HCC support models.

4. Infection Prevention and Control

The primary focus of the IPAC sub-committee is to ensure the DS sector maintains the evidence-based tools, skills, resources and collaboration with Health needed to manage future infectious disease outbreaks, pandemics and/or related health crises safely and effectively. Collaboration between DS sector-embedded IPAC Champions during the COVID-19 pandemic was critical to informing and supporting MCCSS-funded organizations regarding access to appropriate IPAC supports and education as well as vaccine access which needs to be an ongoing priority

The IPAC sub-committee has been working to:

- Capture the important DS-sector-specific IPAC learnings from the COVID-19 pandemic;
- Examine the DS sector's dynamic response to the COVID-19 vaccination effort, as a key system partner with Health, to learn and share what can be accomplished by such cross-sector collaboration;
- Evaluate and document the DS IPAC training and support model for future use in the sector, recognizing that both the IPAC Hub model and Public Health Ontario lacked an understanding/appreciation for the unique characteristics and needs of the DS sector, which resulted in support, guidance and communication deficits;
- Develop an IPAC training evaluation rubric to be shared broadly across the DS sector to aid DS organizations to choose or develop effective IPAC training programs.

Systemic Barriers

- The vast majority of DS organizations do not have in-house regulated health professionals (such as Nurses, Nurse Practitioners and/or Physicians), thus are ill-equipped to prepare for and respond to complex and/or extended infectious disease events without significant collaboration and reliance on IPAC subject matter experts in Health.
- Limited recognition that the DS sector is supporting people with IDD having increasingly complex/high acuity care profiles often with multiple comorbidities – all of which greatly elevate the risk of serious illness, hospitalization or death during infectious disease events in congregate living settings.

- Lack of coordination, collaboration and accountability between Health Ministries, Ontario Health, Public Health Ontario and MCCSS to ensure the DS sector's IPAC preparedness and response strategies keep pace with the ever-changing infectious disease environment. The focus should not solely consider who will fund the model.

Calls to Action

- 1) Commit to annualized funding to support and sustain ongoing IPAC expertise and best practice within the DS sector.
- 2) The IPAC Champion model for MCCSS-funded organizations must be reinstated, developed and sustained through annualized funding.
- 3) Quality Assurance Measures framework must be updated to incorporate mandatory IPAC standards, education and training with regional supports.

5. Data Improvements

Quality data (timely, dynamic, accurate, complete and relevant) is widely recognized as critical and foundational to driving evidence-informed decision-making, proactive quality service provision and improved outcomes while at the same time gaining efficiencies and maximizing the utilization of scarce resources. Quality data and the systems to support it are essential for continuous quality improvement efforts resulting in systemic sustainable change.

Health and DS demonstrated the capacity and commitment to work together during the COVID-19 pandemic to address and resolve system issues. With the right supports, investments and accountability structure, this effective cross-sector collaboration can be leveraged to continue meaningful change and improvement.

The Data Improvement Sub-Committee, recognizing this importance, has been working to:

- Identify and understand the data needs within the DS sector;
- Determine how to best capture and collect quality data to support collaborative efforts between Health and DS;
- Understand how to access and interpret available Health data (and data needs where gaps exist) to help inform and support sector efforts to ensure the best health outcomes for people with IDD, including but not limited to associated challenges with:
 - inappropriate placement in ALC beds, long-term care homes, forensic units or long-term mental health programs;
 - frequent/chronic users of the healthcare system (ER visits, hospital admissions, hospital readmissions);
 - effectiveness of home and community care supports;
 - coordinated care planning where multiple comorbidities exist;

- not having a primary care provider;
- and more...
- Understand the breadth and scope of supports required for persons living with IDD who may also have significant medical, behavioural and/or mental health complexities;
- Understand and align the collection and use of standardized data across all local DS prioritization placement tables (Service Solutions for adults, Service Resolution for children).

Systemic Barriers

- Legislation, funding, political will, and available expertise all impact the capacity to identify the means to effectively share data between Health and DS;
- Each local DS prioritization placement table has a different approach to the collection, management, and use of data and this impacts their ability to share, interpret and prioritize data effectively, also impacting the ability to roll up to a provincial view;
- The province's Developmental Services Consolidated Information System (DSCIS), utilized by the DSOs for client data management (including registries/waitlists) is difficult to use, difficult to extract data and reports from, with data quality being dependent on the ability of staff at DSO's and DS organizations being able to understand, navigate and update the system. Data reports from DSCIS could greatly inform DS sector planning efforts (at the MCCSS level and at the DS organization level) however access and reporting limitations are barriers for such use;
- Government change usually results in reforms that halt strategic initiatives, investments in systems and processes, and quality improvement projects;
- Lack of accountability in systems to ensure recommendations and change are undertaken;
- Lack of resources, resulting in engaged parties completing project work 'off the sides of their desks';
- Loss of hope due to the Health and DS sectors being in constant crisis with extremely limited capacity to support system change - will data really help make a difference for the DS sector when it appears no one is listening?
- There is a lot of DS data already available through administrative healthcare, yet the DS sector is unable to access it;
- Limited representation at the OHTs to:
 - ensure DS data gets included and considered in the Health data analysis and reporting used for planning and decision-making;
 - ensure that DS expertise is engaged to be part of systems planning and problem-solving.

Calls to Action

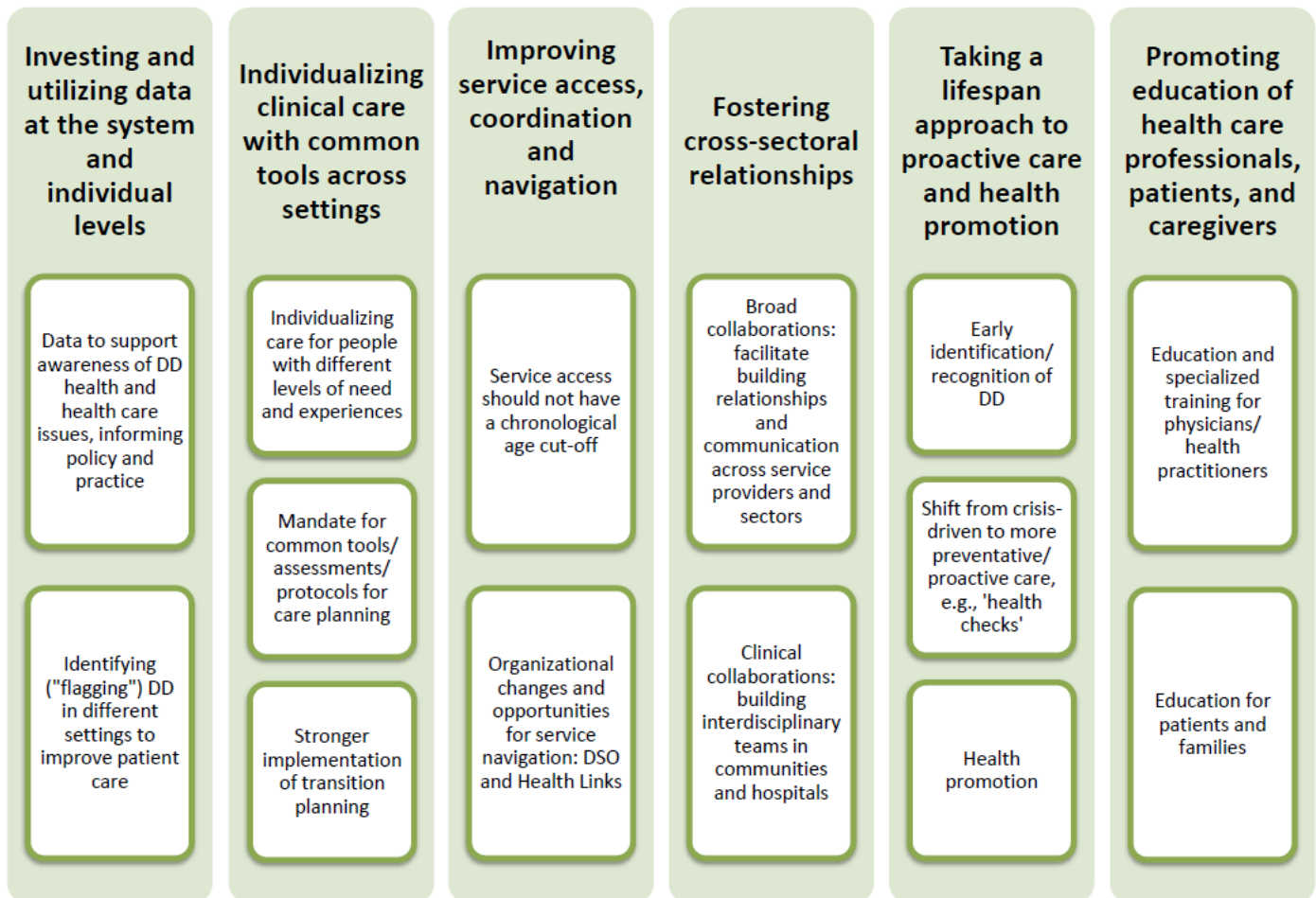
- 1) Develop standards of care for persons with IDD and define key quality indicators.
- 2) Dedicated annualized funding to facilitate data quality improvement and remove barriers to access.

- 3) Governmental commitment of resources and mandate to establish data-driven, evidence-based processes and solutions.
- 4) Fully enact the six recommendations from the 2016 paper “Summary of Proceedings: Making the Invisible Visible”.

Additional observations with regard to Data Improvement opportunities:

The paper “Summary of Proceedings: Making the Invisible Visible | H-CARDD Provincial Meeting, February 23, 2016” highlights six impactful areas of improvement to build on, which had strong agreement across stakeholders. It cannot go unnoticed that many of the opportunities identified in 2016 remain unaddressed and are aligned with many of the Calls to Action contained herein.

From the 2016 paper:



APPENDIX I – Calls to Action - Details

Principal - Calls to Action

- 1) **Establish a Health/DS inter-ministerial position or entity/secretariat, with authority to embed collaboration between sectors.**
 - Establish a dedicated, shared, and resourced inter-ministerial position or entity/secretariate to facilitate discussion, problem-solving, decisions, and accountability between MOH and MCCSS. Past precedent supports this model.
- 2) **Mandated barrier-free DS voting representation at all Ontario Health Teams.**
 - OHT's must be mandated to engage DS organizations as voting members, exempt from membership fees to ensure that persons with IDD are included in all aspects of OHT planning, decision-making, collaborative quality improvement plans and cross-sector system coordination to bolster health equity and remove barriers for persons with IDD; creating opportunities for improvements in areas such as. ALC pressures, ER volumes, hospital readmissions, improved health outcomes for priority populations and more for persons with IDD.

1. Health System Improvements – Calls to Action

- 1) **Reimagine prevention and reduction strategies, processes and pathways to improve health outcomes for persons with IDD.**
 - IDD-specific acute care health system improvements will yield improved health outcomes for persons living with IDD, and contribute to efficiencies in areas such as prevention/reduction of ER visits, prevention/reduction of hospital admissions, minimization of readmissions, ALC prevention, reduction of ALC stays, avoidance hospital-acquired conditions, and more. Reimagining processes and pathways for such inefficiencies will offset investments in IDD-specific improvement investments.
- 2) **Mandated consultation with DS to ensure AODA Healthcare Standards compliance.**
 - As hospitals and primary care providers work towards ensuring compliance with AODA Healthcare Standards (to be in effect by 2025), there must be a mandated requirement to consult with leaders in DS and utilize IDD information resources available to support improved health equity and access for persons living with IDD.
- 3) **National and international jurisdictional review of systems, best practices and models addressing health access inequities.**
 - An in-depth review of systems, practices, and models already in place in the Yukon and the National Health Service (UK) that address health access inequities for persons with IDD and have proven effective in practice change; take action to develop and implement local and provincial quality improvement transformation initiatives based on these evidence-based learnings to improve health access inequities for persons with IDD in Ontario.
- 4) **Integrating patient-oriented tools with EMR systems.**
 - Health to invest in integrating patient-oriented tools with Electronic Medical Record (EMR) systems, with key involvement of e-Health expertise and leadership. Recent examples have been experienced with the Developmental Disability Primary Care Program at Surrey Place.
- 5) **Development and ongoing maintenance of existing evidence-based IDD resources and tools for use by Health.**

- Inter-ministerial cooperation and commitment to support and enable further development and ongoing maintenance of existing evidence-based IDD resources and tools for use by healthcare providers, planning tables, decision-making and governing entities, including health system distribution, dissemination and training protocols.

2. Alternate Level of Care – Calls to Action

- 1) Develop ALC best practice guidelines and framework for a designated ALC discharge pathway for persons with IDD.**
 - A collaboration between MCCSS, Health Ministries, OH and Home and Community Care (HCC) is needed to develop ALC best practice guidelines and framework for a designated ALC discharge pathway for persons with IDD. This will produce informed system planning, an established and comprehensive process to address this contributor to ALC pressures, expedite the alleviation of inappropriate ALC/hospitalizations of persons with IDD, and ensure a person-centred approach in supporting transitions for persons within this very vulnerable population.
- 2) Health must be represented at DS prioritization placement tables and system planning tables.**
 - Health must be engaged at local DS prioritization placement tables (Service Solutions for adults; Service Resolution for children) and local system planning tables to support and inform prioritization efforts and system planning for persons with IDD in ALC.
- 3) Enable digital information sharing between healthcare, hospitals and DS and related community agencies.**
 - There must be technological capacity and infrastructure developed to support information sharing between healthcare/hospitals and DS and related community agencies.
- 4) Annualized funding from MCCSS, Health Ministries and/or Ontario Health must be designated to sustain and grow sector-embedded specialized services in DS..**
 - Annualized funding from MCCSS, Health Ministries and/or Ontario Health must be designated to sustain and grow sector-embedded specialized services in DS, enabling access to a range of specialized behavioural, clinical, health and medical services to people with IDD, which is especially important in supporting discharge from ALC. DS sector-embedded clinicians are skilled in developing and adapting strategies, assessments and interventions, allowing for the integration of behavioural and biopsychosocial approaches when working with a range of functional abilities and disabilities.
- 5) Develop systems, processes and pathways to ensure early engagement of DS in ALC situations involving persons with IDD.**
 - Systems, processes and pathways must be developed in Health to ensure early engagement of DS in ALC situations involving persons with IDD to enable the provision of DS wrap-around supports while in hospital, and to commence the collaborative, cross-sector planning process as early as possible recognizing the resource limitations and waitlist pressures in the DS sector.
- 6) Strengthen tools and systems, formalized process pathways and staff resourcing at provincial DSO's.**
 - Provincial DSO staff already have some cross-sector system knowledge experience, and relationships through their current involvement with identification of, and responding to ALC situations; strengthened tools and systems, formalized process pathways and staff resourcing would better position the effectiveness of DSOs in this capacity.
- 7) Resource and implement process improvement recommendations gained from the Dual Diagnosis ALC committee.**

- Recommendations are currently under development by the Dual Diagnosis ALC committee calling for systemic changes to better support and improve outcomes for persons living with dual diagnosis who may be inappropriately housed in hospital (ALC); these recommendations must be prioritized, resourced and acted upon by MOH and MCCSS once released.

3. Improving Home and Care – Calls to Action

- 1) **Increase access and adaptable support models in the delivery of Home and Community Care through a sustained partnership between HCC and DS across all local communities.**
 - Increased access and adaptable support models in the delivery of HCC given its centralized resource model through OH can be achieved for people with IDD through an established partnership between HCC and DS across all local communities. The partnership must include a team-based approach having HCC Care Coordinators and hospital discharge planners who have strong collaborative relationships with local DS providers having expertise in the unique support needs of persons with IDD. Such strategic partnerships result in significantly improved health outcomes for those living in community, whether at home with family or in a supported / inclusive living environment provided by the DS sector, while also creating HCC and healthcare system efficiencies and impacts, greatly reducing the likelihood of hospital re-admission or return ER visits.
- 2) **Implement and scale evidence-based best practices which have been developed in local HCC support models.**
 - Dr. Karima Velji, Chief of Nursing & Professional Practice; ADM, Ministry of Health, is speaking across the province about 'Team Based' care models, including Home and Community Care and is seeking scalable pilot projects that can be adopted in other areas of the province. Health and DS must commit to and invest in models, as previously mentioned, that can be scaled up to realize desired system improvements to healthcare access and equity for persons with IDD and to address ALC pressures.

4. Infection Prevention and Control – Calls to Action

- 1) **Commit to annualized funding to support and sustain ongoing IPAC expertise and best practice within the DS sector.**
 - Building on the skills, experience, tools, and resources that have been developed in the DS sector out of necessity during the COVID-19 pandemic, government must commit to annualized funding to support and sustain ongoing IPAC expertise and best practice within the DS sector to keep people with IDD out of hospital during significant infectious disease events.
- 2) **The IPAC Champion model for MCCSS-funded organizations must be reinstated, developed and sustained through annualized funding.**
 - The IPAC Champion model for MCCSS-funded organizations must be reinstated, developed and sustained through annualized funding, to equip and enable dynamic local sector-specific expertise, resources and responsiveness. Reinstated, annualized funding for IPAC Champion organizations should include a specific allocation to support sector-embedded regulated health professional role(s) to provide the necessary subject matter expertise at the local level.
- 3) **Quality Assurance Measures framework must be updated to incorporate mandatory IPAC standards, education and training with regional supports.**

- The Quality Assurance Measures framework must be updated to incorporate IPAC mandatory standards in DS and advance provincial and regional supports to sustain and elevate operational IPAC training, preparedness and practices, ensuring alignment with international best practices in community-based settings. Annualized funding and other resources to be assigned to support and sustain DS organizations to remain in compliance with such IPAC requirements

5. Data Improvements – Calls to Action

- 1) Develop standards of care for persons with IDD and define key quality indicators**
 - The Developmental Disabilities Primary Care Program (DDPCP), in collaboration with HCARDD and the College of Physicians and Surgeons of Ontario (CPSO), is prepared to collaborate with Health Quality Ontario to develop standards of care and define key quality indicators. This will support the collection and tracking of meaningful, sector-specific, data. Such a collaboration will require both financial resources and time to develop these resources
- 2) Dedicated annualized funding to facilitate data quality improvement and remove barriers to access.**
 - Cross-sectoral dedicated annualized funding to facilitate data quality improvement, and remove barriers to access to timely, accurate and consistent Health Data will enable scalability, implementation and sustainability of critical tools and systems.
- 3) Governmental commitment of resources and mandate to establish data-driven, evidence-based processes and solutions.**
 - Governmental commitment of resources and mandate to establish data-driven, evidence-based processes and solutions to enable dynamic cross-sectoral decision-making analytics, driving positive change for improved access, quality of service delivery and seamless transitions for people with IDD when accessing health supports throughout the healthcare system.
- 4) Fully enact the six recommendations from the 2016 paper “Summary of Proceedings: Making the Invisible Visible”.**
 - Governmental cross-sector collaboration to fully enact the six recommendations from the 2016 paper “Summary of Proceedings: Making the Invisible Visible”, as referenced below.

APPENDIX II – Supplementary Information

More about: Journey to Belonging

DS sector Transfer Payment Agencies (TPAs) are committed to supporting the success of the Journey to Belonging transformation initiative which clearly establishes a commitment and strategy to improve and promote health, well-being and safety outcomes for people with IDD. Strategic and collaborative partnerships between the DS and Health sectors are critical to the transformation journey's success, following guiding principles:

- **Solutions put people first** – effective planning supports early intervention and improved equity when accessing services across sectors
- **Improving the Service Experience** – modernizing the system to simplify processes that have become systemic barriers, adopting best practices and innovations, and improving digital systems
- **Improving Quality and Accountability** – measurable and demonstrated improvements, structure enabling streamlined and informed cross-sector service improvements
- **2024 Goal** – sector aligned with MCCSS' commitment to implementing evidence-based solutions and testing new, informed, approaches

To learn more about “Journey to Belonging: Choice and Inclusion” visit: www.ontario.ca/page/journey-belonging-choice-and-inclusion

More about: Recent Successful Cross-Sectoral Collaboration

DS sector leaders are committed to undertaking initiatives to find solutions that put people with IDD first. Following are a select few of many successful collaborations and solutions that led to improved health outcomes for persons with IDD. Successful initiatives such as these may be scaled, expanded and diversified to realize greater impacts province-wide.

- a) **Emerging COVID-19 Pandemic DS/Health Collaborations:** During COVID, formal cross-sector collaboration and relationships between DS and MCCSS with Ontario Health, Public Health, Ontario Health Teams and Hospitals identified and achieved new processes and best practices, enhanced DS sector engagement and introduced IPAC strategies, best practices and mobilized innovative immunization rollouts resulting in the prevention of hospitalizations and death.
- b) **Data Access and Simplifying Systems:** The DS sector, through Health Care Access Research and Developmental Disabilities (H-CARDD), has evidence-based tools and processes to help maximize efficiencies and effectiveness when accessing health services. Skilled and experienced data leaders are already in the DS sector to inform and support this initiative.
- c) **Alternate Level of Care:** The unique complexities involved when considering each person with IDD stranded in ALC are not fully understood nor addressed when solely supported by Health. There are examples of local communities having identified processes for early identification, collaborative discharge planning, appropriate and timely wrap-around supports while in ALC,

and successful DS sector and community-based support models that result in successful outcomes for persons with IDD, while at the same time alleviating ALC pressures in the healthcare system. The learnings to be gained by examining these models align with Health's focus on seeking opportunities to scale up and systematize pilot projects reporting improved outcomes and will spur the development of innovative new solutions and discharge pathways across sectors, ensuring people with IDD are receiving appropriate end-to-end health and related supports, how, when and where needed.

More about: Tools and resources developed by DS for use by Health to improve the healthcare experience for persons with IDD

OH, OHTs and other healthcare planning and decision-making entities to actively promote and reference the use of evidence-based clinical guidelines and practice tools for primary care of adults with IDD, developed by DS organizations such as Surrey Place (Developmental Disabilities Primary Care Program) and others to all healthcare service providers and primary care supports. The guidelines, developed in collaboration with the College of Family Physicians Canada, are the core of practice improvement in primary care. In fact, the guidelines are also the core of data improvement, only if a standard exists that can be measured to assess if recommended care is being provided or not to persons with IDD.

The 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities outline standards of care to support clinical decision-making. These guidelines are developed by family physicians, nurses, psychiatrists and other experts who are experienced in the care of people with IDD. An accompanying suite of clinical practice tools facilitates the uptake of the guidelines, resulting in improved health coordination, better healthcare experiences, and outcomes for persons with IDD. A key recommendation in the guidelines is a periodic comprehensive health assessment for adults with IDD (IDD Health Check), an evidence-based intervention which improves early disease detection and preventive care maneuvers in adults with IDD.

More about: Guidelines for Supporting Adults with a Developmental Disability when Applying to, Moving into and Residing in a Long-Term Care Home.

Recognizing that possible placement in long-term care for people with IDD requires collaboration and engagement, specific support considerations and other factors which may and should influence the decision, transition planning and eventual care planning. It is equally important to acknowledge that placement in long-term care for people with IDD is often not appropriate nor in the best interests of the person. Through partnership forged between MCCSS, the Ministry of Long-Term Care (MLTC), the Ministry of Health (MOH), OH and Home and Community Care (HCC) a comprehensive guide was developed and recently updated: "Guidelines for supporting adults with a developmental disability when applying to, moving into and residing in a long-term care home" to inform and highlight these unique considerations, following an integrated approach that endeavours to put people with IDD first. Subject

matter experts in DS continue to have concerns stemming from the November 2022 release of updates to this guideline, including:

- Distribution of the guideline was fragmented in its timeliness and inclusion of all key relevant stakeholders (MCCSS, MOH, MLTC and HCC, as well as DS, Health and Long-Term Care service providers);
- The 40-page guideline is long and unwieldy; it was distributed without providing an education/refresh opportunity (webinar) for users to understand the content and changes from the previous version; and no “plain language” or overview synopsis was provided to encourage its use;
- As a result of the above, the guideline is not well known nor understood;
- The guideline does not speak to what alternatives may be available to LTC placement;
- The guideline includes the following statement, which is counterintuitive to helping to resolve such ALC situations involving persons with IDD:

“There is no additional or enhanced prioritization for MCCSS-funded services and supports under SIPDDA for ALC-designated patients in hospital. Situations involving an ALC-designated patient in hospital for whom an application for determination of eligibility is being completed would not be deemed an urgent response situation. Existing MCCSS requirements and processes relating to urgent response remain unchanged.”

Despite the shortfalls of the aforementioned guideline, its existence demonstrates progress and a cross-sectoral commitment to continuous quality improvement.

To learn more about this guideline, please visit: www.ontario.ca/page/guidelines-supporting-adults-developmental-disability-when-applying-moving-and-residing-long-term-care-home

More about: **Expanding on Principal Call to Action #1**

Establish a Health/DS inter-ministerial position or entity/secretariat, with authority to embed collaboration between sectors.

Similar to the MCCSS and MLTC collaboration, a dedicated, shared, and resourced inter-ministerial position or entity/secretariat must be established, responsible for facilitating discussion, problem-solving, decision-making, and establishing an accountability framework between MCCSS, Health Ministries and Ontario Health.

This Call to Action envisions the inter-ministerial position or entity/secretariate being tasked with and accountable for:

- Enabling effective communication and collaboration between Health Ministries, Ontario Health and MCCSS;
- Being a positive disruptor to implement fundamental strategic change at the system-wide level;

- Developing joint guidelines to support organizations across different sectors to implement best practices;
- Establishing an accountability framework for implementing established guidelines, policies, legislation, tools, and resources;
- Prioritizing common, interdependent priorities between Health Ministries, Ontario Health and MCCSS;
- Understand and align the collection and use of data across both sectors;
- Measure, assess and evaluate impacts and outcomes of Health Ministries, Ontario Health and MCCSS shared strategic improvement initiatives;
- Advance a focus on health equity and inclusion for persons with IDD;
- A timely and immediate need in this area is the establishment of guiding principles for planning and supporting the transition of people with IDD from ALC to community currently from the learnings experienced within the Dual Diagnosis ALC (DD-ALC) pilot project;
 - The inter-ministerial entity will also apply learnings from addressing the ALC challenge for persons with IDD to inappropriately placed individuals in Long-Term Care, living in forensic units or inappropriately housed/stranded in long-term mental health programs;
 - Such guiding principles once developed will require targeted support and resources to fully implement and seek opportunities for synergies, scalability and broad application for other ALC challenges involving persons with IDD.

APPENDIX III – References & Resources

Provincial Network on Developmental Services

The PNDS is a forum for key developmental service groups and organizations who collaborate to help address current and emerging challenges that impact persons with IDD across Ontario.

Other References & Resources

- Ontario Health Business Plan 2022 – 2023
- Ontario Health Strategic Priorities
- *Journey to Belonging: Choice and Inclusion*, MCCSS, 2021
- *Accessibility for Ontarians with Disabilities Act (AODA)*
- *Nowhere to Turn, Ontario Ombudsman's Report, 2016*
- Surrey Place Developmental Disabilities Primary Care Program Guidelines
- Provincial Network on Developmental Services
- Specialized Clinical Developmental Services Network (SCDSN - formerly, Great Lakes Society for Developmental Services of Ontario)
- *Summary of Proceedings: Making the Invisible Visible | H-CARDD Provincial Meeting, February 23, 2016*
- *Infection prevention and control for diverse vulnerable populations: From an emergency response to the COVID-19 pandemic to sustainable improvement*, Bisailon et al., 2023
- *Reimagining Specialized Developmental Services in Ontario*, Great Lakes Society on Developmental Services of Ontario, 2021
- Strategic plans and membership lists of various Ontario Health Teams as of September 2023
- *Improving Homecare and Community Services for Individuals with Intellectual Disabilities and Complex Care Needs*, Complex Needs Working Group, 2017
- Healthcare Access Research and Developmental Disabilities (H-CARDD)
- Institute for Clinical Evaluative Sciences (CES), DS News Release, 2019
- www.ontariohealth.ca/sites/ontariohealth/files/2022-05/OHBusinessPlan22_23.pdf
- www.ontariohealth.ca/about-us/governance-accountability/strategic-priorities-business-plan
- www.ontario.ca/page/journey-belonging-choice-and-inclusion
- www.aoda.ca
- www.ombudsman.on.ca/resources/reports,-cases-and-submissions/reports-on-investigations/2016/nowhere-to-turn
- www.ddprimarycare.surreyplace.ca/guidelines/
- www.provincialnetwork.ca
- www.scdsn.org
- www.porticonetwork.ca/documents/38160/99698/Provincial+Meeting+Report/5b4d97ed-301d-447c-a58f-8121e4ff36d0