



QUEBEC INTELLECTUAL
DISABILITY SOCIETY

Policy Directions and Required Actions

2022





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Policy Directions and Required Actions – 2022

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ISBN (PDF): 978-2-921037-39-6
ISBN (Print): 978-2-921037-40-2

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About the Québec Intellectual Disability Society

The Québec Intellectual Disability Society (the Society) brings together, informs and equips all those who wish to make Québec a more inclusive society, where everyone can find their place and thrive. More than 90 organizations and associations, over 150 employers and thousands of families across the province are already part of the movement.

Guided by the fundamental principles set forth in the Universal Declaration of Human Rights and the Québec and Canadian Charters, the Québec Intellectual Disability Society works to:

- › Promote the interests and defend the rights of people living with intellectual disabilities and their families. This is undertaken in two primary ways:
 1. Through advocating for policy changes that better support people living with intellectual disabilities and their families;
 2. Through intervening in crisis situations or exploitation.
- › Inform and sensitize members, partners, professionals, and stakeholders. Equally important is informing decision-makers and the general public on issues and new developments in the field of intellectual disabilities. It does so through publications and media outreach as well as by organizing events such as thematic workshops, conferences and awareness campaigns.
- › Act as a spokesperson for the individuals, families, associations and organizations it represents before the various political and public authorities or social actors, particularly with regard to the various legislative bills and regulations pertaining to education, work, health, social services, income security or any program that closely or remotely affects the social inclusion of the people whose cause it supports.
- › Encourage and support any initiative that promotes services and support for families or that facilitates the autonomy of persons with intellectual disabilities, and, consequently, that promotes their full inclusion in their respective communities.
- › To promote the sharing of expertise and the creation of solidarity networks.

Foreword

Inclusion in the face of adversity

Inclusion is at the core of the Québec Intellectual Disability Society's actions. It is not an abstract concept, but a goal to be achieved collectively, and a practice to be developed in all parts of society. This work is part of a broader context of changing attitudes and transformation of study, work, and housing environments to adapt to the diversity of people living in Quebec. As an example, integration is giving way to inclusion, to a real sense of belonging and to the development of substantive – not just formal – equality. Though true equality is still a long way off for many individuals and families, its realization must be pursued now more than ever.

Families and individuals are experiencing rationed services, loss of access, and endless waitlists. The entirety of the public system has been weakened and severely burdened by decades of austerity. The time for change is now. People with intellectual disabilities, their families, and all those at the intersection of different forms of social exclusion need a more humane and inclusive society.

It is in this context that the Society is working. This document presents some observations and policy directions in relation to the needs of individuals and families. It is a document that proposes a collective vision, resolutely in favour of the inclusion of all, and which seeks to propose innovative ideas to respond to complex problems and needs that cannot be solved by simplistic solutions.

All the policy directions and demands presented in this document are the result of a consultation process done in early 2022 with the members of the Society, in conjunction with the intellectual disability community. By conducting surveys and thematic workshops, the Society was able to assess and validate its orientations and demands. We would like to thank all the people who participated in the consultations and who took the time to share their ideas and thoughts on the issues surrounding intellectual disabilities in Québec.

Document contents

To facilitate reading, this document is structured around several themes and stages in the lives of people with intellectual disabilities and their families.

The main themes used to develop the actions are as follows:

- › **Making the pathway through life easier and more inclusive** – from birth to the end of life, people with intellectual disabilities and their families should have a simpler and more inclusive pathway through life. Included are administrative burdens, health and social services, education, rights and freedoms, and social and economic participation;
- › **Respecting and promoting people's development and autonomy** – regardless of age, people with intellectual disabilities are capable of learning and making decisions. It is important to respect and promote their development, empowerment, and self-determination; and
- › **Provide necessary support to families** – family members often become caregivers. They need more support, to guarantee them legal rights and to ensure their physical and mental well-being, as well as their financial security.

It should be remembered that people with intellectual disabilities have the same rights as any other person, that they have aspirations, dreams and abilities, even if they often need more time to learn and adapt to their environment. These needs are recognized in the various Charters, as is the need for reasonable accommodation for these people. Our policy directions and actions are not about claiming additional rights, but rather a recognition that substantive equality can only be achieved through significant social and legal changes.

Government Action: A Necessity

The Society sees inclusion as a collective responsibility. Nevertheless, it is the government's responsibility to fund and coordinate services and efforts to promote inclusion in society. The State is the only body that can smooth out social inequalities, guarantee equal access to services in all regions of Québec, and put in place public policies favourable to inclusion in employment and education.

Adequate funding of our collective wealth redistribution instrument is essential to achieve real inclusion. As a society, we should not aim for a two-tier system that separates those who have access to capital and therefore services, from those for which capital is inaccessible and forces a reliance on charity. The necessary reinvestment in the intellectual disability sector must therefore be made within government bodies, by investing in human and physical resources in the health and social services network, by funding new innovative services, by increasing the funding of other services, etc.

More money invested in services also requires more accountability and transparency. At a time when the health and social services network is characterized by a disturbing lack of transparency, it is necessary to have better accountability and public information (especially regarding services' quality) instruments.

The Society therefore hopes that the various social actors in Québec, and particularly those in power, will take the measure of the challenge and respond adequately.

Let us be a society that is proud of the way we treat and value the most vulnerable.



I. Before Birth

Even before the birth of people with intellectual disabilities, a series of questions and issues arise. For more than fifteen years, Québec has had a public prenatal screening program for trisomy and other intellectual or developmental disabilities. This program has raised new ethical and societal issues. Not only are some tests of limited effectiveness, but more importantly, despite government policy, it is all too rare for families to be able to make a free and informed decision when a positive result for intellectual disability is given.

To facilitate the pathway for families and individuals, two proposals that can easily be implemented are outlined below.

Review the Prenatal Screening Program for Intellectual Disabilities

The widespread introduction of prenatal screening for intellectual disabilities has generated new challenges in the community. Many have argued that by introducing such a policy, the state is undermining the value of these individuals before they are even born. Others pointed out that intellectual disability is not a disease, but a medical condition, a state. One does not ‘suffer’ from intellectual disability, one ‘lives’ with it, one has an intellectual disability.

Furthermore, in contrast to the idea of intellectual disability as a fatal condition that does not lead to survival beyond adolescence, the quality of life of people with intellectual or developmental disabilities has improved considerably due to advances in medicine and social services. In particular, life expectancy has increased in recent decades (Bittles and Glasson 2004). Research has also ensured that new tools have been developed to help people with intellectual disabilities fulfil their potential.

The few assessments of prenatal testing programs have also raised serious ethical questions in relation to the significant shortcomings in the prenatal testing procedures currently in place. Although the screening program requires provision of information to parents and a free and informed decision (Ministère de la Santé et des Services sociaux 2017), parents are most of the time subjected to significant pressure to end pregnancy. It is rare that parents benefit from adequate and complete information allowing them to make a free and informed decision based upon the results of the screening tests as well as on the choice to keep the fetus or not. In some cases, adoption is even suggested or encouraged.

While all modern medicine and bioethical questions are founded on the concept of free and informed consent of individuals, in the case of prenatal screening, this criterion is clearly not being met. In the Society’s view, there is a need for neutral resources to support parents in their decision-making regarding prenatal testing, as well as following the decision to keep the child (support groups, psychologists, etc.). There is also a need for better training and information of the medical community. This is also the recommendation of the American Academy of Pediatrics (Bull et al. 2022).

ACTIONS

That the Government of Québec:

- › **Revisit the parent support program in regard to prenatal testing, and upon and after the announcement of intellectual disability to ensure that parents receive adequate and neutral information that enables them to make free and informed choices, divorced from social pressure;**
- › **Works with professional orders to enhance training for the medical community and social services workers on issues related to intellectual disabilities and other forms of disabilities.**

Preregister Individuals for Services as Soon as the Announcement of the Diagnosis is Made

When the prenatal screening for intellectual disability is confirmed (trisomy 21, agenesis of the corpus callosum, Koolen de Vries syndrome, Wieacker-Wolff syndrome, Angelman syndrome, Rett syndrome, etc.), and the parents decide to keep the fetus, they must wait until the child is born before they can register the baby on health and social services waitlists. This situation means that young children do not immediately have access to services and are unable to develop their full potential.

And yet, promoting early stimulation ensures that people with intellectual disabilities can benefit from fuller development and that intervention in later life is less costly. By promoting early stimulation and intervention, the government would be able to save money in the long term, could help accelerate the development of the person's autonomy and abilities, and better support families. It should be remembered that families often enrol their children in childcare long before they are born. Why shouldn't this be the case for health and social services?

ACTION

That the Government of Québec:

- › Implements a pre-registration process for health and social services as soon as the diagnosis of intellectual disability is made.



II. Early Childhood

Early childhood is a crucial period for the development of the abilities of children with intellectual disabilities. In order to ensure that children can develop maximum abilities and autonomy, it is essential to equip families adequately and provide with all the necessary support.

Make Diagnostic Assessments Universally Available in the Public System

Although the Ministry of Health and Social Services has a policy of accessing services based on the needs of individuals, obtaining a diagnosis of intellectual disability is still often required to obtain services that meet the needs of the child. Moreover, the earlier the diagnosis is made, the greater the chances of maximizing the child's potential and social inclusion. It is also important to emphasize that obtaining a diagnosis theoretically allows the family to have access to support services.

In Québec, various laws specify that access to care and services in the public system is to be universal, including the diagnosis of children. However, too many parents are forced to resort to the private sector at their own expense to obtain a diagnosis, due to a lack of resources in the public network or because of excessively long waiting lists.

Despite the announcement of the expansion of the implementation of the Agir tôt program throughout Québec, results have been tenuous for most families. This situation disadvantages families with limited financial means, or who are at the intersection of several identities (such as gender, race, social class, sexual orientation, disability) making them more likely to be socially excluded. It also reinforces an existing two-tier system that penalizes children at present and in their futures.

The Society strongly believes access to health care and social services shouldn't be based on a family's financial means. It is also crucial that children and families have access to services, even while waiting for a diagnosis.

ACTIONS

The Government of Quebec to:

- › Make diagnostic services universally accessible in the public healthcare system as soon as a significant developmental delay is suspected by a healthcare professional;
- › Provide the required services with sufficient intensity to children and their support network, even while they are waiting for an official diagnosis;
- › Provide clarification on the services available for children with special needs;
- › Better refine the implementation of the Agir tôt program in the province and ensure that it really promotes access to services following screening.

What is Intersectionality?

Intersectionality is a concept and a method of analysis that seeks to identify the different identity dimensions of a person (e.g., disability, skin colour, immigration status, gender, sexual orientation, etc.) in order to understand how these dimensions may intersect or amplify instances of domination, discrimination or exclusion (racism, sexism, ableism, xenophobia, homophobia, colonialism, etc.). Intersectionality was defined by Kimberlé Crenshaw in 1989 to speak more specifically about the situation of Black women experiencing both sexism and racism (Crenshaw 1989).

Since then, the concept has been integrated into public policy development in Quebec and Canada in order to understand which populations will be affected by such policies, to assess the expected outcomes of policies, and how to make these policies more inclusive. In the context of public policy analysis, intersectionality allows for a better understanding of the impacts on certain populations that may be affected by different phenomena of exclusion and to question who has been left out and should be included in the future.

In Quebec, the Office québécois de la langue française defines intersectionality as:

“The accumulation of different forms of domination or discrimination experienced by a person, based on, among other things, race, gender, age, religion, sexual orientation, social class, or physical ability, which results in an increase in the prejudice suffered.” (Office québécois de la langue française 2019)

Intersectionality is therefore useful for reflecting on the situation of those more marginalized in society, who may cumulate identities that make accessing services and support more difficult. For example, black women with disabilities have greater difficulties accessing services than other people. Similarly, people with lower literacy levels and who are immigrants often find themselves de facto excluded from certain resources because they do not have the keys to access or understand them. Intersectionality allows us to improve programs and policies to make them more inclusive and develop initiatives that allow for the achievement of substantive equality for certain populations (Robert Masson and Martha Butler 2021, 15) and benefits everyone.

Resources:

- › Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. University of Chicago Legal Forum, 1989(1), 31.: <https://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8/>
- › Gender-Based Analysis Plus Course: Free online training offered by the Government of Canada: <https://women-gender-equality.canada.ca/en/gender-based-analysis-plus/take-course.html>
- › An introduction to the intersectional approach - Ontario Human Rights Commission: <https://www.ohrc.on.ca/en/intersectional-approach-discrimination-addressing-multiple-grounds-human-rights-claims/introduction-intersectional-approach>
- › Section 15 of the *Canadian Charter of Rights and Freedoms*: The Development of the Supreme Court of Canada’s Approach to Equality Rights Under the Charter: <https://lop.parl.ca/staticfiles/PublicWebsite/Home/ResearchPublications/HillStudies/PDF/2013-83-E.pdf>

Promote Early Stimulation for Young Children

Early stimulation is an effective way to develop the overall potential of children with intellectual disabilities. It is also an effective way to limit the long-term health and social costs to the government.

In the Society's view, the number of hours of stimulation for children with intellectual disabilities should be increased to respond to the real needs and abilities of these individuals.

In addition, there is a need to respond more promptly to the global needs of these children (health, social services, education, etc.). There are currently long waitlists, and many families find themselves without any services until they enter the school system, in which services are very limited.

ACTIONS

The Ministry of Health and Social Services to:

- › **Provide sufficient hours of early stimulation consistent with the overall needs and abilities of children with developmental disabilities;**
- › **Provide timely services to children with special needs to support their full development;**
- › **Collaborate with other Quebec government ministries and agencies to establish a support network around families of children with special needs.**

Promote Inclusion in Regular Early Childhood Educational Services

For the Society, the inclusion of children with disabilities in educational childcare is a prerequisite for the inclusion and labour market participation of their parents. In sum, excluding children from educational childcare often means excluding parents, often the mother, from the labour force. This is especially important for families that are non-traditional or at the intersection of several identities that may cause them to experience exclusion or discrimination.

Despite the progress made with the adoption in 2022 of Bill 1, *An Act to Amend the Educational Childcare Act to improve access to the educational childcare services network and complete its development*, the Society continues to call for better inclusion of children with special needs in regular settings (Société québécoise de la déficience intellectuelle 2021).

This includes a review of funding methods for services so that educational childcare services for children with special needs have the means to fully include them.

Unfortunately, too many families with special needs children are still denied childcare because of their children's disabilities. It is therefore imperative to create obligations for childcare services to be truly inclusive towards children with disabilities.

This is further supported by the rights enshrined in the *Convention on the Rights of the Child* (CRC - Organisation des Nations Unies 1989), as well as in the *Convention on the Rights of Persons with Disabilities* (CRPD). These guarantee children full inclusion in society, as well as the “right to benefit from childcare services and facilities” (Art. 18, CRC), notwithstanding their social condition or disability (Art. 23, CRPD). It is important that Québec respects its international obligations and implements these rights.

ACTIONS

The Government of Quebec to:

- › Increase subsidies to educational childcare services;
- › Promote a better work-family-study conciliation for parents with special needs children,
- › Take into consideration intersectional identity factors in the implementation of childcare services and the allocation of seats, as well as in the development of policies on these issues;
- › Prioritize children with special needs in the allocation of early childhood education seats;
- › Forbid educational childcare services from refusing children's participation without serious and proven reasons; or for any reason that is based on a criterion of discrimination prohibited by the *Charter of Human Rights and Freedoms*.

Improve Training, Support and Livelihoods for Parents

Having a child with special needs presents many challenges. Most of the time parents become caregivers, must stop working to take care of their child, etc. In this context, there is a need to better support families with a child who has special needs.

In the past, the intellectual disability and autism spectrum disorder programs offered training to parents. Unfortunately, since the 2015 reform of the health and social services network, in most cases, families are now referred to community organizations for help and there is little support from the health and social services network. Moreover, not all employees in the public system are trained to manage issues related to intellectual disabilities, which can make more difficult the assessment of needs of individuals, and/or further intervention.

In the Society's opinion, a support program for families must be put in place, and families must be better equipped to help their children thrive. Indeed, better equipping and supporting families promotes the well-being and long-term development of the child and their relatives, while allowing parents to continue to work and have a social life.

In addition, parents who must care for a child with particularly high needs should be able to receive additional financial support to that provided by the Supplement for Handicapped Children Requiring Exceptional Care (SEHNSE). The Society asks that parents who had to give up their jobs to provide care for their child be given rapid access to the Basic Income Program. This eligibility should be reviewed in the light of changing family circumstances if necessary.

ACTIONS

The Government of Quebec to:

- › Inform families of the services they are entitled to, how to access them and how to receive them;
- › Implement a support (especially through specialized respite) and training program for the child's support network;
- › Strengthen the training of health and social service workers;
- › Provide access to the Basic Income Program to parents of children with particularly high needs who had to quit their jobs to provide care for their child.



III. Primary and Secondary Education

Every student should have access to and receive quality educational services in a regular classroom in their neighbourhood school, along with the students in their age group. Students with special needs should be provided with the adaptations necessary for them to be able to participate fully in the Quebec School's regular education program. This allows them to develop autonomy and academic and social skills; all while aiming for full participation in their educational environment. Special schools and classes should be a last resort, in cases where it is in the best interest of the student.

Furthermore, the scholar system must recognize parental expertise and involve them in all decision-making processes, particularly in the development of an intervention plan. Parents should have all the information they need to make informed decisions provided by school principals and teachers.

Promote the Inclusion of Students With Intellectual Disabilities in Regular Primary and Secondary Schools

Students with intellectual disabilities are too often directed to special classes or schools before they have even been assessed. Moreover, whether in regular classrooms or in specialized settings, resources are clearly insufficient to adequately support the development of these students (Daniel Ducharme, Johanne Magloire, and Karina Montminy 2018; Protecteur du citoyen 2022). In addition, it is important to highlight the lack of assessments of students' abilities, limitations, and individualized needs, which would allow them to overcome their disability. A response to individualized needs must be based on an assessment for the student and not just fulfil an administrative need for classification.

The journey for students with intellectual disabilities and their families is often characterized by a lack of stability and an unrelenting struggle to obtain adequate and quality services. Moreover, the disparities between regions and school service centres are considerable and do not guarantee an equal exercise of rights for all students with intellectual disabilities in Québec. In fact, whether a student is placed in a regular or special class is often left to the goodwill of school principals, depending on their personal position on the application of the *Education Act*. The ability for an individual to exercise a Right should never be conditional to the goodwill of an individual - particularly an authority figure.

Furthermore, since 2018 the Québec government has prioritized the development of specialized classes to the detriment of students with intellectual disabilities. Austerity policies in the mid-2010s have also resulted in cuts to support services for students with disabilities or social and learning impairments, and insufficient resources in regular settings. Moreover, even when resources are available, they are often ad hoc and do not subsist over time. This creates many difficulties for students and can compromise their academic progress (Protecteur du citoyen 2022).

The constant struggle that families face with a lack of services have pushed many students with disabilities, adaption, and/or learning difficulties into specialized classes, without the opportunity to try learning in a regular setting. Such systematic recourse to school segregation is not to the students' advantage and does not promote learning about difference for the other students in the classroom.

Despite this, special education classes and schools can be useful when the regular setting has proven not to be optimal for learning. This could be due to problems of over-stimulation (particularly in the case of a dual diagnosis with an autism spectrum disorder), leading to behavioural problems or significant learning difficulties; or in case of insufficient stimulation, proving that adaptations put in place are insufficient to meet the academic learning needs of the student. These circumstances could occur despite a true collaboration of the different actors around the child and the child's family. In this context, the choice of regular or specialized school should be made via thorough assessment of the student's needs and abilities; by considering what is the best trajectory to ensure the student's success, personal development, and capacity to acquire knowledge and skills to promote their social participation and self-determination in adulthood. In this case, the most important factors are that choices be made in the best interests of the student, and with the free and informed consent of the parents.

ACTIONS

That the Government of Québec and the Ministry of Education recognize that:

- › As stated in the *Education Act* (Gouvernement du Québec 1988) and in the *Policy on Special Education: Adapting Our Schools to the Needs of All Students* (Ministère de l'Éducation du Québec 1999), inclusion in the regular environment must be the first choice, and all additional resources necessary to include students and support the teachers must be made available. Such resources must be sustained over time, and not just *ad hoc*. These resources must represent a tailored response to the individualized needs of the students who require them;
- › The choice of regular or special school should be made in collaboration with parents and all relevant partners based on a thorough assessment of the student's needs and abilities, and should consider the best trajectory to ensure the student's success, personal development, and ability to acquire knowledge and skills to foster social participation and self-determination as an adult;
- › Hybrid models that include mixed classrooms (regular and specialized in neighbourhood schools) should be developed to accommodate the individualized needs of students, and not just those determined by medical diagnoses. Indeed, mixing neurotypical and special needs children in the community promotes social inclusion from an early age;
- › It is necessary to remove arbitrary decision making from the hands of school principals regarding inclusion. The decision to include a student in a regular or special class must always be made based on the best interest of the student, not on the whim of school principals or organizations seeking administrative responses to individualized needs;
- › The quality of individualized educational plans and the allocation of resources to implement the plans should be a priority for the Ministry of Education, the School Service Centres and every school. The intervention plans must be based on individualized assessments of each student's overall abilities and needs to plan for their success and, eventually, their graduation. The rate of students with disabilities leaving school without a degree or diploma, which exceeds the Québec average, clearly demonstrates the poor quality of the intervention plans that should lead to the student's success.

Better Assessment for Students With Intellectual Disabilities

In recent years, the school system has stopped compiling detailed data on students with special needs, partly because diagnoses are no longer made in the school system. Having had access to statistics made it possible to better understand the prevalence and incidence of certain diagnoses (such as intellectual disability or autism spectrum disorder). This was important for the development of education policies that were in line with how to practically address the needs of students.

Moreover, school and health and social services networks often pass the buck to parents, entangling them in complex and lengthy administrative procedures. This is detrimental to children who do not have access to the resources they need to succeed.

ACTIONS

That the Government of Québec and the Ministry of Education ensure:

- › Students with an intellectual disability are evaluated prior to their placement in elementary school, as stipulated in the *Education Act* and the *Special Education Policy*;
- › The evaluation of students focuses on their academic abilities in addition to other factors that may have an impact on their educational success (behavioural problems, sensory overstimulation, etc.) to ensure that the necessary accommodations are in place for their success;
- › Schools respond to the needs corresponding to their mandates and specialties: to educate, socialize and qualify;
- › Diagnosis should be the responsibility of a single ministry, through a one-stop shop. Parents should not have to navigate between several ministries to access diagnostics and inclusion services for their children;
- › The assessment of the student's abilities and needs be done by the public system in all areas of youth development to identify necessary accommodations. These assessments must meet an academic and social need, not just an administrative need;
- › The school system compiles detailed data on student needs in relation to their intervention plans. The statistics compiled should include indicators of success rates of the intervention plans for students.

Build Capacity for Students With Intellectual Disabilities and Implement Specialized Programs Aimed at Furthering their Social Participation

The capacities of students with intellectual disabilities are frequently underestimated. Often, those who can read and write have learned at home and not in schools. This contributes to a problem in recognizing the capacities of students with intellectual disabilities, which furthers their marginalization in the long run. While developing the potential of people with intellectual disabilities would make them more self-reliant and involved in society; they are instead neglected, and their potential is not fully developed. The first obstacle to inclusion is associated with prevailing attitudes in the community that naturally discriminate against students' potential simply because of an existing diagnosis or an apparent disability.

Consequently, educational programs should be designed to truly enable the development of autonomy and self-determination of students with intellectual disabilities, in addition to basic literacy and numeracy skills, whether in the regular or the special education settings.

For students with more severe intellectual disabilities, it is important to focus on the development of social behaviours that allow them to develop some form of autonomy and agency.

ACTIONS

That the Government of Québec and the Ministry of Education:

- › **Ensure that specialized programs at the elementary level are focused on the acquisition of basic literacy and numeracy skills so that students with special needs can enter secondary school with the tools to develop new knowledge and abilities;**
- › **Adapt secondary education programs for students with intellectual disabilities to enhance their academic skills and help them achieve maximum independence as adults. This includes not only the development of basic literacy and numeracy skills, but also skills related to activities of daily living and domestic life. This should be done in accordance with the student's education plan;**
- › **Conduct a series of evaluations once the deployment of the "CASP: A Competency-Based Approach to Social Participation" and the Educational Program for Students with Profound Intellectual Disabilities is completed, to measure their impact on the development of young adults with intellectual disabilities. Such a series of evaluations should be done to make the necessary adjustments, especially in relation to literacy and numeracy skills. These two competencies are essential for developing students' self-determination and social participation.**

Better Equip and Train Teachers

Teacher training is limited with regard to the accommodation of students with special needs. This can lead to problematic situations due to a lack of understanding and tools to interact with students. It is necessary to include more courses related to the educational inclusion of students with special needs in the initial curriculum of primary and secondary schools' teachers, but also throughout their continued professional development.

ACTIONS

That the Government of Québec:

- › **Improve initial training for teachers to ensure that they are exposed to different student populations through differentiated instructional models, including helping them to implement appropriate teaching techniques and providing them with proven tools;**
- › **Enhances initial training for teachers to include more information on how to interact with students with special needs and how to include them in regular classrooms;**
- › **Requires all school personnel, including teachers, professionals and support staff, receive training on the inclusion of students with special education needs throughout their careers in order to develop and maintain educational strategies for the full inclusion of these students;**
- › **Hire inclusion counsellors in the School Service Centres to support the school teams in opening horizons and increasing behaviours that promote the full participation of students in schools.**

Ensure School Supervision Services for Students With Disabilities Are Available

School supervision services are important for families, particularly for parents of children with special needs. Their availability is one of the factors that enable parents to continue working and maintain some form of work-study-family balance. School supervision services can allow parents to work mornings, late afternoons, holidays, school breaks, summer holidays, or school days without having to actively care for their child during these times.

Unfortunately, more and more parents are experiencing the removal or limiting of school supervision services in secondary schools, due to a lack of resources. When these services are offered in the community, the application process to receive funding is long and complex.

In the end, it is the parents who have to fight for services. This is not sustainable. The instability created by this mode of operation means that some parents are reluctant to use these services, not wanting risk having these services cancelled in the middle of the year and being left without alternatives. In the end, this lack of services has a disproportionate impact on women, who are often the ones who reduce their professional activities in order to care for children.

ACTIONS

That the Government of Québec:

- › **Revises and stabilizes the organization of school supervision services by promoting coordination between the Ministries of Family, Education and Health and Social Services;**
- › **Designate the Ministry of Families to coordinate and implement school supervision services;**
- › **Promote school supervision services in order to facilitate parents' conciliation of work, family and studies;**
- › **Ensure the availability of adapted transportation to and from school supervision services.**

Harmonize the Implementation of the “School to Work Transition” (TEVA) Program Across Québec

The School to Work Transition (TEVA) program is a program designed to ensure that students with significant and persistent needs experience a smooth transition from school to work. The framework for TEVA is well designed, but its implementation is often chaotic. There are significant disparities in its implementation across Québec. It is often the school service centres, schools or teachers who decide how TEVA is to be implemented. As a result, some regions in Québec have excellent TEVA programs, while others simply do not provide any services related to these programs.

Nonetheless, a smooth transition from school to work is a key to success for these students and their future inclusion in the labour market and society. For the Society, the responsibility for implementing a smooth transition from school to work should rest with a multidisciplinary team in schools and service centres – in collaboration with the student and their family – not with already overburdened teachers. This would not only take the pressure off teachers but would also allow for greater stability in TEVA’s operations.

ACTIONS

That the Government of Québec:

- › **Make the provision of services related to the transition from school to work mandatory for students with significant and persistent functional limitations who wish to receive these services;**
- › **Harmonize the resources and services available among school services centres so that regional disparities are eliminated;**
- › **Make sure TEVA lead to services that are structured and promote the social and economic participation of young adults leaving high school based on their areas of interest;**
- › **That TEVA be implemented as early as age 14-15 to allow students to have access to several training paths leading to their graduation with a diploma (DEP, work preparation training, general adult education, among others).**



IV. Services for People Aged 21 and Over

In Québec, schools can be attended by people with disabilities up to the age of 21. After this point, individuals and families are for the most part faced with a lack of activities favouring their inclusion and social participation, and limited services that encourage skill building. Previously, the health and social services network provided day activities for adults aged 21 and over. These have gradually been transferred to community organizations without adequate budgets, thus limiting the possibilities for service development.

For people who find themselves without services and support, their social life deteriorates rapidly. This is also true for families who are often forced to stop working to look after their loved ones. Such a situation therefore exerts a double strain: first on individuals and families; but also on community organizations, who are forced to offer services with inadequate budgets. This insidious offloading of the activities of the health and social services network through the ever-increasing use of community organizations also creates major regional disparities.

Worse, since the health and social services network has abdicated its responsibilities in relation to the coordination and monitoring of services, there are concerns about the quality of those services. The offloading of services to community organizations

does not allow for the development of coherent, quality programs throughout the province, as each organization is left to its own devices in service provision; often with variable results. Many of these services for adults aged 21 and over focus too little on the acquisition of skills and competencies that will enable the development of an active social role relevant to these individuals, due to a lack of resources. Instead, they are often occupational programs aimed at “maintaining skills” and are not offered full-time.

The Society would like to see this situation change, for more services to be available, for community organizations to be better equipped and funded to offer these services, and for their quality to be reviewed and improved.

The ‘Active Social Role’: A Renewed Vision of Inclusion and Active Social Participation for People with Intellectual Disabilities

Services for people with intellectual disabilities aged 21 and over are globally insufficient and too rarely aim at their real inclusion and full social participation. It is therefore necessary to reflect on how to improve these services. Further, there is a lack of full understanding of the meaning of truly inclusive social participation that benefits both the individual and the community at large. Based on examples of innovative and bold services, the concept of an ‘active social role’ has been developed.

The active social role is one of the components of truly inclusive social participation. It clarifies elements of the concepts of ‘social participation’ and ‘inclusion’ as understood in the field of disability studies. By making it a *sine qua none* component of inclusion and social participation, the concept of an active social role makes these two concepts qualitatively more precise.

To this end, an active social role is useful for the development and implementation of programs for adults aged 21 and over with mild to moderate intellectual disabilities. This is in contrast to the relatively under-stimulating activities that are sometimes considered as forms of social participation or inclusion (mostly 'maintenance' and purely occupational activities). The active social role aims to truly include people in their community and give them a full role in social and economic life. While it does not necessarily involve paid work, this form of social participation should lead to mobilization within the community.

An active social role is therefore defined as an active, relevant, and interactive participation in the community. The impact of this participation is tangible and generates mutual exchanges that are positive for all members of the community.

A Cornerstone of Programs for Adults Aged 21 and Over

Introducing the concept of active social role does not mean that all occupational programs are bad, or that all people can play an active social role at all times. It is important to respect everyone's needs and desires. However, the majority of people currently engaged in social participation activities could do much more to develop their full potential. They need to be enabled and empowered to do better.

The active social role should be the cornerstone on which programs for adults aged 21 and over are built. This will allow for the offering of activities that are truly inclusive, that allow people to learn new skills and feel a sense of achievement.

The positive impact on the community could, in the long run, be a guarantee for a greater form of social inclusion for all, not only for people with disabilities.

Ensure Public Services Are Universal

For the Society, public services must be universal, of high quality and easily accessible. The current way in which services are organized creates significant disparities between regions and results in many individuals and families being deprived of services. It is essential that this situation change.

Thus, the Québec government should develop a core offering of services throughout the province, to which the complementary services provided by community organizations would be added.

ACTION

That the Government of Québec:

- › **Ensure a universal, public, and uniform quality service offering exist within the health and social services network throughout Québec. This will provide an opportunity to address existing regional disparities.**

Reorganize and Improve the Quality of the Services and Activities Offered to Adults Aged 21 and Over

For too long, rehabilitation services in the health and social services network have been limited to “making muffins, soup and colouring”, totally neglecting the acquisition, development, and reinforcement of social and professional skills.

There is a need to rethink services for adults aged 21 and over, particularly with regard to the services provided by the Ministry of Health and Social Services, which are mainly delivered in community organizations.

ACTION

That the Government of Québec set up a work group on programs for adults aged 21 and over living with intellectual disabilities, aimed at:

- › Redefining the orientations, content, and scope of these programs in order to truly promote the development of an active social role relevant to people accessing and using services. This exercise should be supported by evidence from the research community and be based on the principles enshrined in the *Convention on the Rights of Persons with Disabilities*;
- › Avoiding the use of maintenance programs that are limited to occupational activities, more often than not used as a way to provide parents with respite instead of building new skills for people with intellectual disabilities;
- › Properly supervise and develop an additional offer of respite services for families;
- › Create and develop adapted vocational and social programs in adult education centers (CEA) in Quebec for semi-specialized trades for people living with an intellectual disability.

Review the Way Community Organizations Are Funded and the Services They Provide on Behalf of the Government

Community organizations often provide services on behalf of the government but do so without having the budgets and funding to operate properly. Greater funding is needed, while ensuring that services are provided in a way that genuinely promotes social participation, whenever possible.

ACTION

That the Government of Québec reviews and considers the proper financing of services offered by community organizations to people with intellectual disabilities who are aged 21 and over. Encapsulated in that review would be ensuring these organizations are providing an adequate level of quality. To do this, the government should:

- › Develop, in collaboration with community organizations, new tools to help them offer quality services aimed at achieving an active social role for people with intellectual disabilities;
- › Adequately fund organizations that implement innovative programs that do not always meet the rigid criteria of government funding programs;
- › Change the funding of organizations that only offer maintenance services and occupational activities in order to accompany them in developing programs that promote real and relevant active social participation;
- › Develop and enforce quality standards in collaboration with the research community and organizations representing people with disabilities.

Develop Measures to Support Autonomy and Self-Determination

Developing the autonomy and self-determination of people with intellectual disabilities is fundamental to enable them to live truly inclusive lives. The prejudice, discrimination, and social exclusion that people with intellectual disabilities experience as a result of ableism are very real. While there is a need to raise public awareness, there is also a need to develop people's capacities to enable them to achieve greater autonomy and self-determination to the extent of their abilities.

ACTION

That the Government of Québec:

- › Raises awareness in Québec about the capacities of people with intellectual disabilities to develop their full potential when given the necessary support and tools;
- › Develop measures that fund community and research initiatives that support life-long autonomy and self-determination. These measures may take the form of support for assisted decision-making, the realization of a life project, and/or other forms of support for self-determination.

What is Ableism?

The Ontario Human Rights Commission defines ableism as “attitudes in society that devalue and limit the potential of persons with disabilities” (Ontario Human Rights Commission 2022). This form of discrimination against persons with disabilities exists broadly in society and must be actively addressed.



V. Employment and Vocational Services

A complex ecosystem with multilayered challenges

The ecosystem of employability and sociovocational services for people with disabilities in Québec is very complex. Many stakeholders are supposed to work together, while in reality there are many silos. It is essential to reconsider this dynamic.

Historically, the health and social services network has set up sheltered work and internship programs, as well as tutoring and development of social and professional skills services. However, these services have largely disappeared in the last decade, leaving only sheltered work and internship programs, often relegated to community-based organizations.

For its part, the Ministry of Labour, Employment and Social Solidarity (MTESS) is responsible for implementing the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons, as well as for managing last-resort financial assistance programs (social assistance, social solidarity, and basic income). This ministry also funds employment services for adults with disabilities (SEMOs) and other employability measures for people with disabilities (work integration contract, adaptation measures).

Government reports highlight problems

Despite considerable budgets invested in the employment of people with disabilities, outcomes are considered insufficient by government bodies. In 2020, a report by the Vérificateur général du Québec (VGQ) highlighted the fact that services are inadequate and do not succeed in leading young adults with disabilities to employment (Vérificateur général du Québec 2020), while the report by the Office des personnes handicapées du Québec showed in 2021 that services were also inadequate and did not meet needs (Office des personnes handicapées du Québec 2021).

The National Strategy for Labour Market Integration and Maintenance of Handicapped Persons is not “evolutionary” enough

The National Strategy for Labour Market Integration and Maintenance of Handicapped Persons, published in 2019, has proposed solutions, but they are slow to be implemented and generally too feeble.

Moreover, although the Strategy is supposed to be ‘evolutionary’, changes are slow to emerge. There have been only few changes to the Strategy since it came into force.

Problematic practices still very much alive

In recent years, problematic employment practices for people with intellectual disabilities have been brought to light. The Walmart case, in which the company fired people “in internship programs”, made the headlines as the public learned that employees could be in “internships for life” without being paid. These practices of “internships” and the use of unpaid sheltered work labour continue throughout Québec, largely funded by the Ministry of Health and Social Services (Institut de recherche et de développement sur l’inclusion et la société 2021).

Employment, Social Solidarity and Basic Income

Finally, the employability of people with intellectual disabilities is closely tied to social assistance programs across the country. In Québec, the social solidarity program only allows people to keep employment earnings of \$200 per month. Even though people can now keep their claim slip for a period of 4 years when they are employed, many still decide not to work, for fear of losing access to other government programming and services.

This will change when the new Basic Income Program comes into force on 1 January 2023. Eligible individuals will be able to work and earn up to \$13,000 per year (for 2023) without negative impact to their existing benefits. This change will allow for a more adequate treatment of people with intellectual disabilities who are recipients of the Basic Income Program. Such a paradigm shift should also allow for a broader reflection on employability services to make them more inclusive.

However, not all people with intellectual disabilities will have access to the Basic Income Program, and it is important to develop services for these people before they must resort to applying for last resort financial assistance programs.

Develop a New Practice and Policy Framework - For a Transfer of Employability Services to the Ministry of Labour, Employment and Social Solidarity

As mentioned earlier, employability services for people with intellectual disabilities are shared between the Education, Health and Social Services networks and the Ministry of Labour, Employment and Social Solidarity (MTESS). This creates significant silos and service gaps. There is little coordination between the Education and Health and Social Services networks. The MTESS itself often acts at another level without necessarily having links with the rest of the ecosystem. There is therefore a need for coordination and planning of services.

To improve the coherence of the services offered, programs and employability measures, the Society would like the Ministry of Labour, Employment and Social Solidarity to supervise all employability services between the different ministries. This would allow for the development of more coherent, unified programs, managed by a single ministry in charge of employment, rather than having a multitude of ministries with overlapping mandates. The Health and Social Services network would be involved in supporting the development of social skills, who are complementary to employability services. This proposal excludes occupational services for adults aged 21 and over.

ACTIONS

That the Government of Québec:

- › Transfer employability services to the Ministry of Labour, Employment and Social Solidarity to develop and implement coherent, uniform services and public policy directions that lead to employment and not only to “occupational” services;
- › Give the Ministry of Health and Social Services the mandate to support the Ministry of Labour, Employment and Social Solidarity in order to help it properly support people with intellectual disabilities in employment. This is particularly critical with regard to the acquisition and development of social and work skills;
- › Ensures that services have a specific purpose, are governed by quality standards, and are supervised to ensure that they function properly.

Promote Inclusive Employment

There are too few programs in Québec that focus on inclusive employment. The Society has hosted the Ready, Willing, Able program for several years, but this program is not available across the province and is limited in terms of human and financial resources.

Community organizations have also developed inclusive employment programs, often without financial or logistical support from the Québec government. These initiatives need to be supported, so that inclusive employment is truly a priority in the province.

Other provinces, such as New Brunswick, have been innovative in their approach to employability services, focusing on inclusive employment as a first option. It is important to build on the successes in that province.

What is Inclusive Employment?

According to the Institute for Research and Development on Inclusion and Society (IRIS),

- › “Inclusive employment refers to forms of employment in which people with disabilities work alongside their non-disabled peers in the competitive labour market (with access to the same benefits and career opportunities),
- › Inclusive employment ensures that no one is segregated or excluded from quality employment opportunities because of their disability,
- › Inclusive employment ensures that people with disabilities have access to the same work, facilities and benefits as their non-disabled counterparts, with the tools and accommodations they need to succeed.

Inclusive hiring is about giving people work that pays, and in which they can achieve and be part of society.” (Institut de recherche et de développement sur l’inclusion et la société 2021)

In addition, there is a lack of mentoring, coaching and business development programs for people with disabilities. Such programs need to be developed to favor inclusion and peer training in workplaces.

ACTIONS

That the Government of Québec:

- › Fund more initiatives related to inclusive employment, based on the New Brunswick model (Government of New Brunswick 2021);
- › Increase funding to the mission of community organizations providing innovative services;
- › Develop mentoring, coaching and business coaching programs for people with disabilities in collaboration with organizations representing them;
- › Make adapted training programs (towards semi-specialized trades) of adult education centres more accessible, in particular by modulating them according to the learning rhythms and particularities of people with an intellectual disability.

Update the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons

The National Strategy for Labour Market Integration and Maintenance of Handicapped Persons, published in 2019, proposed actions to be implemented to promote the hiring and retention of people with disabilities. The document was based on a renewed vision of disability, identifying environmental, social, and personal factors to propose elements of action that could lead to greater participation in the labour market for people with disabilities.

From the outset, the Strategy was presented as being “evolutionary”, i.e., it would be improved over time, according to the needs identified and the innovative solutions proposed.

Unfortunately, this has been slow to materialize, particularly with regard to the employment of people with intellectual disabilities. It is therefore necessary for MTESS to develop stronger ties with the intellectual disability community and the research community.

ACTIONS

That the Government of Québec:

- › **Update the National Strategy for Labour Market Integration and Maintenance of Handicapped Persons to include specific measures on the employment of persons with intellectual disabilities;**
- › **Fund new programs to support the inclusive employment of people with intellectual disabilities (coaching, mentoring in the workplace, etc.);**
- › **Funds innovative employability programs in community-based organizations offering services complementary to those of the state.**

Give Equal Status to Persons with Intellectual Disabilities to the Equivalent of Other Workers

Persons with intellectual disabilities are still often susceptible to be excluded from the labour norms that apply to the general population (Institut de recherche et de développement sur l'inclusion et la société 2021). Many employability programs benefit from the work of these people without actually paying them. This can occur through operating grants paying for other activities or by generating added value through the sale of the benefits of their labour. Due to the lack of services, it is at times the people themselves who must pay to attend socio-professional activities, without receiving any pay.

Yet the *Convention on the Rights of Persons with Disabilities* - which Québec and Canada have ratified - outlaws forced labour and exploitation of persons with disabilities (Organisation des Nations Unies 2006, art. 27):

- c) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
- d) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances.

It is therefore necessary to strengthen the rights people with intellectual disabilities who participate in programs that benefit from their work without paying them.

ACTIONS

That the Government of Québec:

- › Give the same equal status as enjoyed by the general public to persons with intellectual disabilities who are employed or participating in socio-professional programs in which employers make a profit on their work;
- › Put in place monitoring and enforcement mechanisms to prevent the exploitation of persons with intellectual disabilities participating in programs in which they are not paid adequately or at all.

End Sheltered Work Programs

Sheltered work programs have existed for over a hundred years in North America (Beckwith, 2016). In Canada, almost all provinces and territories have decided to restrict or eliminate these programs. Québec is one of the rare provinces that subsidize these activities rather than focusing on inclusive employment (Institut de recherche et de développement sur l'inclusion et la société 2021).

In the spirit of respecting the *Convention on the Rights of Persons with Disabilities*, the Society asks the Government of Québec to follow the recommendations of the report of the Institute for Research and Development on Inclusion and Society (IRIS) on sheltered work programs (Institut de recherche et de développement sur l'inclusion et la société 2021), in order to transition these programs to inclusive employment programs **by 2032**, and only allow sheltered work programs as part of time-limited training activities.

ACTIONS

That the Government of Québec:

- › **Make a clear and firm political commitment sheltered that work programs (including internships) will no longer be publicly funded. The only exception will be if these programs are used for training purposes and transition to inclusive employment, limited in scope and time (BC model);**
- › **Adopt a gradual approach to these reforms, to avoid “pulling the rug out from under” organizations, particularly in regard to funding;**
- › **Adopt policies aimed at the full social participation and economic inclusion of people with disabilities, including new social assistance and financial assistance programs that are truly tailored to the needs of people with disabilities, outside the current last resort financial assistance programs.**

Develop Alternatives to Employment

Not all individuals necessarily have the full range of skills required to participate in the labour market, therefore it is necessary to formulate alternatives to work.

ACTION

That the Government of Québec provide:

- › Holistic and individualized supports to people with disabilities, using person-centred approaches;
- › Adequate, universal, and quality services (social, artistic, sports, civic participation, etc.) for those unable to enter the labour market.



VI. Eradication of Poverty - Financial Security

The eradication of poverty and achieving financial security for people with intellectual disabilities and their families are prerequisites for their inclusion. Despite considerable efforts in recent years, the Quebec government still has work to do.

Many public policies are about to expire and while the Basic Income Program is an important step forward, many details of how it works still need to be improved.

Review and Update the Government Action Plan to Foster Economic Inclusion and Social Participation (PAGIEPS)

The Government Action Plan to Foster Economic Inclusion and Social Participation (PAGIEPS) is the cornerstone of the Québec government's strategy to fight poverty. The current PAGIEPS was adopted in 2017 and is due to end in 2023, making it necessary for the Government of Québec to begin work on renewing the Plan.

When it was introduced in 2017, the PAGIEPS included the creation and implementation of the Basic Income Program by 2023, which has been done. The PAGIEPS can therefore have a major impact on the living conditions of people with disabilities and a range of other communities who may be living on the margins of society.

ACTION

That the Government of Québec:

- › Review and update the PAGIEPS in 2023 by including structuring measures to eradicate the precariousness and poverty of people with disabilities and of other populations at the intersection of exclusion systems;
- › That the disability community be involved in the development of the new Plan.

Review Social Assistance and Social Solidarity Programs in Order to Shift Financial Assistance Programs for People With Disabilities Out of the Realm of Last-Resort Financial Assistance Programs

The work surrounding the creation of the Basic Income Program has shown that it is possible to do better in terms of financial assistance for people with disabilities. Moreover, the number of recipients of last-resort financial assistance is at its lowest, generating substantial savings for the Québec government.

For the Society, it is clear that the *Individual and Family Assistance Act*, from which the social assistance and social solidarity programs are derived, should be thoroughly overhauled in order to move these programs away from the punitive logic of last-resort financial assistance and the “welfarization” of disability.

To truly promote the inclusion of all people, social assistance and social solidarity programs should cover basic needs, allowing beneficiaries to live in dignity, while compensating for the additional costs associated with disability. This is far from being the case right now. It should also be noted that these programs have disproportionate reporting requirements and do not promote a rehabilitation approach.

What is “Welfarization”?

“Welfarization: from the word “welfare” and the suffix “-ization”, meaning an act, a process or the result of an action.

Welfarization is the process of linking financial assistance programs for people with disabilities (especially those who have severe employment constraints) with social assistance programs created for people who have no other source of income or who have temporary employment constraints.

The use of programs that were not designed to meet the needs of people with disabilities creates more problems than it solves and makes them more vulnerable.

Rehauling social assistance and social solidarity programs would also be an opportunity to evaluate the possibilities of decoupling these programs from medical support measures such as the “carnet de réclamation” or RAMQ coverage of certain procedures for last-resort financial assistance programs recipients.

ACTION

That the Government of Québec:

- › **Modernize the *Individual and Family Assistance Act* with the goal of overhauling social assistance and social solidarity programs to move them away from the punitive logic of financial assistance of last resort and the “welfarization” of disability by 2027,**
- › **Modernize the assessment of severe constraints to employment for people with disabilities, through a more comprehensive assessment of psychosocial factors and the use of the definition of disability under the *Convention on the Rights of Persons with Disabilities*,**
- › **Evaluate the possibility of decoupling programs under the *Individual and Family Assistance Act* from health and drug benefits for individuals.**

Improve the Basic Income Program

Since 2018, the Society has worked in collaboration with the Ministry of Labour, Employment and Social Solidarity to outline, work on and help implement the Basic Income Program (PRB). This program represents a major step forward for people with severe employment constraints, but much remains to be done to improve it.

In particular, the Society would like to see the PRB really lift recipients out of poverty, cover their basic needs and for them to be truly socially included. Several details of the program's bylaws would also benefit from improvement.

Furthermore, the Society would like to see admission to the PRB extended to categories of people with greater responsibilities as caregivers. These people are often forced to leave their jobs and live in precarious conditions. It is therefore important that the Government of Québec allow them to live a more dignified life as long as they are caring for loved ones requiring constant care or support.

ACTIONS

That the Government of Québec improve the Basic Income Program in order to:

- › Increase the benefit to the average sustainable income as calculated annually by the Institut de recherche et d'informations socioéconomiques (Hurteau, Labrie, and Nguyen 2021; Vivian Labrie, Minh Nguyen, and Julia Posca 2022);
- › Immediately admit to the Basic Income Program all people with severe employment constraints, without any passage through the Social Solidarity Program, OR ALTERNATIVELY: Reduce the length of time required to qualify to 30 months of participation in the Social Solidarity Program within the last 36 months;
- › Eliminate completely the reduction rates tied to earnings and work income;
- › Fully individualize the benefit by removing the consideration of spousal income;
- › Review the method of calculating the personal expenses allowance for PRB recipients in RI-RTF and CHSLDs;
- › Without going through the Social Solidarity Program, give immediate access to:
 - Persons under guardianship and persons who will be subject to a modulated guardianship equivalent to the level of the incapacity of the current guardianship after the provisions of the *Act to provide better protection for persons in vulnerable situations* come into force;
 - Caregivers who had to leave their jobs to take care of a loved one full-time;
 - Parents of children with particularly high needs who had to quit their jobs to provide care for their child.

Implement the Canadian Disability Benefit

In 2021, the Government of Canada announced its intention to create a Canada Disability Benefit. This benefit is expected to lift out of poverty hundreds of thousands of Canadians with disabilities across the country. It is important, however, that the Benefit be well designed and not lead to cutbacks in the provinces and territories.

The Society believes that while the benefit is a good idea, it must be built with simplicity and the needs of people at the heart of its design. The benefit must be implemented in collaboration with provincial and territorial governments so that it does not create confusion and does not undermine existing social benefits.

ACTIONS

That the Government of Canada:

- › **Implement the Canada Disability Benefit as soon as possible to allow people with disabilities to live with dignity across the country. This should be done in collaboration with provinces and territories;**
- › **Work with the provinces and territories to ensure that programs and benefits are complementary and do not adversely affect people receiving provincial or territorial disability assistance programs.**

Review the Disability Tax Credit and Promote the Registered Disability Savings Plan

The Disability Tax Credit (DTC) is an important fiscal tool for people with disabilities in Canada. This federal tax credit reduces the tax burden of many people with disabilities who have employment gains. However, eligibility is sometimes difficult, and the credit does not provide any benefit to people with low incomes.

On the other hand, the Registered Disability Savings Plan (RDSP) is a plan that allows funds to grow tax-free, while receiving additional funds from the Government of Canada. This financial instrument is very useful to people with disabilities, especially for parents with children with disabilities who wish to secure their financial future. However, it would be better if the RDSP was more flexible, particularly to promote access to property or the possibility of covering larger one-off expenses without penalty.

Unfortunately, application rates for the DTC and enrolment in the Registered Disability Savings Plan are significantly lower in Québec than in the rest of Canada. It is therefore important that the Government of Canada promote the DTC and RDSP to Francophones across the country and to financial institutions, so that they offer it more broadly.

ACTION

That the Government of Canada:

- › **Revise the criteria and procedures for accessing the DTC and make it refundable;**
- › **Improve the Registered Disability Savings Plan to make it more flexible and responsive to the real needs of those who receive it;**
- › **Work to promote the DTC and RDSP in Québec and among Francophones across the country;**
- › **Assist individuals who may be eligible for the DTC and RDSP in applying for these programs.**



VII. Transportation, Justice, Marginality

Inclusion in society is not just about access to work or generous financial support programs, it is also about being able to be mobile, having access to justice and having an adequate social safety net.

Review and Modernize the Paratransit System

Transportation is a key element in achieving an active and relevant social role, as well as in developing a form of independence for people with intellectual disabilities. Renewed efforts should be made to facilitate its availability. Like all other citizens, people with intellectual disabilities should be able to move around in accordance with their real needs, without budgetary, organizational, or temporal obstacles, in all regions of Québec.

The adoption of the *Act respecting remunerated passenger transportation by automobile* (“Bill 17 on taxi”) raised both fears and hopes with regard to the supply of paratransit in Québec. Some feared that by almost completely deregulating the taxi industry in Québec, services would be negatively impacted. Others thought that the end of the taxi monopoly would have a positive effect on the supply of paratransit. Ultimately, the situation of paratransit continued to deteriorate, despite having been relatively protected in the new law.

The Society considers that given the continuing deterioration of services—particularly in the rural regions of Québec—some flexibility in the supply of paratransit services would be appropriate, as long as training for drivers is adequate. Transportation needs remain immense and the supply is not sufficient to meet the demand (Lamotte, Lavigne, and Émond 2017). Everywhere in the regions of Québec, associations and families report problems with access to paratransit. Activities are cancelled due to lack of transportation, travel is limited to certain days and times of the day, medical transportation is cancelled, etc.

ACTIONS

That the Government of Québec:

- › Invest massively in paratransit or alternative transportation means to increase the service offer;
- › Develop an adapted training program for people living with intellectual disabilities to prepare them for the use of paratransit;
- › Compel regional transportation services to offer paratransit services covering the basic needs of people, regardless of the time of day;
- › Imposes mandatory training elements on transportation services that were authorized following the adoption of the *Act respecting remunerated passenger transportation by automobile* in order to ensure that the quality of service and the safety of users are maintained;
- › Promotes the development and use of technological tools to improve the flexibility of paratransit systems and alternative modes of transportation, while ensuring their accessibility.

Adapt the Justice System to the Particularities of People With Intellectual Disabilities

People with intellectual disabilities are often subjected to excessive judicial proceedings, with little provision for them to exercise their rights and understand the situations in which they find themselves. In addition, a number of people with intellectual disabilities who may live with other difficulties (mental health, drug use, etc.) end up unnecessarily in prison due to a lack of support from the justice system and the health and social services network (Reingle Gonzalez et al. 2016).

The Society believes that the justice system should consider the particularities of persons with intellectual disabilities, in order to avoid their judicialization, while relieving the pressure on the justice system.

Furthermore, the initial and ongoing training of various justice professionals (e.g. lawyers, police officers) is not sufficient to make them aware of the particularities of persons with intellectual disabilities. The fact that these persons are overrepresented in the prison system is an indicator of the fact that the social net and the justice system do not really consider their particularities and needs. It is therefore important to improve the training and awareness of justice professionals.

ACTIONS

That the Government of Québec:

- › **Ensure, in collaboration with the professional orders and relevant professional schools:**
 - **That justice professionals be trained to recognize individuals with intellectual disabilities and to interact with them appropriately;**
 - **That the initial and ongoing training of these professionals be reviewed to better include people with disabilities, in particular people with an intellectual disability.**
- › **Develop and implement adaptations in the justice system for persons with intellectual disabilities, in particular to enable them to:**
 - **Exercise a full defence when they are offenders;**
 - **Understand how the system works;**
 - **Be believed when they report violence or other criminal acts.**
- › **Develop support and assistance solutions for people with an intellectual disability in the justice system who may be experiencing other problems (drug use, mental health, homelessness, etc.) in order to prevent them from being criminalized and falling into extreme poverty.**

Strengthen the Right to Legal Capacity

The right to legal capacity is a fundamental right for all individuals, whether or not they have an intellectual disability. The right to legal capacity is the right to make decisions for yourself, and to be assisted in making those decisions when necessary. This right, and the duty to accommodate, are enshrined in Article 12 of the *Convention on the Rights of Persons with Disabilities*, which Canada and Québec have ratified.

Legal capacity, also sometimes referred to as the “equal right to decide”, implies that no one should make decisions for someone else, and that people who need support in making decisions should have access to assistance and support measures.

In Québec, the reform of the *Public Curator Act* and the *Civil Code of Québec* has enshrined this principle in provincial legislation. This is a good start, but there is still much to be done, particularly with regard to the obligations of support and accommodation for those who need it. In order to continue to work towards the effective exercise of legal capacity for all and to meet its international obligations, Québec must continue to improve its legal capacity support programs and raise awareness on this important right.

ACTIONS

That the Government of Québec continues to strengthen the right to legal capacity in the province, in particular by:

- › **Including the necessary supports for people to promote their ability to decide on an equal basis, as provided for in Article 12 of the *Convention on the Rights of Persons with Disabilities*;**
- › **Funding initiatives aimed at strengthening the legal capacity of people in the community;**
- › **Abolishing the remaining provisions in guardianship regimes that deprive people of their civil rights;**
- › **Monitoring the impacts of the *Public Curator Act* reform.**

Develop Interministerial Strategies to Create a Safety Net for People With Intellectual Disabilities Living on the Margins of Society

People with intellectual disabilities often live on the margins of society and may have to contend with other factors of vulnerability. Some of them may fall through the gaps of the safety net and find themselves in situations of homelessness, exploitation, or abuse. People with intellectual disabilities are often at the intersection of multiple systems of oppression that make them vulnerable and socially isolated.

It is therefore important to reflect on ways to help people who fall through the cracks and on preventive actions that can prevent these situations from happening.

ACTIONS

That the Government of Québec:

- › **Develop interministerial programs that take into account the intersectional identities of people so as not to abandon those most marginalized in society, particularly those living with an intellectual disability;**
- › **Fund community-based programs in harm reduction, sexual exploitation and homelessness support that take into account the specificities of people with intellectual disabilities;**
- › **Strengthen collaboration between Québec government ministries and agencies (e.g., Ministry of Labour, Employment and Social Solidarity, Ministry of Health and Social Services, Ministry of Families, Public Curator, Youth Protection Services) to ensure that people with intellectual disabilities who present vulnerability factors do not fall through the gaps of the social safety net.**



VIII. Housing

The state of housing in Quebec has deteriorated in recent years. Both the general population and people with intellectual disabilities have difficulty finding adequate and affordable housing that meets their needs.

For people with intellectual disabilities, this situation is complicated by the shortage of available spots in subsidized living environments in the health and social services network. The resurgence of small institutions also raises concerns about the quality of life and autonomy of the people who live there.

Faced with this situation, families and community organizations are trying to develop alternatives.

Putting an End to Institutions and Strengthening the Monitoring of Residential Resources

Although Québec experienced a major deinstitutionalization movement in the 1970s and 1980s, the trend is for institutions to return, albeit in different forms. Indeed, due to a lack of funding, human resources, and supervision, many living environments seem to be transformed *de facto* into institutions. There is a trend towards the opening of highly regulated living environments, bringing together large numbers of people in the same space.

To understand what an institution is, the following definition was proposed by the Institution Watch task force of Inclusion Canada and People First of Canada:

An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise, control over their lives and their day-to-day decisions. An institution is not defined merely by its size. (Inclusion Canada and People First of Canada 2021).

In Québec, a lot of substitute living resources meet this definition in whole or in part. Whether it is because of a lack of staff or resources, or to maximize the profits of private companies that have a stranglehold on these living facilities, the use of institutions and the deprivation of liberty and dignity is an extremely worrying situation.

Furthermore, as alternative living facilities are increasingly privatized, there is very little supervision of the activities and services provided. Several cases of abuse have been reported in recent years. The COVID-19 pandemic further highlighted these problems, as people living in these situations were isolated for months without any contact with their families, being able to leave the facilities, and sometimes without even being able to leave their rooms. The principle of proportionality between risks and protection of people living in these environments was totally flouted and clearly demonstrated that many living environments are in fact institutions.

The COVID-19 pandemic also raised numerous questions and highlighted shortcomings in the quality of staff training, the type of activities offered, and highlighted significant deprivation of liberty in these living conditions. Outbreaks in these settings have caused concern, and the opacity of the actual living conditions have shocked the public.

The government needs to re-establish mechanisms for monitoring the quality of residential facilities through adequate funding. These controls existed in the past and were abandoned. They must be reinstated.

ACTIONS

That the Government of Québec:

- › Set up a task force on the state of substitute living environments that would exercise constant surveillance of these resources and ensure the autonomy, freedom and quality of life of their residents remains at an acceptable standard;
- › Immediately reduce the number of people allowed to live in the same residence for people with disabilities, to limit the re-emergence of institutions;
- › Ensure that people living in RI-RTF have real autonomy and can live their lives as they wish, without being constrained by the rigid routines imposed by the facilities' staff (mealtimes, outings, toilets, etc.),
- › Increase the training of workers and staff in intermediate resources (RI), family-type resources (RTF) as well as continuously assisted resources (RAC);
- › Implement a process of regular visits and quality assessment in all residential settings in the health and social services network, particularly in partnership with users' committees and associations representing individuals and families.

Foster the Development of Alternative Living Environment Models

The health and social services network have seen its housing models transformed in the last decade, notably by tending towards greater privatization of housing resources and the closure of government resources. Although there are still different types of housing resources in the health and social services network, these models lack diversity and rarely meet the needs and aspirations of people with intellectual disabilities.

Moreover, waiting times can be years long before having access to a resource in the public system. In addition to the lack of diversity, there is also a major access problem.

Faced with the dissatisfaction of the community and families, in recent years most of the innovative living environment models that meet the needs of individuals and families have been developed by parents who want to offer their children something better. Generally speaking, there has been little openness on the part of the Ministry of Health and Social Services to help these families. For the Society, it is necessary that the Ministries of Health and Social Services and Municipal Affairs listen to families and invest in the creation of different residential resources that meet the needs of individuals and families.

The Ministry of Health and Social Services should also prioritize the opening of alternative living environments managed by and for the community, not by private for-profit businesses. The commodification of living environments has led to a decline in the quality of services and the re-emergence of institutions.

ACTIONS

That the Government of Québec:

- › **Promote the development of alternative living environments, managed by and for the community, and not by private for-profit businesses;**
- › **Allocate funding and services to these environments instead of systematically resorting to intermediate resources;**
- › **Promote and fund new models of residential settings in collaboration with the community, parents' associations and relevant government departments and agencies;**
- › **Promote the creation of alternative living environments within the community, based on models of real social inclusion, and not reproducing segregationist models; and**
- › **Ensures that any new social housing constructed includes units for people with disabilities.**

Promote Home Care and Services

The presence of universal public services is one of the keys to success in keeping people with disabilities at home, regardless of the type of limitations.

In theory, home support services are a priority in Québec. However, the last update of the home-care policy was in 2004 (Ministère de la Santé et des Services sociaux 2004). As with other people living with disabilities or older people, home support is the key to ensuring stability and prolonging life expectancy. Thus, people with intellectual disabilities should be able to live in their homes for as long as possible.

Over the past four years, the Québec government has made significant reinvestments in home care and services, which is encouraging, but most of this money has gone to seniors and has been invested in private services rather than in public resources (Anne Plourde 2022). Very few additional services were mobilized for people with disabilities. Additionally, people have experienced many cuts in service hours, particularly in connection with the COVID-19 pandemic.

It is therefore necessary that the Québec government provide sufficient home care and services to all people who wish to remain in their homes. These services should include activities of daily life and activities of domestic life, as well as in-home health care.

ACTIONS

That the Government of Québec:

- › Increase the intensity of home care and services for people who wish to remain at home so that they can live independently and the services available to them meet their needs. These services should also be provided in supervised housing and alternative living environments;
- › Train home care workers on the specific needs of people with intellectual disabilities;
- › Update the policy “*Chez soi : Le premier choix - La politique de soutien à domicile*” and put in place an action plan to clarify its application;
- › Fund home support services adequately.



IX. Health and Social Services

The health and social services network has undergone numerous changes in recent years. The introduction of episodes of service has weakened the continuity of care, while COVID-19 has severely affected the lives of individuals and families who were left without any support overnight.

Furthermore, funding for services is not keeping up with an increased level of need. While more and more individuals and families are expressing need and requiring support, the network seems to be investing in administration instead.

This approach must be reconsidered and strong public services must be rebuilt.

Proceed With an Overall Increase of Intellectual Disability Services and Funding

Over the last decade, budgets for intellectual disabilities services have been relatively stagnant, not reflecting the increase in cohorts within programs and the growing need for services in the population. During this period, there has also been a marked decrease in actual services provided in the health and social services network and an increase in administrative expenditure. The network is also still trying to reorganize following the 2015 reform.

Yet the needs are great, and many families are without services at key stages in the development of their family member with an intellectual disability. Whether in early childhood or after age 21, the lack of service is obvious, and the sense of urgency is real.

The decline in services and stagnation of intellectual disabilities budgets has also meant that more and more families are turning to the private sector for services. These shortages and reliance on the private sector pose a serious threat to the principles of free and universal health services and public services in general.

It should be noted that, in addition to the issue of the equality of citizens in front of the government, a population with access to health services and, in particular, social services (Dutton et al. 2018), is generally healthier, has greater independence and costs less in future medical costs (Surgeon General of the United States of America 2011).

ACTIONS

That the Government of Québec:

- › **Significantly increase budgets and services for people with intellectual disabilities; and**
- › **Ensure that services for people with intellectual disabilities be provided by the public network on a universal basis, free and of high quality.**

Review the Organization of Services for People With Intellectual Disabilities in Order to Promote the Continuity of Services

The organization and continuity of services for people with intellectual disabilities are very important to ensure that individuals and families receive the help they may need, on an ongoing - and sometimes on demand - basis. Unfortunately, the pressure to reduce waiting lists in the network and a curative vision of health and social services have led to the introduction of episodes of services. Episodes of services are characterized by time-limited services aimed at working on specific elements of the person's functioning. Once the episode is over, the person falls back to the bottom of the waiting list or has their case closed altogether. This creates instability in the follow-up and services, and often lead to significant disorganization and behavioural problems in the long term, in addition to a feeling of abandonment on the part of individuals and families. Since intellectual disability is a permanent condition, which requires constant follow-up, albeit variable in intensity over time, episodes of service are fundamentally incompatible with the needs of individuals and families.

It is therefore necessary to review the organization of services for people with intellectual disabilities. Unfortunately, the latest reference framework published by the Ministry of Health and Social Services does not solve this issue.

ACTIONS

That the Government of Québec review services for people with intellectual disabilities in order to:

- › **Ensure continuity in the follow-up of people with an intellectual disability throughout their lives;**
- › **Promote upstream interventions to help and support individuals and families, rather than "putting out fires";**
- › **Give back to health and social services professionals a role of support and accompaniment, not simply that of managing episodes of service and managing waiting lists;**
- › **Leave cases open wherein people appear to have no specific needs, thereby ensuring a greater likelihood of access to services later;**
- › **Ensure that people are assessed annually and that they benefit from a relevant intervention plan adapted to their needs and not only to inadequate administrative requirements.**

Better Support Family Caregivers

Family members of people with intellectual disabilities often find themselves becoming caregivers. This situation, contrary to others, is generally for life. Due to the lack of support that individuals and families have from the health and social services network or the lack of adequate employability services, one or more family members often ends up leaving their job.

It is important to better support caregivers and to ensure their physical, mental, and financial well-being.

In 2020, the Québec government adopted the *Act to recognize and support caregivers*, which was a good start, but was insufficient. The Act does not provide for any elements to alleviate caregivers' poverty, does not create formal obligations for the government towards caregivers, does not consider the different needs of people based on an intersectional analysis, and does not give any clear legal status to caregivers. Furthermore, the scope of the Act was limited to the health and social services network, which considerably reduces the possibilities for caregivers.

The Society believes that the law should recognize the reality and diversity of the needs of caregivers. It is therefore necessary to reopen these issues to provide real support to caregivers.

ACTIONS

That the Government of Québec:

- › Update the laws, policies and actions plans on support for caregivers in order to:
 - Give a clear and well-defined legal status to caregivers;
 - Formalize and guarantee social and economic services and rights to caregivers;
 - Recognize the importance of addressing the incidence of poverty among caregivers;
 - Use an intersectional analysis to establish action plans and policies on caregiving;
 - Extend the provisions of the Act, policies and action plans to all ministries and agencies of the Québec government; and
- › Update the Family Support Program to ensure that services, program allowances, and eligibility criteria meet the real and diverse needs of families.

Thoroughly Review the Complaint System in the Health and Social Services Network

The health and social services network is marked by major disparities in access to services, as well as by violations of the network's obligations towards individuals. In this context, it is important that effective and efficient recourse mechanisms be available to people.

Unfortunately, in recent years, the role of Service Quality and Complaints Commissioners has been increasingly questioned. Their independence is contested by many individuals and families, who often see commissioners making decisions in favour of the network, even when situations are obviously problematic. In addition, individuals and families often fear the negative repercussions of lodging a complaint. For instance, filing a complaint against a residential resource or developmental services may expose the individual to direct or indirect reprisals. This fear often discourages families to go ahead with the process.

Adopted in 2020, the Act broadened the scope of the Network's complaint system. The Act's goal was "*to strengthen the complaint examination process in the health and social services network, in particular for users receiving services from private institutions.*" Despite this, the dispute resolution mechanisms remain inadequate.

From the Society's perspective, a thorough review of functioning within the health and services network's complaint system is in order. Additionally, more resources, independence, and importance should be accorded to users' committees. As the primary resource in the network (apart from community organizations) that can support people with concerns or complaints, it is imperative that they receive greater resources and attain formal independence.

ACTIONS

That the Ministry of Health and Social Services:

- › **Thoroughly review the complaint examination system in the health and social services network, to:**
 - **Guarantee the independence of the Complaints and Service Quality Commissioners;**
 - **Ensure that complaint review mechanisms are fair, based on a rights-based approach and independent of institutional management policies;**
 - **Allow collective complaints in certain cases where more than one person is affected;**
 - **Create a National Complaints Commissioner for Physical Disability, Intellectual Disability and Autism Spectrum Disorder;**
- › **Give more resources to users' committees and guarantee them greater independence;**
- › **Make it easier for workers in the public network who are aware of situations of abuse to report it;**
- › **Promote the *Act to combat maltreatment of seniors and other persons of full age in vulnerable situations* and its enforcement for persons with intellectual disabilities.**

Strengthen Accountability and Transparency in the Network

The health and social services network is a complex and relatively opaque machine. The data available at the Ministry level is quite limited and does not give a clear picture of the situation of the services provided, or the populations receiving them.

The difficulty of having up to date and reliable data is not new, but it has been exacerbated by changes in the network and by the use of monitoring tools that are only marginally accurate and are used randomly within the network. Thus, accountability systems must be improved and transparency in the network increased.

Additionally, in recent years whistleblowers have denounced problematic instances, mistreatment, reduced services, etc., yet a culture of silence still remains entrenched. In the Society's view, whistleblowers should be protected, rather than threatened or sued, in order to encourage the voicing of problematic situations in the network.

ACTIONS

That the Ministry of Health and Social Services:

- › **Improve accountability systems and increase transparency in the network, especially with respect to the use of financial, material, and human resources;**
- › **Focus accountability not on the quantity of services provided, but rather on the quality of those services;**
- › **Protect whistleblowers in the network when they report problematic situations.**



X. Representation of People With Disabilities in the Government Apparatus

People with disabilities are still relatively under-represented in the governmental apparatus in Québec. While the Office des personnes handicapées du Québec is supposed to play an advisory role with the ministries, agencies, municipalities and Government of Québec, this role is limited.

Furthermore, within the government apparatus, disability issues are shared between several deputy ministers of health. There is no secretariat or ministry dedicated to disability issues that can play a coordinating and supervisory role in public policies and programs related to people with disabilities.

For the Society, such a lack is insufficient and it is time for the Government of Québec to follow the example of other governments (including Canada) by creating a secretariat or ministry responsible for the inclusion of people with disabilities.

Create a Secretariat for the Inclusion of Persons With Disabilities

As mentioned, issues related to people with disabilities are mostly relegated to deputy ministers of health and social services and to the Office des personnes handicapées du Québec. As a result, disability issues are largely overshadowed in the priorities of the Ministry of Health and Social Services and other ministries and agencies of the Government of Québec. There is also a lack of coordination and a shared vision among the ministries and agencies of the Québec government.

Yet, disability issues cannot only be curative. Government action on disability issues should take into account all dimensions of people's lives, as prescribed by the Human Development Model - Disability Production Process (Réseau international sur le Processus de production du handicap 2019); and develop a holistic view of health.

Furthermore, it is imperative that elected officials be accountable for issues related to people with disabilities. For these reasons, it is necessary to create a secretariat for the Inclusion of Persons with Disabilities.

ACTION

That the Government of Québec:

- › **Create a secretariat responsible for the inclusion of persons with disabilities.**

Review the Status of the Office des personnes handicapées du Québec and Make it Independent

Since the Office des personnes handicapées is a government agency under the authority of the Ministry of Health and Social Services, it is very difficult for the Office to exercise real political autonomy. The Office's lack of independence means that the handling of problematic situations is often relegated to the Québec Protecteur du citoyen or the Vérificateur général du Québec. Actions taken regarding mismanagement or problematic circumstances are often dependent upon the availability of staff to field those complaints.

Although the Office performs important advisory work for the Québec government's departments and agencies, its lack of independence makes its action less effective and raises many questions in the community of people with disabilities.

ACTION

That the Government of Québec:

- › **Make the Office des personnes handicapées du Québec an independent entity from the rest of the Government of Québec, with a status similar to that of the Protecteur du Citoyen and the Vérificateur général du Québec.**



XI. Old Age and the End of Life

People with intellectual disabilities have seen their life expectancy increase significantly in recent decades. However, the ageing of this population is often premature and presents significant challenges in terms of ethics, health and social services, and available treatments. A specific approach to this population is needed to promote a dignified ageing and end of life.

Furthermore, the legislative and social changes surrounding medical assistance in dying in the last decade led to a reflection on the ethical issues surrounding this practice, the validity of consent, and ableism.

Develop Expertise and Services for Aging Adults With Intellectual Disabilities

There is a growing number of aging adults with intellectual disabilities. However, the understanding of their needs and specificities is very limited. Developing new knowledge and programs to better support these people is therefore crucial.

Moreover, few living environments are adapted to aging people with an intellectual disability. It is especially important to address this issue because many aging individuals with intellectual disabilities live with their elderly parents.

ACTIONS

That the Government of Québec:

- › Support the development and dissemination of new knowledge about aging individuals with an intellectual disability;
- › Sensitize Quebec government agencies and departments to the specific needs of this population;
- › Develop a service offering adapted to this population (particularly with regard to living environments), both to support families and individuals.

Protect Vulnerable Persons From Opening Medical Assistance in Dying Based on Disability

Historically, individuals with intellectual disabilities often had their rights to health and life denied when they suffered from serious or degenerative illnesses. People with intellectual disabilities have seen their life expectancy increase rapidly in recent decades, but they still experience a significantly higher mortality rate for preventable deaths than the rest of the population (Trollor et al. 2017). These factors, coupled with a higher risk of developing serious or degenerative diseases at a younger age (Strydom et al. 2009; 2007) make it necessary to protect the more vulnerable in provisions for access to medical assistance in dying (MAiD).

Since medical assistance in dying is provided in Québec and there is a possibility of extending it to cases other than those currently provided for in the Act, it is important to ensure that vulnerable persons are adequately protected.

Disability should never be a qualifying criterion for medical assistance in dying

For the Society the presence of a disability can never be a sufficient condition for access to medical assistance in dying.

People with disabilities experience ableism, often see their lives devalued in society, and live more in poverty than many other segments of the population. Therefore, if people experience intolerable suffering in relation to their intellectual disability, it is because society does not include them, and they lack services.

Rather than opening medical assistance in dying, we need to provide services and guarantee an adequate standard of living to everyone.

A firm opposition to substituted consent for incapacitated persons

It is clear to the Society that substituted consent in relation to MAiD should never be allowed for incapacitated persons.

The request for MAiD should always be tied to the validation of free and informed consent on the part of the person who will receive it; but it is important to consider that it may be difficult to assess this consent for incapacitated persons, particularly those with more severe intellectual disabilities. While these people may experience distress in relation to the death of someone close to them (Chow et al. 2017), it is generally more difficult for them to understand the permanent and irreversible nature of their own death (Anne Dusart 2008). It is therefore impossible to ensure free and informed consent for these people and under no circumstances should parents or family members be able to make such decisions without the person's consent.

Advance directives and consent

With regard to advance directives provided by a person before they become incapacitated, the Society has concerns about the validity of both consent and the procedure as such. Asking a third party to give substituted consent to a procedure that leads to death is different from making advance requests to refuse certain procedures that may lead to natural death.

In the case of advance directives in relation to MAiD, substituted consent is used to carry out a procedure leading to the person's death. The person therefore does not consent at the time of the procedure and there is no way of knowing whether the person still wishes to pursue the procedure. In the case of refusal of care directives, the person chooses to stop care and provides direct consent for natural death to occur.

In this sense, opening the door to substituted consent, even for people who had previously consented, seems dangerous and not in accordance with the essence of the *Carter* decision which placed consent at the centre of access to MAiD.

A need for more statistics and monitoring

Reports on access to MAiD lack sufficient detail and evidence to really assess the impacts of opening that option to an increasing range of people. Thus, it is very difficult to know whether people requesting medical assistance in dying have received sufficient services, and if they are of adequate quality. As more news reports point to the fact that people with disabilities are resorting to medical aid in dying due to a lack of adequate services or because they are living in extreme poverty, this poses a major concern. All levels of government must improve their statistical compilation methods so that we can understand this phenomena better.

In this respect, the Vulnerable Persons Standard (Michael Bach and al. 2016) was developed by experts, ethicists, physicians and researchers in the field and provides additional protections for vulnerable people to ensure that they do not receive MAiD without their free and informed consent. The Standard has received broad consensus from groups representing vulnerable people across Canada. The Society therefore endorses it.

ACTIONS

That the Governments of Québec and Canada:

- › Do not allow medical assistance in dying to be provided simply on the basis of the presence of a disability when people are not at the end of their lives;
- › Do not allow the use of substituted consent for persons with an intellectual disability, especially those who are incapacitated;
- › Do not allow the use of advance directives for people with intellectual disabilities;
- › Implement the "Vulnerable Persons Standard";
- › Strengthen the collection of statistical data on the use of medical assistance in dying by persons with disabilities, including the social determinants of health and the socio-economic conditions of people with disabilities.

Provide Palliative Care Adapted to the Needs of People Living With Intellectual Disabilities

As mentioned previously, people with intellectual disabilities have seen their life expectancy increase rapidly in recent decades. The ageing of this population creates new issues surrounding the end of life and the palliative care needed to ensure dignity in these moments (Tuffrey-Wijne 2003).

In this regard, it is worth noting that the *Act respecting end-of-life care* (Québec 2014) adopted in 2014 called for an integrated approach to end-of-life care, including palliative care. In reality, palliative care is far from being developed throughout Québec (CATHERINE HANDFIELD 2018) and funding has not followed (Cormier 2018). In order to prevent people from resorting to medical aid in dying due to a lack of palliative care, as is currently the case (Davide Gentile 2018), it is necessary to provide quality palliative care that is adapted to people's needs throughout Québec.

ACTION

That the Government of Québec:

- › Invest in palliative care and develop new models of palliative care adapted to the needs of people with intellectual disabilities.

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