

**The Future of the VPA:
Recommended Amendments to the
*Vulnerable Persons Living with a Mental Disability Act***

October 25, 2019



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Introduction

The *Vulnerable Persons Living with a Mental Disability Act* (“the *Act*”) was proclaimed in October 1996, enacted to promote and protect the rights of adults with intellectual disabilities who need assistance to meet their basic needs.

The *Act* replaced Part II of the *Mental Health Act*, which presupposed that people with intellectual disabilities were necessarily lacking in decision making capacity, and included five guiding principles which were considered groundbreaking at that time. These principles, from the preamble of the *Act*, are as follows:

Whereas Manitobans recognize that vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise;

And whereas it is recognized that vulnerable persons should be encouraged to make their own decisions;

And whereas it is recognized that the vulnerable person's support network should be encouraged to assist the vulnerable person in making decisions so as to enhance his or her independence and self-determination;

And whereas it is recognized that any assistance with decision making that is provided to a vulnerable person should be provided in a manner which respects the privacy and dignity of the person and should be the least restrictive and least intrusive form of assistance that is appropriate in the circumstances;

And whereas it is recognized that substitute decision making should be invoked only as a last resort when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself or with the involvement of members of his or her support network.

In the 23 years since its proclamation, the *Act* has been used to protect the rights of adults with intellectual disabilities who require support and assistance in making decisions. However, vulnerable persons, their supporters, their advocates and their families have reported that the *Act*'s impact and

implementation have delivered less than promised, often failing to reflect the principles said to inform the legislation and its administration.

The *Act* excludes individuals to whom it should be providing protection, erodes the rights of vulnerable persons by allowing for and encouraging overly restrictive and intrusive decision making schemes, fails to protect vulnerable victims of abuse and neglect, and fails to establish and explain strong and clear relationships between government bodies, stakeholders and vulnerable persons. These failings exacerbate the vulnerability the *Act* aims to mitigate.

Method

The present report compiles and summarizes recommendations put forward by attendees of the *Vulnerable Persons Living with a Mental Disability Act* Think Tank, which took place on March 20, 2019. In turn, these recommendations draw upon research completed by the Public Interest Law Centre (PILC) at the request of Community Living Manitoba.

Community Living Manitoba approached PILC in 2017, seeking assistance with a review of *The Vulnerable Persons Living with a Mental Disability Act*, which would identify ways in which the *Act* could be updated to address human rights concerns and implement best practices that have emerged since the *Act* was passed in 1996.

PILC reviewed the *Act* and case law considering it, analogous legislation in other North American jurisdictions, and reports, working papers and social scientific literature that set out best practices as identified by advocates and scholars alike. This culminated in the Review of *The Vulnerable Persons Living with a Mental Disability Act*, completed in 2018 with input and feedback from Community Living Manitoba and other stakeholding agencies in the province.

On March 20, 2019, Community Living Manitoba gathered 26 individuals from 18 stakeholder nonprofit and community organizations for *The Vulnerable Persons Act* Think Tank. Think Tank Attendees met to discuss possible solutions to shortcomings in the *Act* and its administration, drawing on their training, experience, and provided materials.

Literature provided to attendees included PILC's Review, the Canadian Association for Community Living's Statutory Framework for the Right to Legal Capacity and Supported Decision Making ([CACL], 2014), and the Report on the Examination of the Implementation and Impact of the *Vulnerable Persons Living with a Mental Disability Act (VPA)*, prepared in 2007 following a review undertaken by the Minister of Family Services and Housing. The recommendations made in those documents were also relied upon in the preparation of the present report. Also considered were 25 responses to questions provided to various Manitoba agencies, together representing 2374 people.

Think Tank attendees were asked to provide examples to illustrate some of the issues faced in their work that can be traced to inadequacies in the *Act*, some of which are excerpted below.

Update the principles guiding the *Act* to provide that the best interests of the individual should be based on their will, preferences and rights, or the best interpretation thereof

Our support network was developed 20 years ago and is vital to my daughter's quality of life. Through the years this circle of support has grown in their commitment to my daughter and has supported her through obstacles, discrimination, harm, ignorance and bias. They have helped her understand what was happening and alleviated her fears.

My daughter and I have never felt exempt from problems with regards to Community Living Disability Services (CLDS) especially in the area of residential supports. The support circle was incensed when my daughter was put in harm's way because of a mismatched roommate and that police were called to my daughter's home several times to deescalate a situation. The network assembled a joint meeting with the residential agency executive, the agency Board and CLDS representatives to resolve the situation.

The people in my daughter's support circle are the key to providing friendship, comfort, and stability helping her live a happy and safe life.

For the most part, five principles guiding the interpretation and application of the *Act* continue to reflect the best practices in legislative protections for individuals with impaired mental capacity. The *Act* resembles the United Nations' *Convention for the Rights of People with Disabilities* ("the CRPD") by including a presumption of decision making capacity, and similar language about protecting the independence, privacy and dignity of vulnerable persons.

Issues with this legislation arise in the gap between these principles and the policies and processes provided for by the *Act*. For instance, when making decisions on behalf of vulnerable persons, "best interests" are too often determined according to what is considered safe, appropriate, efficient or in the best interests of family, friends and supporters, rather than according to what the vulnerable person says they want or need.

Most of these issues are best addressed by amending the legislation and clarifying its language, bringing the provisions of the *Act* in closer alignment with the progressive principles intended to guide them. However, some amendments to the principles, recommended by the Canadian Association for Community Living, would facilitate better promotion and protection of the vulnerable persons' rights.

First, the principles of the *Act* should be expanded to note that decisions made with or on behalf of the vulnerable person should be determined according to their will, preferences and rights, or the best interpretation thereof. Here, "best interpretation" means the most reasonably justified inference of

the vulnerable person's will and preferences, where the support network can provide a reasonable account for its interpretation and for the decision made. Similar language is used in the CRPD, in British Columbia's *Representation Agreement Act* and recommended by the Law Commission of Ontario and the Canadian Association for Community Living (CACL).

Second, the *Act* should identify *The Human Rights Code*, the *Canadian Charter of Rights and Freedoms* and the CRPD as the primary sources of guidance for interpreting the *Act*. As well, the definitions provided in the *Act* should be consistent and compliant with the CRPD, reflecting the social model of disability and protecting the right of people with intellectual disabilities to enjoy legal capacity and social inclusion.

Update Eligibility Criteria in the *Act* to Always Align with the Most Up-to-Date Diagnostic Tool

The *Act* defines a *vulnerable person* as “an adult living with a mental disability who is in need of assistance to meet his or her basic needs with regard to personal care or management of his or her property” (s 1(1)). In turn, *mental disability* means “significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour and manifested prior to the age of 18 years” (s 1(1)).

These definitions are based on the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (the DSM-IV), which was a recent and widely used diagnostic tool when the *Act* came into force. However, the DSM has been updated twice since then, and the DSM-5, released in 2013, includes changes that are relevant to the *Act*’s evaluative criteria and should be reflected within it.

The DSM-5 is the first DSM to be a living document – that is, rather than introducing changes in new editions issued every few years, going forward, diagnostic criteria will be updated incrementally, as new best practices come to light (American Psychiatric Association [APA], 2013, p 13). For this reason, **the *Act*’s eligibility criteria should link to the most up-to-date version of the diagnostic tool**, rather than reiterate a standard which may become dated shortly thereafter.

Alternatively, the *Act* and its regulations and policies should be updated to reflect significant changes to the DSM by removing the reliance on intelligence quotients (IQs) in diagnosing intellectual disability, and removing the age of 18 as a strict developmental threshold.

Remove the Reliance on IQ in Diagnosing Intellectual Disability

The DSM-5 still makes reference to intellectual functioning, measured using standardized intelligence testing, but departs from previous editions in shifting focus and emphasis from IQ scores to clinical judgments of adaptive functioning (APA, 2013, p 33). Adaptive functioning is an individual’s ability to manage everyday tasks in the conceptual, social and practical domains – this includes skills such as reading, writing and math, social judgment and communication, and self-management in personal care, managing money and school and work tasks.

Like the DSM-IV, on which Manitoba’s policy is based, the DSM-5 provides that individuals with scores below 70(±5) are deemed to have intellectual disabilities (Community Living disAbility Services, n.d.). However, the DSM-5 notes that IQ scores should not be interpreted as precise

measures used to inform strict thresholds. The DSM-5 calls assessors to provide a comprehensive, flexible and individualized assessment that provides information about individuals' actual abilities and capacities. This change addresses criticisms of the IQ test related to its insensitivity to differences in culture and context.

Currently, policy under the *Act* is not to provide supports for individuals who have an IQ above 70. In Manitoba, individuals with IQs above the threshold have been denied services under the *Act* despite demonstrated impairments to adaptive functioning. Adaptive functioning is a better predictor of whether an individual requires supports, and if so, what kind. **Eligibility criteria in the *Act* should be updated to remove reliance on IQ in diagnosing intellectual disability.**

Remove “Manifested Prior to the Age of 18 Years” as a Strict Developmental Threshold

The DSM-5 requires the onset of intellectual and adaptive deficits during the developmental period, rather than before the age of 18 like the DSM-IV and the *Act*. This change reflects scholarly disagreement about the scope of the developmental period, and the existence of a specific, uniform age at which it can be said to end.

The *Act* has been criticized, before and following its implementation, for limiting its scope to intellectual disabilities. This limitation arbitrarily and unnecessarily excludes individuals whose mental disabilities manifested after 18, including people with traumatic brain injuries or Fetal Alcohol Spectrum Disorders, despite a frequent need for robust resources for members of these groups.

Requiring a strict developmental threshold excludes individuals who meet the criteria, but cannot provide proof that their intellectual and adaptive deficits began to manifest before the age of 18.

Eligibility criteria in the *Act* should be **updated to include all individuals who may need assistance and support in meeting their basic needs**. In the alternative, and at minimum, **the criteria should be amended to remove the age of 18 as a strict developmental threshold**, reflecting best practices in diagnosing intellectual disabilities.

Give Consideration to the Inclusion of Manitobans On Reserve

The *Act* and the regulation under it fail to contemplate or provide services for vulnerable Manitobans living on reserve. This is a significant gap in services, and the Manitoba government should dedicate resources to addressing it. Consideration should be given to the ineligibility of people on reserve who may need assistance, through legal research, collaboration with the federal

government and consultation with First Nations and other stakeholders. Canada's relatively new Jordan's Principle Child First Initiative program assists in closing service gaps for First Nations children, including those living on reserve, but does not address gaps for adults.

Provide Legal Status and Protections to Support Networks to Encourage Supported Decision Making

A vulnerable woman needed to have surgery to remove a second set of eyelashes that was growing into her eyes and causing irritation. With support from her network, she was able to attend doctor's appointments, understand what the doctor wanted to do, and consent to the surgery. However, her healthcare providers refused to recognize her consent, indicated that they needed a substitute decision maker to approve the surgery. The woman's cousin was appointed as a substitute decision maker, for both property and personal care, for the maximum time allowed, simply so she could get this surgical procedure.

It is a principle of the *Act* that substitute decision making “should be invoked only as a last resort, when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself or with the involvement of his or her support network” (Preamble). Substitute decision making appointments and renewals may not exceed five years (ss 57(4), 92(6), 144(6)).

Despite this principle, in practice, substitute decision making is invoked not as a last resort, but as a routine part of planning for people with intellectual disabilities. Appointments and renewals are frequently set at the maximum time allowed by default, especially when the Public Guardian and Trustee is acting as substitute decision maker.

This is troubling, as substitute decision making is an extreme measure that deprives vulnerable persons of their right to make choices about their own lives, and gives that right to a third party or to the state. Substitute decision making has been called a “civil death”, as it denies people with intellectual disabilities their legal personhood and thus, their legal capacity (see Perlin, 2013, p 1162; Szmukler, 2019, p 35). For this reason, the CRPD calls on State Parties to completely end the use of this practice.

Stakeholders have indicated that part of the reason for the overuse of substitute decision making is the lack of viable alternatives. Though the existence of supported decision making with support networks is acknowledged and encouraged in the *Act*, legal status or protections are not provided.

The *Act* defines a support network as “one or more persons” chosen by the vulnerable person to “provide advice, support or assistance to a vulnerable person”. These supporters engage in supported decision making. Through their relationship with the vulnerable person, the supports know and respect the vulnerable person's will, preferences and rights, and honour the vulnerable person's decisions. A

lack of rights and protections for supporters may compel them to apply to be substitute decision makers, accessing a regime with clearer rights and responsibilities.

Supported decision making is widely accepted as a best practice in allowing and assisting vulnerable persons to exercise their legal capacities (CACL, 2014; Browning et al, 2014 at 34). The *Act* **should ensure that supported decision making, a less restrictive option than substitute decision making, is viable by providing legal status and protections for support networks and supported decision making.** The government should accompany this amendment with a strategy for vigorous development of support networks, aimed at reducing the reliance on substitute decision making.

The use of support networks and substitute decision makers should be based on the will and preferences of the vulnerable person. If the vulnerable person communicates their desire for an individual with whom they have an established trusting relationship to provide support in the vulnerable person's exercise of their legal capacity, and the individual is dedicated to the vulnerable person's well-being and able to communicate with the vulnerable person to ascertain their will and preferences, the vulnerable person and the prospective supporter should be able to apply for the latter to be recognized as a supporter and recorded as part of the vulnerable person's support network.

Among the duties of formal supporters would be the duty to act diligently, honestly and in good faith, and to be guided by the vulnerable person's will and preferences, values, beliefs and wishes. Vulnerable persons are entitled to the dignity of risk (Perske, 1969), meaning that the supporter's duties should prioritize vulnerable person's right to self-determination.

The *Act* should also provide an avenue by which supporters can access information and documents to which the vulnerable person is entitled, where those documents relate to the supporter's area of appointment under the relevant arrangement, and protect supporters from liability for injury, death, financial damage or loss as long as the supporters were complying with their duties as specified in the *Act*.

Address Barriers to Appointing Necessary Substitute Decision Makers

Jane spent several years in an institution, with the Public Trustee acting as her supported decision maker for property and personal care. After Jane moved into the community, her agency observed increasing challenges in helping Jane to access her money from the Public Trustee, especially when plans were outside of Jane's annual financial plan. Accessing funds was time-consuming and sometimes impossible. When Jane asked how much money she had, no one in her support network knew.

The agency told Jane's family that they could improve Jane's quality of life by replacing the Public Trustee as Jane's supported decision maker. The family did not know that this was possible, nor much about substitute decision making at all. With information from the agency, two of Jane's nieces stepped forward, applied and were appointed as substitute decision makers for Jane. The entire support network was surprised at how much money Jane had – she had the means to do many of the things on her wish-list, including traveling to visit friends and family. Her family involves Jane in financial decisions, and when she faced serious health issues, gave Jane advice and advocated on her behalf.

When a vulnerable person's support network has exhausted other mechanisms, and must resort to allowing a member of the network to apply to be a substitute decision maker, the *Act* and its regulation should not be a barrier to doing so.

Members of vulnerable person's support networks, including family and friends, have observed an excess of unnecessary red tape that has prolonged the application process or prevented individuals from choosing to apply to be substitute decision makers.

Applicants report navigating an overwhelming amount of bureaucracy, and being treated as suspicious and untrustworthy when appearing before hearing panels, the advisory panels established to provide the Vulnerable Persons' Commissioner with recommendations regarding substitute decision making appointments. Consideration should be given to addressing the barriers faced by those applying to be substitute decision makers for personal care and/or property management, where such an arrangement has been shown to be necessary.

Update the Approach to Abuse and Neglect in the Act

Two workers witnessed a colleague hit a vulnerable person across the face, reported this to their supervisor, and filled out incident reports, which were sent to the Department of Families. The accused worker confirmed that she hit the vulnerable person, and submitted a written version of events that matched that of the witnesses. The vulnerable person does not communicate verbally, so was unable to speak to the impact of the event on him, though staff reported some subtle changes in his behaviour.

The result of the investigation was determined to be “inconclusive”, primarily due to lack of evidence of physical or psychological trauma. The accused was dismissed, but not placed on the Adult Abuse Registry, and continued to work with another agency, sometimes working with the same vulnerable person. This was brought to the Department’s attention, but the Department responded that it could not notify the other agency.

Update the Definitions of Abuse and Neglect

The definitions of *abuse* and *neglect* in the *Act* both require the act or omission to be “reasonably likely to cause death”, “serious physical or psychological harm” or “significant loss” to property (VPA, s 1(1)). *Serious physical or psychological harm* are not defined in the *Act*, and stakeholders have suggested that this has led to inconsistent interpretations and thus, inconsistent reporting.

The *Act* imposes a duty to report abuse or neglect on any person who has reasonable grounds to believe that such maltreatment is occurring or is likely to occur. In practice, some service providers believe that only extreme or easily identifiable instances of abuse or neglect should be reported. This excludes, for instance, ongoing mistreatment that has a cumulative effect on a vulnerable person, the arbitrary denial of ordinary privileges and freedoms by service providers, and general nastiness or cruelty. The *Act*’s failure to clarify what abuse or neglect can entail may contribute to the normalization of such mistreatment in the minds of vulnerable persons, service providers and others.

The scope of protection in the Act should be expanded or clarified to address a wider range of acts and omissions that deny people with intellectual disabilities their dignity and humanity.

Investigations into allegations of abuse are in the hands of CSWs in rural areas. This results in inconsistent turnaround times and inconsistent outcomes. One CSW took well over 4 weeks to investigate, while others investigate within a few days. Depending on the situation, it means that the vulnerable person may not be asked for their side of the story for weeks and staff may be suspended for weeks, waiting for the all-clear to return to work. Outcomes of the investigations are typically “inconclusive” or “not substantiated”, and frequently result in a statement from the department that the staff should not work with that particular vulnerable person anymore. This puts agencies in a precarious position, as they try to make sense of why the staff should not work with one vulnerable person but should be allowed to work with another. It’s as if keeping the complainant safe is enough, but it’s okay to roll the dice as to whether the next vulnerable person will be safe.

Provide Guidelines for Reporting and Investigating Allegations of Abuse and Neglect

The *Act* empowers the executive director or a designate to investigate reports or reasonable suspicions that a vulnerable person is being or is likely to be abused or neglected. Executive directors are appointed by the minister responsible for the *Act*, currently the Minister of Family Services and Housing and can, in writing, authorize a designate, often a community service worker (CSW) to perform their duties or exercise any of their powers.

However, neither the *Act* nor the regulations under it provide guidelines for the investigative process, and stakeholder feedback suggests that existing processes are inaccessible and ineffective. Agencies are often left in the dark regarding the investigative process or outcome, making it difficult for them to manage staff and provide suitable aftercare to vulnerable victims. In rural areas, the designate selected to exercise the executive director’s duties and powers of investigation is often a community service worker, which may present a conflict of interest.

Guidelines should be created that provide better training for the investigations of allegations of abuse and neglect, in order to increase transparency and consistency across the province. These guidelines should account for the risk factors that may increase a vulnerable person’s vulnerability, affect their perception of maltreatment and hinder their willingness or ability to report it. Risk factors may stem from the vulnerable person’s personal characteristics, from their upbringing and background or from external considerations, such as the existence and the capacity of a support network.

Where alleged abuse or neglect may reasonably constitute criminal behaviour, agencies should be compelled to notify the police, allowing mistreatment to be taken seriously, and vulnerable persons to access victim services, such as counselling. Conflicts of interest, actual and perceived, should be strictly avoided during the investigative process.

These guidelines should make clear that experiencing or being suspected to have experienced abuse or neglect does not, in and of itself, rebut the presumption that the vulnerable person is capable of making their own decisions. The fear that reporting maltreatment will undermine the vulnerable person's ability to exercise their legal capacity is a significant deterrent to coming forward.

Update the Model for Individual Plans Provided in the *Act*

Clarify the Individual Planning Model Provided in the *Act*

The *Act* requires that an executive director, or a designate, “develop an individual plan for every person who receives support services...”, and provides that the director, or a designate, may review and vary or eliminate the plan.

The *Act* does not require scheduled reviews of individual plans, does not provide guidance as to how reviews are to be conducted, and does not specify that the plans must be implemented. While the allowance for variation in planning processes may provide necessary flexibility, it is also leading to lack of clarity and consistency in program administration.

A provincial tracking mechanism for planning schedules would help to ensure that the implementation and review of plans is actually occurring. The *Act* and its regulations should be amended to clarify the purpose of individual planning, and to mandate that individual plans are reviewed annually and implemented as long as they continue to represent the vulnerable person’s will and preferences. Amendments should establish clear lines of authority, responsibility and accountability for the process of planning and implementing plans.

Introduce the Will, Preferences and Rights Standard

In developing a plan, the executive director is to “take reasonable steps to ensure that the vulnerable person and [their] substitute decision maker or committee, if any” have an opportunity to participate in developing a plan, and are informed of changes to it. However, the *Act* does not explain what “reasonable steps” are, what the planning process entails, nor what principles, besides those informing the *Act* as a whole, should guide the inclusion of vulnerable persons and their supports in this process.

Individual planning should be guided by the will and preferences of the vulnerable person for whom the plan is being made. Where the Public Guardian and Trustee is the vulnerable person’s substitute decision maker, they should be mandated to participate in the individual planning process, to ensure that the will and preferences standard is reflected and followed. The Public Guardian and Trustee’s knowledge of the vulnerable person’s will and preferences should be acquired through personal engagement with the person. Where vulnerable persons are unable to express their will and preferences, decision-making should be driven by the best interpretation thereof. This mirrors the

provision in the CRPD that the rights, will and preferences of persons who require support should guide decision making processes of which they are a part. Though this standard should be imported as a principle of the *Act* as a whole, it can be emphasized in this section as well.

Eliminate or Reduce Reliance on the Supports Intensity Scale

The Supports Intensity Scale (the SIS), a tool designed to assess the pattern and intensity of required supports based on standardized areas of life activities, behavioural and medical areas, has been criticized as a step in the wrong direction, as it continues to medicalize disability and dehumanize people with disabilities. In Manitoba, Community Living disAbility Services uses the SIS to determine a support budget level for vulnerable persons.

The SIS cannot and is not designed to reflect the complex support needs of people with disabilities with regard to the context of their individual, specific lives, environments and experiences. The American Association on Intellectual and Developmental Disabilities (AAIDD), the organization that owns and distributes the SIS and associated materials, markets this tool as “a part of person-centred planning processes that help all individuals identify their unique preferences, skills and life goals” (American Association on Intellectual and Developmental Disabilities, n.d.).

While purported to be part of a person-centred planning process, in practice in Manitoba, the SIS is the sole determinant. Much like IQ testing, SIS testing is rigid and not designed to reflect the actual, nuanced needs of vulnerable persons deemed eligible for CLDS services. The SIS should not be the sole determinant of funding, but should rather be used as a source of additional information about the person with an intellectual disability, if at all.

Compartmentalizing people with disabilities into groups, based on norm-referenced scores, and using this grouping to determine the funds and resources allocated to those people is ineffective, inaccurate, and fails to honour the intention of the VPA, which is to provide needs-based services.

Clarify the Role and Duties of the Public Guardian and Trustee

Several individuals have been unable to access information about their finances. An individual I knew wanted to go on a trip, but could not save enough money in his personal account. The Trustee would take the money away when it was over \$1,000.00. The individual was frustrated as he could not see the money and did not receive balance statements from the Public Trustee. He wanted to see his savings but could not, due to the barrier of his saved money going through the Trustee account. This was very frustrating for the individual and created much stress and upset.

The *Act* provides that the Public Guardian and Trustee may be appointed as the substitute decision maker in the absence of a capable adult without a conflict of interest who consents to being appointed. The Public Guardian and Trustee may be appointed as a substitute decision maker for property matters, for personal care or for both. As reported in the 2017/18 annual report (p 15), there were 1,153 individuals for whom the Public Guardian and Trustee was appointed as substitute decision-maker under the *Act*.

A recurrent criticism of the Public Guardian and Trustee's office is that, in practice, it focuses on risk management and efficiency, rather than on recognizing and advocating for the will, preferences and rights of the vulnerable person. Examples of such behaviour included denying requests by vulnerable persons in favour of pre-established individual plans, despite clear expressions of the vulnerable person's shifting will and preferences, and a tendency to favour choices deemed healthy or appropriate, rather than allowing vulnerable persons their legal capacity, agency, and dignity of risk.

Stakeholders have also indicated that the Public Guardian and Trustee's office is difficult to reach, disconnected from the vulnerable persons it represents and the community that supports those people, and focused on finances at the cost of the capacity and agency of represented individuals.

The role and duty of the Public Guardian and Trustee should be clarified in the *Act*, as should their duty to adhere to the *Act*'s principles, and to best practices regarding the legal capacity and agency of people with intellectual disabilities. Supports provided by the office should be guided by the will and preferences of the vulnerable person, or the best interpretation thereof.

Guidelines regarding caseload size and consultation strategies should be implemented, in order to ensure that the agents of the Public Guardian and Trustee's office are familiar enough with their clients to make decisions on their behalf. Amendments to the *Act* and its regulation should address the

role of substitute decision makers, including the Public Guardian and Trustee, regarding the use of supplemental trust funds where relevant.

The Public Guardian and Trustee office should be subject to periodic external evaluation from actors and evaluators, in order to ensure that the program remains efficient and adherent to emerging best practices in the field.

Update the Vulnerable Persons' Commissioner's Role and Duties to Include Activism and Advocacy to Safeguard the Rights of the People They Serve

The Vulnerable Persons' Commissioner, appointed in Part 4 of the *Act*, is tasked with implementing the substitute decision making provisions of the *Act*. The Vulnerable Persons' Commissioner's office is empowered to conduct preliminary investigations for substitute decision making applications, to appoint substitute decision makers and hearing panels, to receive and investigate complaints about substitute decision makers, and to provide information to vulnerable persons and supporters about the *Act*, their rights and their responsibilities.

Stakeholders have expressed a desire for the Vulnerable Persons' Commissioner's role to be more active than it is currently. Article 12(3) of the CRPD mandates that "State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity". The Canadian Association for Community Living interprets this as imposing a positive obligation on governments to provide supports that allow vulnerable people to exercise their legal capacity. While Manitoba is home to advocacy organizations that provide some of these supports, the office of the Vulnerable Persons' Commissioner should be mandated to work alongside these organizations, acting in an activism and advocacy role rather than solely an administrative one.

The *Act* should be amended to clarify the role and duty of the Vulnerable Persons' Commissioner. Part of the Office's duty should include ensuring that substitute decision making remains a last resort by providing resources that encourage and empower supported decision making.

The Commissioner should conduct periodic, meaningful reviews of substitute decision making appointments, including those made with the Public Guardian and Trustee, to determine which can be converted to supported decision making, and how.

To this end, the Office should provide ongoing, proactive outreach to all stakeholders about the principles, provisions and processes that are involved in administering the *Act*. Stakeholders to be considered include persons with a disability, families, community service workers, advocacy agencies, service providers in the fields of healthcare, banking, social services and law. This should include orientation, education and training, which should be available on a continuing basis, accommodating staff turnover, changes to support networks and best practices. Information about the *Act* and its related policies and practices should be easily accessible, provided in plain language, and

must clarify key concepts in the *Act*, to ensure uniform understanding and application among agencies and their staff, individuals with an intellectual disability and family members who may play a role in administering the *Act*. Online training and informational resources should be considered.

The Vulnerable Persons' Commissioner should track examples of systemic barriers that have stood between vulnerable persons and their right to exercise their legal capacity, and make these barriers known to the relevant Ministry and to the general public as part of the Annual Report.

Clarify the Role and Duties of Community Service Workers

Community Service Workers (CSWs) are case managers, responsible for providing and coordinating a range of community-based services and supports. CSWs' duties include determining eligibility, assessing service needs, developing and overseeing casework and financial plans, reviewing and following up on abuse allegations, and connecting vulnerable persons and their families to resources.

Community feedback indicates that, in practice, CSWs are expected to undertake a range of tasks beyond their formal job descriptions. Some tasks, such as acting as a proxy for the Public Guardian and Trustee, and determining funding levels, often constitute or appear to constitute a conflict of interest. This is particularly prevalent in rural communities, where CSWs are often the only easily accessible and available government representatives.

Consideration should be given to how to resolve this, through consultation and engagement with vulnerable persons, regional agencies, community members and CSWs themselves, giving particular thought to challenges arising in rural areas.

Introduce a Periodic Review Clause

The provisions in the *Act* once placed Manitoba on the forefront of protecting and respecting the rights of people with intellectual disabilities. However, as advocates and academics have advanced the way society understands disability and capacity, Manitoba has fallen behind.

The *Act* has not been meaningfully revised since it was proclaimed 23 years ago. The Report on the Examination of the Implementation and Impact of *The Vulnerable Persons Living with a Mental Disability Act*, completed in 2007, identified many of the same shortcomings and concerns as the present report.

The *Act* should include a mechanism for systematic statutory review as a proactive means of ensuring the *Act* is effective and up-to-date, reflecting lessons as they are learned.

By way of example, the systematic review could be structured so that the Minister may choose to appoint a board of three to five people who are not affiliated with the Commissioner's office or the Public Guardian and Trustee. Every three years, this appointed board should commence a review of the *Act*, including eligibility criteria, decision-making and individual planning mechanisms, and the roles of the Vulnerable Persons' Commission, the Public Guardian and Trustee and other system players.

In the course of the review, the reviewing board should provide an opportunity for public consultation, obtaining advice and recommendations from experts and persons or groups of persons affected by the *Act*. While the board may be free to determine how to conduct this consultation, people with intellectual disabilities should be prioritized and centred as experts in their own experiences. The board may also choose to appoint experts, or persons with special knowledge, to assist in the review.

Within six months of commencing the review, the board should be tasked with preparing and submitting a report to the minister, detailing a description of the consultation and results of the consultation, and the board's recommendations about the reviewed matters. The minister should subsequently review the effectiveness of the *Act* and its regulations, and decide whether to recommend changes or to require further review.

Additional Considerations

Stakeholders did not have the opportunity to conduct a complete consultation about areas of concern within the *Act* which were raised prior to the completion of this report. In an effort to reflect the full scope of the conversation about the shortcomings in and surrounding the *Act*, these areas are discussed in brief below.

Informing and Empowering Vulnerable People

Stakeholders suggested that vulnerable people are too often kept in the dark about their scope of their substitute decision maker's powers and responsibilities, or, where applicable, those of the Public Guardian and Trustee. Vulnerable people party to the substitute decision making regime should be informed of their substitute decision maker's exact powers and responsibilities in writing, and efforts should be made to ensure that the vulnerable person understands the content of that document.

Policies and Procedures around Bonds and Sureties

A stakeholder felt that Manitoba government's policies and procedures on bonds and sureties for substitute decision makers for property are too strict. Where a vulnerable person's assets are valued at \$5,000 or more, a person applying to be a substitute decision maker may have to provide a personal bond, a surety and/or evidence of unencumbered assets equal to or greater than the value of the vulnerable person's assets.

While these policies are designed to guard against financial mismanagement and abuse, they may present a financial and bureaucratic barrier for substitute decision makers and alternates who have difficulty understanding the process, or who do not have enough money or assets to provide what is requested. These policies may also discourage the vulnerable person's family and friends from applying to become the substitute decision maker, increasing the number of vulnerable persons referred to the Public Trustee.

Annual Accounting Forms and Others

Stakeholders felt that annual accounting forms, which substitute decision makers are required to fill out, were too difficult for laypersons in this role to understand and complete. They suggested that

these form, as well as other forms presenting a barrier to comprehension, should be made more accessible through conversion to plain language. As well, sample forms and tutorials for completing these forms should be made available in person and online.

Appendix A
VPA Think Tank Participants

Abilities Manitoba
Arcane Horizon
Braunstein and Associates
Cerebral Palsy Manitoba
Community Living Manitoba (4)
Continuity Care
enVision Community Living
Inclusion Selkirk
Inclusion Winnipeg
Innovative LIFE Options
New Directions (2)
People First of Manitoba
People First of Selkirk (2)
Public Interest Law Centre (3)
Pulford Community Living
St. Amant (2)
Winnserv
Dr. Zana Lutfiyya

References

Legislation

Canadian Charter of Rights and Freedoms, Part I of the *Constitution Act*, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11.

The Human Rights Code, CCSM c H175.

Representation Agreement Act, RSBC 1996, c 405, s 2.

Vulnerable Persons Living with a Mental Disability Act, CCSM 1983, c 29.

Vulnerable Persons Living with a Mental Disability Regulation, Reg 208/96.

Other

American Association on Intellectual and Developmental Disabilities, “Supports Intensity Scale”[®], online: <<https://aaid.org/publications/supports-intensity-scale>>

American Psychiatric Association. (2013). Anxiety Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.) <<https://doi-org.uml.idm.oclc.org/10.1176/appi.books.9780890425596>> at 13.

Bach, M., & Kerzner, L. (2014). A New Paradigm for Protecting the Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice. Commissioned by the Law Commission of Ontario. Retrieved from <<https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf>> [perma.cc/46SX-PZFH].

Browning, M., Bigby, C., & Douglas, J. (2014). Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 34-45.

Community Living disAbility Services – Services denied – dismissed, Reasons for Decision: Order

#1718-0244, n.d., online: <www.gov.mb.ca/fs/ssab/decisions/pubs/1718-0244.pdf> [perma.cc/LRE6-8B8Z];

Community Living disAbility Services – Services denied – confirmed, Reasons for Decision: Order #AP1617-06-0225, online: <www.gov.mb.ca/fs/ssab/decisions/pubs/1617-0225.pdf> [perma.cc/2YSE-CVTS].

Lutfiyya, Z. M., Updike, M. A., Schwartz, K., & Mactavish, J. (2007). Report on the Examination of the Implementation and Impact of The Vulnerable Persons Living with a Mental Disability Act with a Mental Disability Act (VPA).

Manitoba, Family Services and Consumer Affairs, Community Living disAbility Services – Assessment and Eligibility (Winnipeg: Family Services & Consumer Affairs, 2011).

Perlin, M. L. (2012). Striking for the Guardians and Protectors of the Mind: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law. *Penn St. L. Rev.*, 117, 1159.

Perske, R. (1974). The dignity of risk and the mentally retarded. *National Association for Retarded Citizens*. (Robert Perske, “The dignity of risk and the mentally retarded” (1969) 10:1 *Mental Retardation* 24.)

Public Guardian and Trustee Annual Report 2017/18, p 15, online: <<https://www.gov.mb.ca/publictrustee/pdf/2017-2018-annual-report.pdf>>.

Szmukler, G. (2019). “Capacity”, “best interests”, “will and preferences” and the UN Convention on the Rights of Persons with Disabilities. *World Psychiatry*, 18(1), 34-41.

UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106.

The Working Group on Legal Capacity and Supported Decision Making (2014). A Statutory Framework for the Right to Legal Capacity and Supported Decision Making: For Application in Provincial/Territorial Jurisdictions in Canada. Canadian Association of Community Living. Retrieved from <<https://cacl.ca/wp-content/uploads/2018/05/Draft-Statutory-Fmwk-Legal-Capacity-June-9.pdf>>.