

Position Statement

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

Plain Language Version

Adopted February 2024

Everyone should be able to go to the doctor or the hospital when they're sick and get the help they need. It's important that the government, people who give money, and the doctors and nurses work together to make sure everyone gets the care they need. They should also make sure that people who need extra help because of a disability can get the right support to make their lives better. We need professionals in different areas working together to make sure nobody is left out when it comes to health care.

Everyone, no matter how old they are, should always be able to get the healthcare they need. This position statement highlights the specific healthcare needs and calls to action for adults with intellectual and developmental disabilities.

We want to change racist, ableist and other unfair ideas about people with disabilities. We believe everyone should be included in our community, no matter how much money they have, where they come from, or if they have a disability. We think everyone deserves respect and a chance to be a part of our community.

We support the rights of Indigenous people in British Columbia. We support the rules set by the United Nations and the recommendations of the Truth and Reconciliation Commission. We also support the laws in British Columbia that protect the rights of Indigenous people.

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Background

Rights of people with intellectual and developmental disabilities

In the 1990s, many people with disabilities were being released from big institutions in British Columbia. To help them, the province started two services: [Health Services for Community Living](#) (including nursing support and other healthcare professionals) and Medical Consulting Services (from a doctor and a nurse). These services gave guidance and help to the community. For a long time, they connected doctors, families, and community helpers, making sure everyone got the care they needed.

In the last 15 years, there is less help from Health Services for Community Living, and the Medical Consulting Services stopped. Since then, it has been hard for people, their families, and community helpers to get fair and good healthcare. This has been a big problem.

Canada agreed to follow the United Nations Convention on the Rights of People with Disabilities in 2010. One of these rules, called [Article 25: Health](#), says that people with disabilities have the right to good health, just like everyone else. But a [group](#) that watches over these rules had some worries about Canada. They said that people with disabilities still have a hard time getting information and healthcare. There are problems with how they are treated because of their disability, and it's also difficult for them to afford healthcare.

Community Living BC (CLBC) understands that people still face difficulties. In [CLBC's plan](#) for the next few years, they talk about making healthcare better. This plan fits with [other projects and plans](#) in our province that aim to make our community more inclusive for everyone.

The Ministry of Health has a [plan](#) for the next few years. They want to make sure everyone is treated fairly when they get healthcare. They will look at things like culture, race, and disabilities to make sure healthcare is equitable for everyone, including Indigenous people, immigrants, people of color, people with disabilities, and the 2SLGBTQIA⁺ community. They want to break down the barriers these groups face.

¹ 2SLGBTQIA+ means Two-Spirit Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual. The “+” stands for all other identities not included in the acronym.

Community Living BC and the Ministry of Health created [guidelines](#) for working together to make sure adults with developmental disabilities can get better healthcare. They are planning and putting new ideas into action. Although these organizations working together is good and should have happened earlier, there are still disagreements between Health Authorities and Community Living BC. They can't agree on who is in charge and who should pay for things. Because of this, people have to wait for a long time to get the help they need. These arguments shouldn't stop people from getting the healthcare they deserve.

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

The problem of not having fair access to healthcare has been talked about a lot by the government. They've studied it and written about it, but it's time to do something real about it. The [Ministry of Health's purpose](#) is to make sure everyone in British Columbia can get good healthcare no matter where they are. But for many people, this is just words because there hasn't been enough action or cooperation to actually make healthcare accessible for everyone. People's healthcare needs are not being met, and there hasn't been enough effort or money put into fixing this problem.

In a survey done in 2023 by the BC CEO Network, community organizations in British Columbia said their top priority is making sure the people they help can see a family doctor for their healthcare needs.

People with intellectual and developmental disabilities often have more complicated health problems and can be dealing with multiple health issues at the same time. Studies have shown that even though people with intellectual and developmental disabilities might now live longer than before, they tend to have more health problems than the general population. Some people have shared that when they go to the hospital, the doctors sometimes focus too much on their disabilities and not enough on their immediate health problem. This can lead to **getting the wrong treatment**, delays in getting the right treatment, or in some cases, not getting treated at all.

Even though we are aware that people with disabilities often have multiple health problems, and there are more people with disabilities, we still face problems. The responsibility for their healthcare is divided and not well organized. There is a lack of

communication between different services, and the help from nurses, which is important for their health, is decreasing. This makes it hard for people to get the care they need in their communities.

People with intellectual and developmental disabilities often face challenges because their health needs aren't well understood. Researchers in a study from 2018 showed that there are gaps in rules and services that make it hard for adults with intellectual disabilities to use healthcare services without unnecessary complications.

In small towns or Indigenous communities, it can be even harder to get medical help. A doctor named [Dr. John Pawlovich](#) said that people in these areas have more problems getting the healthcare they need compared to people in cities.

To make sure everyone gets fair access to healthcare, we need to think about all the different things that affect people with disabilities. We have to consider all the challenges they face to make sure they can get the healthcare they need.

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

When the two positions and functions of the [Provincial Medical Consultant Services](#) were stopped, the province lost its ability to watch over and guide the health of people with intellectual and developmental disabilities. This decision created big problems for people, their families, and the community groups helping them.

Right now, there is no one in charge of:

- collecting important health information and data,
- reviewing deaths to understand what happened and how it can be prevented,
- organizing education and practice guidance for healthcare professionals who work with people with intellectual and developmental disabilities, and
- supervision of healthcare services and making sure that health care rules are followed across the province.

The electronic health records in British Columbia don't keep track of people who should be able to get help from Community Living BC when they go to the hospital. Also, the hospitals don't know enough about Community Living BC and Health Services for Community Living. Even the important [guidelines](#) made in 2018 for adults with intellectual and developmental disabilities aren't well known in the BC healthcare system.

Because there isn't enough data collection or someone making sure things are done right across the province, people with disabilities across of British Columbia often face serious challenges when trying to get healthcare.

Community organizations use the [Personal Assistance Guidelines](#) to know how to help the people they support with healthcare tasks. The Ministry of Health said they would update these guidelines. But instead, they called the 2008 Guidelines outdated and said they shouldn't be used, but the Ministry of Health hasn't provided new ones. This means community organizations don't have the right instructions and information to create healthcare plans or to handle healthcare tasks when someone leaves the hospital or for their daily needs.

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

When initiatives aren't coordinated, it means different groups and programs are not working in sync. This lack of organization can make it harder for people with complex health needs to get the right support. It leads to confusion, inefficiency, and often results in people not getting the help they truly require.

There isn't much research specific to British Columbia about the healthcare outcomes of people who get Community Living BC services. However, [research from Ontario](#), conducted by Surrey Place, shows that adults with developmental disabilities there have worse health outcomes compared to those without disabilities.

For example:

- They are more than three times likely to be readmitted to the hospital within 30 days after being discharged.
- They are almost four times more likely to die before the age of 75.

- They are about 6.5 times more likely to stay in the hospital even after they are well enough to leave.

In Ontario, they are keeping a close eye on how long people stay in the hospital even after they are feeling better. A 2023 survey by the BC CEO Network shows that a similar situation is happening here in British Columbia. Many community organizations say that they've had to refuse to bring someone home from the hospital because they were not able to give them the right care at home. Plus, there are rules that make it hard to get the help people need while they're in the hospital because of contract issues and lack of funding.

In our province, there are some regional projects to help with the complex healthcare and support needs of adults, but these projects are disconnected from one another. There are problems between the Health Authorities and Community Living BC. These problems have been there for a long time and are making it hard for the plans to be effective to help people.

The people who decide about healthcare don't always understand how community living services work. They might think there are more services available for people at their homes than there actually are. This puts a lot of pressure on families and service providers to provide care without proper planning, which puts people at risk.

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

The number of people that need services funded by Community Living BC keeps growing and their characteristics are also changing. People are getting older and some of the younger adults have more complex healthcare needs. The 2023 BC CEO Network survey showed more people need Health Services for Community Living and less services are available in every health authority in the province. The number of nurses and other healthcare professionals like Occupational Therapists, Physiotherapists, and Nutritionists has not increased. So, even though more people need care, there aren't enough healthcare professionals and medical specialists to help them.

Many services for adults that are mentioned in the [Guidelines for Collaborative Service Delivery for Adults with Developmental Disabilities](#) are not available. Some

reasons are because staff are asked to do more than what they can do, or the individual Health Authorities decided to stop providing some services, for example:

- screening, assessment, training, referral and planning of support services for ongoing health issues.
- planning and training with people, caregivers, families and Community Living BC staff as well as connecting with other professionals as needed to ensure good coordination of health services.
- development by Health Services for Community Living clinicians of specific health care plans that match with the British Columbia College of Nurses and Midwives (BCCNM) standards of practice.
- coordination of access to specialized support services.

There are too many people who need services from Health Services for Community Living but not enough people to help them. People who need nursing help all the time used to get it, even after normal working hours. But recently, Community Living BC has said these extra nursing services are not part of a person's disability-related needs and should be paid for by the Health Authorities. This means many people are not getting the help they need, putting them in danger. Community Living BC and Health Authorities are disagreeing on what services are essential or who should provide them, causing confusion and leaving people at risk.

Calls to Action

It is the job of the provincial government to improve access to health and coordinating support for people with intellectual and developmental disabilities 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.
- 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 should get all the help they need to stay healthy. It is their right. We need strong and clear actions to make our healthcare system better and make sure we have enough resources to support everyone.