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BCCEO SOCIAL SERVICE LEADERSHIP NETWORK

Position Statement

Access to Health and Coordination of Care for Adults with Intellectual and Developmental Disabilities

Technical Version

Adopted February 2024

All people should have equitable access to quality health care to meet their primary, acute, and palliative care needs. Governments, funders, and health care providers must take all the right measures to provide health care and other disability-related supports to improve quality of life. The measures should also provide coordination of care between health and disability-related supports.

Access to health care should exist in a continuum of care across ages. For the purpose of this position statement, we are highlighting the specific healthcare needs and calls to action for adults with intellectual and developmental disabilities.

Our position statement strives to challenge racist, ableist, ageist, and colonial views about people with intellectual and developmental disabilities. Our goal is to promote the inclusion of all members of the community regardless of income, ethnicity, background, culture, gender identity and expression, sexuality, and disability.

We recognize and support the inherent Indigenous rights and titles throughout the province of British Columbia, the implementation of the UN Declaration on the Rights of Indigenous Peoples, the 94 Calls to Action by the Truth and Reconciliation Commission, and the B.C. Declaration on the Rights of Indigenous Peoples Act

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Background

Rights of people with intellectual and developmental disabilities

In the 1990s, in response to the number of people with intellectual and developmental disabilities and complex healthcare needs leaving BC's large institutions, the province introduced Health Services for Community Living including nursing support and other allied healthcare professionals (e.g. Occupational Therapists, Physiotherapists, Nutritionists, Dental Hygienists, etc.). These services provide direct supports, such as nursing and rehabilitative consultation, that allow people to have their health-related needs met in their community. In addition to supports provided by Health Services for Community Living (HSCL), contracted nursing services were used to provide 24-hour support when access to nursing oversight and judgment was required outside of business hours worked by HSCL nurses.

In addition to the community-based services, prior to 2017, there were two provincial roles that provided key functions for safeguarding people with intellectual and developmental disabilities. These roles were filled by healthcare professionals with expertise and experience related to developmental disability and health care. There was a Medical Consultant who was a physician with specialized knowledge, skill, and experience providing medical treatment and care to adults with developmental disabilities and a Provincial Clinical Consultant for Adults with Developmental Disabilities who was a registered nurse. The services provided by these roles were instrumental in providing leadership and coordination to the medical community. They also provided a bridge between the health care system, people, their families, and community service providers.

During the last 15 years, Health Services for Community Living and contracted nursing supports have eroded, and the Medical Consulting Services were discontinued. In this decline, equitable access and quality health care have become a significant challenge for people with intellectual and developmental disabilities, their families, and community service providers.

Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010. Article 25: Health says that State parties recognize that persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. In its concluding

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observation about Canada's first report,[1] the Committee of the Rights of Persons with Disabilities notes concerns that people with disabilities continue to face physical, financial, and attitudinal barriers in accessing information and healthcare services in our country.

Community Living BC (CLBC) has recognized the barriers people continue to experience. Their strategic direction in the Service Plan for Community Living BC: 2023/24 – 2025/26 refers to the need **to strengthen health care** as one of their four key areas of focus. This Service Plan aligns with the Re-Imagining Community Inclusion Initiative and the 2023 mandate letter from the province.

The Service Plan for the Ministry of Health: 2023/24- 2025/26 refers to the application of an **equity lens** for the design and delivery of health services and programs to embed cultural safety, anti-racism, and equity of Indigenous Peoples, immigrants, racialized groups, **persons with disabilities**, the 2sLGBTQIA+[2] community, and other populations who face systemic barriers.

In 2010, Community Living BC and government partners agreed to the Guidelines for Collaborative Service Delivery for Adults with Development Disability. The purpose of the guidelines is to "provide direction and support to regional providers in the development of policies and processes to meet the needs of adults with developmental disabilities in an **integrated and sustainable manner**." (emphasis added)

To improve access to health care services for people with intellectual and developmental disabilities, Community Living BC and the Ministry of Health co-lead the exploration and implementation of a provincial health leadership initiative and an inter-Ministry table in support of the Re-imagining Community Inclusion Work Plan. Although this collaboration is positive and long overdue, the long-standing and ongoing dispute between Health Authorities and Community Living BC about who is accountable, who is responsible, and who should pay for what continues to leave people without their needs being met for unreasonable periods of time. Jurisdictional issues between the Health Authorities and Community Living BC should not be the barrier or reason to delay access to health care.

[1] Canada submitted its second and third periodic reports on the Convention on the Rights of Persons with Disabilities in August 2022. As of October 2023, the UNCRPD Committee has not issued its observations.
[2] 2SLGBTQIA+ stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, Androgynous and Asexual.

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The importance of ensuring that all adults with an intellectual and developmental disability have equitable access to health care

The issue of lack of equitable access has been well-defined and documented by multiple government-funded engagement processes. It is now time to take meaningful actions. The Purpose of the Ministry of Health states, "*The Ministry of Health has overall responsibility for ensuring that health services meet the needs of all in B.C., through accessible services no matter where you are in the province, and to support timely, high-quality, appropriate, equitable, and cost-effective service delivery.*" For many, this statement remains an aspiration as there has been little to no action, collaboration or investment to ensure accessibility or that people's healthcare needs are met.

The 2023 BC CEO Network Health Information Survey revealed that the number one priority for community organizations is access to a primary care provider for the people they support.

People with intellectual and developmental disabilities have unique, often more complex health needs and a greater presence of co-existing health issues than neuro-typical people. For example, Baumbusch's, et al, research shows that despite having a longer life expectancy than in previous generations, people with intellectual disabilities can have higher rates of co-morbidities and obesity than the general population.[3] It has been the experience of some people that when they arrive at the hospital, the diagnosis of intellectual and developmental disabilities overshadows their acute health issue and can result in delayed treatment, inappropriate treatment, or even no treatment.

Despite knowing the co-existence of health issues and that this population group will double every 20 years, we continue to see fragmented responsibility of healthcare services, lack of coordination, and erosion of nursing services through Health Services for Community Living and contracted nursing providers.

The lack of recognition and understanding of the unique health needs of people with intellectual and developmental disabilities by the healthcare community has left them significantly marginalized. Baumbusch, et al, identified a group of factors that impact the experience of aging adults with intellectual and developmental disabilities when using healthcare services. Their research found "there continues to

[3] Baumbusch, et al (2018), "Using Healthcare Services in the Community," *Journal of Policy and Practice in Intellectual Disabilities*, p.1.

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be a policy and service gap that can create unnecessary and avoidable difficulties in using healthcare services."[4]

Additionally, these challenges can be more pronounced in rural and remote areas of the province. Dr. John Pawlovich, Rural Doctors' UBC Chair in Rural Health accurately explained, "residents of rural, remote and Indigenous communities face much greater healthcare disparities than other residents in BC."

The pursuit of equity in access to healthcare needs must consider the multiple factors that impact the experience of people with intellectual and developmental disabilities.

Gaps in provincial leadership and data collection in health care for people with intellectual and developmental disabilities

The elimination of the two positions and multiple functions of the Provincial Medical Consultant Services[5] marked the end of provincial oversight and leadership with respect to health outcomes for people with intellectual and developmental disabilities in our province. This decision left significant gaps and a lack of an identified area of expertise for people, their families, and the community organizations that provide support.

There is currently no:

- data collection,
- death reviews,
- provincially coordinated education and practice guidance for Health Services for Community Living practitioners or other key health care providers, and
- provincial oversight of health care delivery or accountability for health care policy.

[4] Baumbusch, et al, *op cit*, p. 1.
[5] Provincial Medical Consultation Service Medical Consultant job posting available at: http://medicalstaff.fraserhealth.ca/getattachment/Careers/Strips/Medical-Leadership-Vacancies/Application-Process/Vacancy-Listing/Medical-Consultant-Provincial-Medical-Consultation-Service.pdf.aspx/ as of November 2023.

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Health Authorities report that the electronic health records do not track people who are eligible for Community Living BC services when admitted to acute care. Moreover, professionals working in acute care have limited knowledge of Community Living BC and Health Services for Community Living. The BC Health Care community is not familiar with the 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities. These guidelines identify that "people with intellectual and developmental disabilities often have complex health care needs and factors affecting their health that can vary in kind, manifestation, or severity from others in the community. They require approaches to care and interventions that are adapted to their needs."

The community living sector relies on the Personal Assistance Guidelines to guide their staff on what they can and cannot do regarding health care tasks for the people they support. Another significant gap is that the Ministry of Health promised to update the guidelines. However, without giving an alternative, they have deemed the 2008 Guidelines as outdated. This leaves community organizations without guidelines to direct their unregulated staff and the proper delegation and coordination of healthcare tasks after a person is discharged from the hospital and to support their daily healthcare needs properly.

Impact of uncoordinated initiatives to support people with intellectual and developmental disabilities

There is very little BC-specific research about healthcare outcomes for people eligible for Community Living BC services. Ontario-based research out of Surrey Place found that adults with developmental disabilities experience worse health outcomes than people without a developmental disability[6].

For example:

- More than 3 times more likely to have a repeat hospitalization within 30 days of discharge.
- Nearly 4 times more likely to die before the age of 75.

[6] Lin E, Balogh R, Chung H, et al. (2021), "Looking across health and healthcare outcomes for people with intellectual and developmental disabilities and psychiatric disorders: population-based longitudinal study," *The British Journal of Psychiatry*, 218(1): 51-57.

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- About 6.5 times more likely to remain in the hospital despite being recovered enough to be discharged.

Health Authorities in Ontario are closely monitoring the length of stay and when people spend extra days in the hospital after treatment is no longer needed. The 2023 BC CEO Network Health Information Survey results confirm that the Ontario experience most likely exists in BC. Seventy percent of responding community organizations reported they have had to refuse to bring someone home from a care setting (such as a hospital) because they were unable to support the medical needs in the person's home. In addition, there are limitations to accessing disability-related supports while in the hospital, usually related to contract and funding restrictions.

Even though there are some regional initiatives across the province trying to address the increasingly complex healthcare and support needs of adults, they are not well coordinated. Often, long-standing and systemic issues between the Health Authorities and Community Living BC obstruct productive work and negatively impact service delivery.

The healthcare system does not seem to understand the community living service system and, therefore, can make assumptions about what health services are available for people in their home and community. The pressure on families and service organizations to accept discharge or provide support without adequate health care planning and support (e.g. nursing, etc.) is immense and can result in unsafe care and support.

Access to Health Services for Community Living nursing services and long-term healthcare providers

The population served by Community Living BC has steadily increased and is projected to continue to increase in the future. The demographics of the population served by Community Living BC have also shifted. People are aging, and some of the younger population coming into the system have more complex healthcare needs. According to the 2023 BC CEO Network Health Information Survey, there is an increased demand for Health Services for Community Living and a reduction in service provision in every single health authority in the province.

Despite this growth and the changing needs of people eligible for Community Living BC services, Health Services for Community Living nursing services and other allied

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health care professional supports (e.g. Occupational Therapists, Physiotherapists, Nutritionists, etc.) have not increased.

Many of the services required and referenced in the Guidelines for Collaborative Service Delivery for Adults with Development Disability are not available due to the workload of Health Services for Community Living staff or have been discontinued by individual Health Authorities, including but not limited to:

- screening, assessment, training, referral and planning of support services for ongoing, acute, and complex health issues.
- consultation based upon the development of individual health care plans and specific training of individuals, caregivers, and families.
- consultation with clients, caregivers, families and Community Living BC staff as well as liaise with other professionals as needed to ensure appropriate coordination of health services.
- development by Health Services for Community Living clinicians of specific health care plans consistent with the British Columbia College of Nurses and Midwives (BCCNM) standards of practice.
- coordination of access to specialized support services, including seating, nutrition, and dysphagia, through the relevant interdisciplinary services.

In addition to the erosion in services provided by Health Services for Community Living, access to 24/7 nursing oversight or intervention has also been eroded. Health Services for Community Living is only available during business hours. People with complex health care needs that require nursing oversight or intervention after business hours have traditionally been provided by contracted nursing support agencies (e.g. Vinge & Associates, etc.) or nursing staff hired by the service-providing agency. These services have traditionally been funded by Community Living BC. However, in recent years, Community Living BC has determined that these services are not part of the person's disability-related needs and have consequently reduced, eliminated, or refused to fund new services required. This decision and the mandate conflicts between Community Living BC and Health Authorities are leaving people with complex care needs with significant service gaps and at risk.

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Calls to Action

The provincial government is responsible for improving access to health and coordinating support for people with intellectual and developmental disability and must act immediately to do so.

Maximum Impact Priorities

- Develop and sufficiently fund the development and implementation of a **healthcare strategy** to adequately respond to the health needs of people with intellectual and developmental disabilities, and that includes adequate data collection.
- Allocate an annual targeted amount for recruitment and retention in health to **strengthen the Health Services for Community Living program** to ensure equitable access to community nursing supports and to respond to ongoing population growth.
- Provide **reliable access to primary care** that ensures continuity of health care.
- Create a **provincial oversight structure** to provide leadership to support the implementation of the healthcare strategy and related services.
- Develop **regional health strategies** that respond to the unique needs of rural and remote areas of the province.

Systemic Priorities

- Establish an action plan with provincial targets to attract more medical specialists with expertise in health care related to people with intellectual and developmental disabilities to BC and different areas of the province.
- Establish mechanisms to include people with lived experience in designing and redesigning healthcare services, including using an intersectional lens to account for the multiple factors that could impact a person's life.
- Update and uphold policies, processes, practices, and guidelines to ensure equitable access to healthcare for people with intellectual and developmental disabilities.

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- In the process of reviewing and updating policies and procedures, address the needs of different ages and stages. Including ensuring continuity of access to healthcare for youth as they transition to adult services and the unique needs of aging adults.

People with intellectual and developmental disabilities must have all the support needed to realize their right to health. The UN Convention on the Rights of Persons with Disabilities recognizes that people have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. We need decisive actions to build back and increase the capacity of the healthcare system from a place of abundance.

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