

INCLUSIVE POLICY-MAKING FOR PEOPLE WITH INTELLECTUAL DISABILITIES

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CHAMPIONS FOR INCLUSIVE HEALTH STAKEHOLDER COALITION

Eliminating Health Disparities Faced by B.C. Individuals with Intellectual Disabilities

Initiated by

**Special
Olympics**
British Columbia



INCLUSIVE POLICY-MAKING FOR PEOPLE WITH INTELLECTUAL DISABILITIES

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INCLUSIVE POLICY-MAKING FOR PEOPLE WITH INTELLECTUAL DISABILITIES

INTRODUCTION

WHY

Despite the benefits of inclusive policy-making, people with intellectual disabilities remain largely excluded from policy discussions and face needless barriers to self-determination.

The following guide introduces the core themes and components of inclusive policy-making, and is designed to help you through the process. This guide can be used at any stage of the process, regardless of whether the policy is directly concerned with disability, and each section can be used as applicable. It is designed for individuals or organizations responsible for policy development, implementation, and evaluation, as well as for self-advocates seeking to participate in policy-making processes.

WHAT

At its core, inclusive policy-making involves:

1. Engaging individuals with intellectual disabilities, their networks, and communities at EVERY stage of the policy-making process, and
2. Actively considering the needs of individuals with intellectual disabilities, their supporters, and service providers during the development of ALL policies.

HOW

Universal Design: The design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. This can be achieved by incorporating user-driven design principles into the policy such as inclusive language materials.

Supported Decision Making: Involves identifying and providing support to help a person with a disability understand, make, and communicate their own preferences. Historically, most policies concerning people with intellectual disabilities implemented a substitute decision-making model, where an expert made decisions perceived to be in the person's best interest.

Inclusivity: Be as inclusive as possible, with concerns of people with intellectual disabilities considered alongside the concerns of others, not in separate programs. Due to the cross-cutting nature of intellectual disabilities, these considerations should extend to all levels and sectors of policy.

NOTHING ABOUT US WITHOUT US

No policy should be developed without the direct and full participation of those it most affects. People with intellectual disabilities should be involved in all stages of the process, including the design, implementation, and evaluation stages, and not simply engaged to offer feedback on draft or existing policies.

Every community is different so there is no one size fits all approach. You can engage individuals with intellectual disabilities in many ways, including focus groups, conferences, individual meetings, surveys, formal advisory groups, appointed panels, support for self-advocacy, and more. Reaching out to local community organizations that serve people with intellectual disabilities is a great first step. In BC, both Special Olympics BC and Community Living BC can help you engage with self-advocates.

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PLANNING AND DESIGN

GETTING STARTED

Have I...

<input type="checkbox"/> Established a definition for 'intellectual disability'?	<i>The most accepted definition comes from the American Academy on Intellectual and Developmental Disabilities.</i>
<input type="checkbox"/> Established a definition for inclusivity in the context of the policy?	
<input type="checkbox"/> Established a goal for the policy or desired outcome?	<i>What am I trying to achieve and is policy the best way to get there? If this policy is enacted, what will happen? Have people with intellectual disabilities and their supporters been consulted in establishing the goal or desired outcome?</i>
<input type="checkbox"/> Used data to back assumptions about how the policy will affect people with intellectual disabilities?	<i>If not, does the data exist? Do you need to collect it?</i>
<input type="checkbox"/> Built in new resources required for policy implementation from the beginning?	
<input type="checkbox"/> Excluded some or all people with intellectual disabilities throughout the process – by design or unintentionally?	<i>If so, is there valid rationale for having excluded them?</i>
<input type="checkbox"/> Provided support services and/or assistive devices and technologies under a community-based approach?	<i>Policies must aim to facilitate community inclusion and involvement wherever possible.</i>
<input type="checkbox"/> Developed innovative policy solutions that include the contributions and assets of people most affected?	<i>Nothing about us without us!</i>
<input type="checkbox"/> Seen individuals as active participants in society, rather than only in terms of their abilities?	<i>Remember, it is not the disability that impairs an individual. Society causes the impairment.</i>
<input type="checkbox"/> Ensured document accessibility by formatting for browser or Microsoft Office text-to-speech applications?	

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REVIEW OF EXISTING SERVICES AND POLICIES

Have I...

<input type="checkbox"/> Integrated as many assistance and support services as possible into existing policies and programmes to increase access?	<i>Perhaps it's not a new service or policy that is needed, but more support accessing existing resources, supports and services.</i>
<input type="checkbox"/> Considered implementing more widely existing policies?	<i>For people with intellectual disabilities, policies that have the potential to promote desired outcomes may already be "on the books". Rather than creating new policies, an ideal solution may include increased education about the given policy.</i>
<input type="checkbox"/> Identified current policy and system disconnects relevant to the population?	<i>Many individuals with intellectual disabilities and their supporters report difficulties transitioning from youth to adult services, which are often accessed via different providers.</i>
<input type="checkbox"/> Identified existing supports and services to ensure that the policy does not negatively impact access to existing services and entitlements?	<i>What are the access requirements for other services used by this population? Is it possible that your policy will provide a benefit that results in an individual no longer meeting access requirements for other services they depend on?</i>
<input type="checkbox"/> Ensured personal supplements enhance, not replace existing supports?	
<input type="checkbox"/> Recognized and supported existing social networks and community resources, while ensuring that informal supports do not become a replacement for necessary formal supports?	<i>Community based supports are preferable for community inclusion, however, policies that rely on informal supports must consider the needs and limitations of those helping.</i>

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INCREASE STAKEHOLDER BUY-IN

Have I...

<input type="checkbox"/> Sought the input of individuals with intellectual disabilities and their supporters?	<i>Stakeholders may be less keen on participation if the process is perceived as not inclusive.</i>
<input type="checkbox"/> Demonstrated the costs of not addressing equity issues?	<i>To the untrained observer, equity for people with intellectual disabilities may seem too expensive. However, estimates fail to consider the cost of inaction. The International Labour Organization estimates that the cost of exclusion of people with disabilities can amount to 7% of a countries' GDP.</i>
<input type="checkbox"/> Considered how public perception and attitudes will affect the implementation of the service, program, or benefit?	<i>Stigma and misconceptions surrounding people with intellectual disabilities are highly prevalent in Canadian communities and can inhibit a policy's effectiveness. For example, some people with intellectual disabilities think public attitudes make certain facilities feel unwelcoming.</i>
<input type="checkbox"/> Ensured those implementing the policy understand the values underpinning them?	<i>Doing so may increase staff willingness to challenge their pre-conceived notions and reduce resistance to change.</i>
<input type="checkbox"/> Considered running pilot or demonstration projects to gain insight and highlight the potential for change to key stakeholders?	<i>Seeing a proposed change in action may influence the beliefs of stakeholders and can highlight unforeseen consequences of the action.</i>
<input type="checkbox"/> Created forums for debate and discussion among stakeholders for the given policy?	<i>Doing so may help overcome some of the negative attitudes held about the policy.</i>
<input type="checkbox"/> Provided reasons if feedback offered by a person with intellectual disabilities has not been utilized?	<i>Providing reasoning can help create confidence and a feeling of respect that will facilitate future interactions.</i>
<input type="checkbox"/> Involved individuals who might resist change in different aspects of the policy's design and implementation?	<i>Gain an understanding of their concerns and priorities which can be addressed prior to implementation.</i>
<input type="checkbox"/> Reviewed existing educational and training mechanisms to ensure that they promote values consistent with inclusive policy-making?	<i>Understanding of the implications of disability has transformed rapidly in recent years. Educational and training mechanisms developed previously may promote harmful stereotypes or misguided beliefs about capability.</i>

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REFLECTION

Have I...

<input type="checkbox"/> Considered Universal Design principles?	<i>Programs and services should be designed to be accessible by people with intellectual disabilities without the need for specialized supports or supplements.</i>
<input type="checkbox"/> Considered the needs of individuals facing multiple barriers to accessing supports and services?	<i>For example, some individuals with intellectual disabilities face additional barriers stemming from health or financial concerns.</i>
<input type="checkbox"/> Utilized policy lenses, including the Disability and Inclusion Based Policy Analysis lens to identify implications of the policy?	<i>These tools help highlight issues and concerns overlooked due to personal biases and knowledge gaps.</i>
<input type="checkbox"/> Focused on personal outcomes and their enhancement?	
<input type="checkbox"/> Considered needs-based service entitlements where appropriate?	<i>Set entitlements are ideal from a budgetary perspective, but they often fail to meet the needs of unique and/or complex cases.</i>
<input type="checkbox"/> Considered the cross-cutting nature of disability and its relationship to the policy?	<i>Regardless of theme or topic, it's rare for a policy to have no impact on persons with intellectual disabilities.</i>
<input type="checkbox"/> Considered the multiple and intersecting forms of discrimination faced by persons with disabilities?	<i>A woman with an intellectual disability will experience gender-based discrimination in addition to discrimination based on ability.</i>
<input type="checkbox"/> Considered how this policy will affect the families and supporters of individuals with intellectual disabilities?	<i>Supporting an individual with intellectual disabilities can require significant additional support and financial investment compared to the general population. Policies should seek to reduce these additional requirements rather than add to them.</i>
<input type="checkbox"/> Considered the changing demographics and how the policy will affect individuals with intellectual disabilities in the future?	<i>People with intellectual disabilities are experiencing a rapid increase in life expectancy which will have profound implications for service delivery.</i>
<input type="checkbox"/> Allowed opportunities for supported decision making?	<i>Wherever possible, people with intellectual disabilities should be empowered to exercise self-determination.</i>
<input type="checkbox"/> Considered the role that the 'circle of support' plays in accessing the service?	<i>Does the policy depend on friends or family members driving to the point of service access? If so, have the needs of the driver been considered?</i>
<input type="checkbox"/> Developed a vision of what inclusion looks like in relation to the policy?	

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IMPLEMENTATION

Have I...

<input type="checkbox"/> Identified means for individual identification/verification that aligns with existing diagnosis and classification systems?	<i>Using existing classification systems can reduce the need for individuals with intellectual disabilities to retell their stories.</i>
<input type="checkbox"/> Developed a network of institutions undergoing similar change?	<i>Learning from the experiences of others can enhance the chances of success.</i>
<input type="checkbox"/> Created procedures for succession planning that facilitate introductions to key partners?	<i>If service delivery requires developed relationships, what will happen when key staff quit or retire?</i>
<input type="checkbox"/> Ensured affordable access to assistive technologies required for accessing policy benefits and entitlements?	<i>Assistive technologies can be prohibitively expensive for individuals with intellectual disabilities, many of whom are classified as low income.</i>
<input type="checkbox"/> Considered different needs for assistive technologies to support service access?	<i>Individuals with intellectual disabilities have a diversity of needs. Not all assistive technologies are effective for everybody.</i>
<input type="checkbox"/> Considered assigning funds in each mainstream program budget for individuals with intellectual disabilities?	<i>Ensures that mainstream program administrators will actively consider outreach to this population.</i>
<input type="checkbox"/> Considered implementing specific usage and access targets to accelerate or achieve de facto equality?	<i>Helpful for programs accessed broadly by the general population.</i>
<input type="checkbox"/> Addressed structural barriers that make it difficult for people with intellectual disabilities to access services in times of emotional crisis?	<i>For example, stigma, low expectations, lack of flexibility, lack of resources or legal reasons.</i>

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STAFF

Have I...

<input type="checkbox"/> Considered current professional skillsets and their ability to implement the policy?	<i>Historically, services for people with intellectual disabilities were provided by specialists in institutions. Do not assume that professionals in the community have the required skills to promote inclusion.</i>
<input type="checkbox"/> Provided detailed policy guidance and education to support frontline staff, including staff with intellectual disabilities?	<i>Staff without disability specializations may need significant training and support to feel comfortable and able to serve people with intellectual disabilities.</i>
<input type="checkbox"/> Established mechanisms to hold those responsible for implementing the policy accountable?	<i>Goals, measurement, and incentives are needed to counter harmful attitudes towards inclusion.</i>
<input type="checkbox"/> Offered ongoing opportunities for staff and community members to raise concerns?	
<input type="checkbox"/> Ensured that those implementing the policy understand their application to people with more severe intellectual disabilities?	<i>Staff attitudes and prejudices towards the capabilities of people with severe intellectual disabilities can be a barrier to implementation, particularly in supported decision-making.</i>

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EVALUATION

Have I...

<input type="checkbox"/> Ensured that people with intellectual disabilities access programs, services, and benefits on an equal basis with others?	<i>Distinguish between equal access and equitable access.</i>
<input type="checkbox"/> Celebrated successes?	<i>Highlight and celebrate successful policies to encourage their adoption and remind policymakers to disrupt the status quo.</i>
<input type="checkbox"/> Identified indicators and data to analyse the extent to which the policy contributes to removing barriers or creating opportunities for people who risk exclusion?	
<input type="checkbox"/> Promoted the grouping or separation of people solely based on disability-related need?	<i>If so, are there plans to transition to universally designed services?</i>
<input type="checkbox"/> Imposed unreasonable costs to the person with an intellectual disability, solely because of their disability?	<i>Will it cost an individual with an intellectual disability more to access the service than the public? Many already face financial barriers to inclusion.</i>
<input type="checkbox"/> Created policy or program requirements that serve as obstacles to people with intellectual disabilities accessing the program, service, or benefit?	<i>Complex or new verification/identification systems may discourage people with intellectual disabilities from registering for service access.</i>
<input type="checkbox"/> Discouraged people with intellectual disabilities from accessing other needed programs, benefits or services provided by another level of government?	<i>A new provincial level program may result in an individual no longer meeting federal requirements for access to required services or supplements.</i>
<input type="checkbox"/> Separated all indicators by disability status?	<i>Failure to review statistics by disability type will prevent you from understanding the extent to which people with intellectual disabilities benefit from a policy to the same extent as others.</i>
<input type="checkbox"/> Used publications such as the Washington Group on Disability Statistics to facilitate transnational comparisons and learning?	<i>Research into best practices remains scarce in key areas. By facilitating transnational comparisons, you can better identify the impact in relation to efforts conducted elsewhere.</i>
<input type="checkbox"/> Incorporated stakeholder consultation into policy evaluation mechanisms?	

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SUPPORTED DECISION MAKING

EMPOWERMENT

Have I...

<p><input type="checkbox"/> Created opportunities to enhance decision making capacity through formal or informal supports?</p>	<p><i>May include support networks, support agreements, peer and self-support groups, and support for self-advocacy.</i></p>
<p><input type="checkbox"/> Avoided all forms of substitute decision-making where possible, and where not possible, allowed people with intellectual disabilities to nominate an alternate decision-maker based on their own opinions and desires?</p>	<p><i>Substitute decision-makers should only be considered if an individual is incapable of providing informed consent. In all such cases, appropriate safeguards must be in place prior to the assignment of decision-making capacity.</i></p>
<p><input type="checkbox"/> Implemented advance plans allowing the individual in question to offer guidance and nominate alternate decision-makers during times of emotional crisis?</p>	<p><i>Advance plans ensure the opinions, needs and desires of the individual are respected during times of emotional crisis.</i></p> <p><i>Consider provisions contained in the Patients Property Act, the Mental Health Act, the Adult Guardianship Act, and for legal representatives. Organizational policies concerning alternate decision-making should be reviewed by legal counsel prior to implementation.”</i></p>
<p><input type="checkbox"/> Provided training to staff and supporters to enhance capacity to implement supported decision-making?</p>	<p><i>Substitute decision-making has long been the norm. Implementing supported decision-making may require a new set of skills.</i></p>

BEST PRACTICES

Have I...

<p><input type="checkbox"/> Designed support arrangements to enable direct control and choice for people with intellectual disabilities?</p>	<p><i>The standard implies determining what the person would have wanted instead of deciding on their best interest. According to the Special Rapporteur on the Rights of Persons with Disabilities, the process should include consideration of the previously manifested preferences, values, attitudes, narratives, and actions, inclusive of verbal or non-verbal communication, of the person concerned.</i></p>
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INCLUSIVE POLICY-MAKING FOR PEOPLE WITH INTELLECTUAL DISABILITIES

- Taken a community-based approach to supported decision making, which builds on existing social networks and community resources, and enables stakeholders (family, friends, neighbours, peers, and others) to play a significant role in supporting persons with disabilities?
- Offered flexibility in policies to avoid overreliance on existing relationships in supported decision making?

SAFEGUARDS

Have I...

- | | |
|---|---|
| <input type="checkbox"/> Provided time limits or mandated periodic reviews for supported decision-making arrangements? | <i>Pay extra attention to any arrangement in which an individual's autonomy has been restricted.</i> |
| <input type="checkbox"/> Allowed for multiple supporters to be included in support arrangements? | <i>Diversity of perspectives can reduce the risk of undue influence.</i> |
| <input type="checkbox"/> Considered implementing written agreements between the individual and the supporter recognizing the individual's autonomy, outlining the nature of support, and holding the supporter accountable? | <i>Having an agreement in writing helps clarify responsibilities and obligations.</i> |
| <input type="checkbox"/> Provided training to staff and supporters to ensure the values embedded in supported decision-making are respected? | <i>Staff may be supportive of values such as independence in principle but may not view them as feasible in a particular context.</i> |
| <input type="checkbox"/> Included accountability mechanisms to ensure that the person's will and preferences are respected in the provision of support? | |
| <input type="checkbox"/> Established mechanisms to challenge the action of a support person if there is a belief that the support person is not acting in accordance with the will and preferences of the person concerned? | |
| <input type="checkbox"/> Provided access to independent advice and guidance? | <i>Doing so can reduce the risk of undue influence experience by an individual with intellectual disability.</i> |

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ENGAGEMENT

COMMUNICATIONS

Have I...

<input type="checkbox"/> Used person first language?	<i>Persons with a disability, not disabled person.</i>
<input type="checkbox"/> Made inclusive language materials available?	<i>Short sentences, plain language at a 6th grade reading level.</i>
<input type="checkbox"/> Considered using adapted formats where appropriate?	<i>For example, pictures, charts, audio, or videos.</i>
<input type="checkbox"/> Used images that represent a full range of diversity, and show people who are at risk of exclusion in an active, positive light?	<i>Not all people with intellectual disabilities are the same, be careful to avoid promoting stereotypes.</i>
<input type="checkbox"/> Identified and utilized communication platforms commonly accessed by the relevant populations?	<i>Due to their unique needs and networks, people with intellectual disabilities may not respond to traditional outreach. Engage self-advocate networks and service providers to determine an effective outreach strategy.</i>
<input type="checkbox"/> Engaged people with intellectual disabilities directly, even if a supporter is present?	<i>Often professionals speak directly with a supporter to determine the needs of an individual with intellectual disabilities right next to them.</i>

STAKEHOLDERS

Have I...

<input type="checkbox"/> Cultivated champions?	<i>Individuals with power to amplify views within a given circle can drastically enhance the uptake or implementation of a policy.</i>
<input type="checkbox"/> Engaged perspectives of people with intellectual disabilities from a range of social groups?	<i>Cultural backgrounds, genders, ages, rural/urban, wealth etc.</i>
<input type="checkbox"/> Engaged a cross-section of organizations?	<i>Diversity of stakeholder groups and their changing perspectives can have serious implications for policy formation.</i>
<input type="checkbox"/> Distinguished between organizations “of” persons with disabilities and organizations “for” persons with disabilities?	<i>Organizations “of” people with disabilities are led by persons with disabilities, while organizations “for” people with disabilities are usually non-profit organizations that provide services to people with disabilities and often also advocate on their behalf.</i>

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Included people with intellectual disabilities in mainstream engagement projects in addition to disability-specific activities?

Engaged people with intellectual disabilities at every stage of the policy-making process?

Inclusive policy-making is not limited to design. People with intellectual disabilities and their supporters can be invaluable at all stages including research, design, implementation, and evaluation.

BARRIERS

Have I...

Considered the cost (direct and opportunity) of participation for the individual and their supporters?

A meeting held at noon with no compensation for participants will prevent many individuals and their supporters with jobs from attending.

Established a supportive environment for self-advocates?

People with intellectual disabilities are more likely to be confident about their participation if they have a supportive unit.

Considered the transportation needs of participants?

Many individuals with intellectual disabilities rely on public transportation.

Considered the supports individuals with intellectual disabilities need to participate in the identified engagement format?

For example, many individuals with autism spectrum disorder benefit greatly from the assistance of communication supports such as iPads.

Considered the diversity of people with intellectual disabilities and provided an appropriate range of supports to facilitate the participation of all sub-groups?

People with intellectual disabilities are diverse and may not require the same supports to facilitate participation. For example, one individual may require assistive communications technologies, another may require access to a sensory room.

Considered the varied experiences of individuals with intellectual disabilities from different cultural backgrounds in relation to the policy?

How individuals with intellectual disabilities are viewed and supported by their community may not be uniform across all cultural groups present in a community. Understanding the unique ambitions and perspectives of these communities is critical to successful engagement.

VALUING OPINIONS

Have I...

Considered the rationale for discounting a given opinion or suggestion?

Was it unworkable? Or perhaps has your decision been influenced by your personal biases?

Recorded answers given by participants?

By recording, you are implicitly stating that an opinion is valued and will be considered.

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CURRENT POLICY LANDSCAPE

HOW WE GOT HERE

Deinstitutionalization and Community Living – In the name of protecting individuals and society, people with intellectual disabilities were historically removed from communities and placed in institutions. Beginning in the 1930's, parents of individuals with intellectual disabilities began to form networks calling for the increased provision of community-based supports and services. These networks led to the establishment of community associations that provided services, additional community-based government services, and eventually, the shuttering of institutions across the country. [This short video](#) by Inclusion BC explains the closure of institutions in BC and honours the history of the Community Living movement.

FRAMING OUR POLICIES

Rights-based approach to policy – People with intellectual disabilities are rights holders, rather than mere receivers of protection, rehabilitation and/or welfare. In Canada, the relevant legal sources of rights for people with intellectual disabilities include: the [UN Convention on the Rights of Persons with a Disability](#) (ratified by Canada), [Human Rights Act](#) and the [Canadian Charter of Rights and Freedoms](#).

Medical Model vs Social Model of Disability – The medical model of disability views the underlying impairment as the source of disability. Alternatively, the social model of disability views disability as a social consequence of having a disability, presuming it is societal barriers, not the impairment that causes disability.

Disability and Inclusion Lens – Recently, several analytical frameworks can assist policymakers in identifying policy implications for people with disabilities. The [Disability and Inclusion Based Policy Analysis](#) lens has been developed by the Institute for Research and Development on Inclusion and Society. The lens identifies some of the main policy implications and provides a set of guiding questions for policy planning, implementation, evaluation, revision, and coherence.

BARRIERS

<i>Barrier</i>	<i>Example</i>
Institutions	Policies limiting legal capacity
Attitudes	Stereotypes limit expectations of people with intellectual disabilities
Understanding	Public lack of education and awareness of people with intellectual disabilities
Physical	Lack of sensory considerations at community forums
Communications	Failure to provide inclusive and/or adaptive language materials
Research	Little evidence to understand service needs and trends
Financial	Transportation costs and lost wages prevent participation