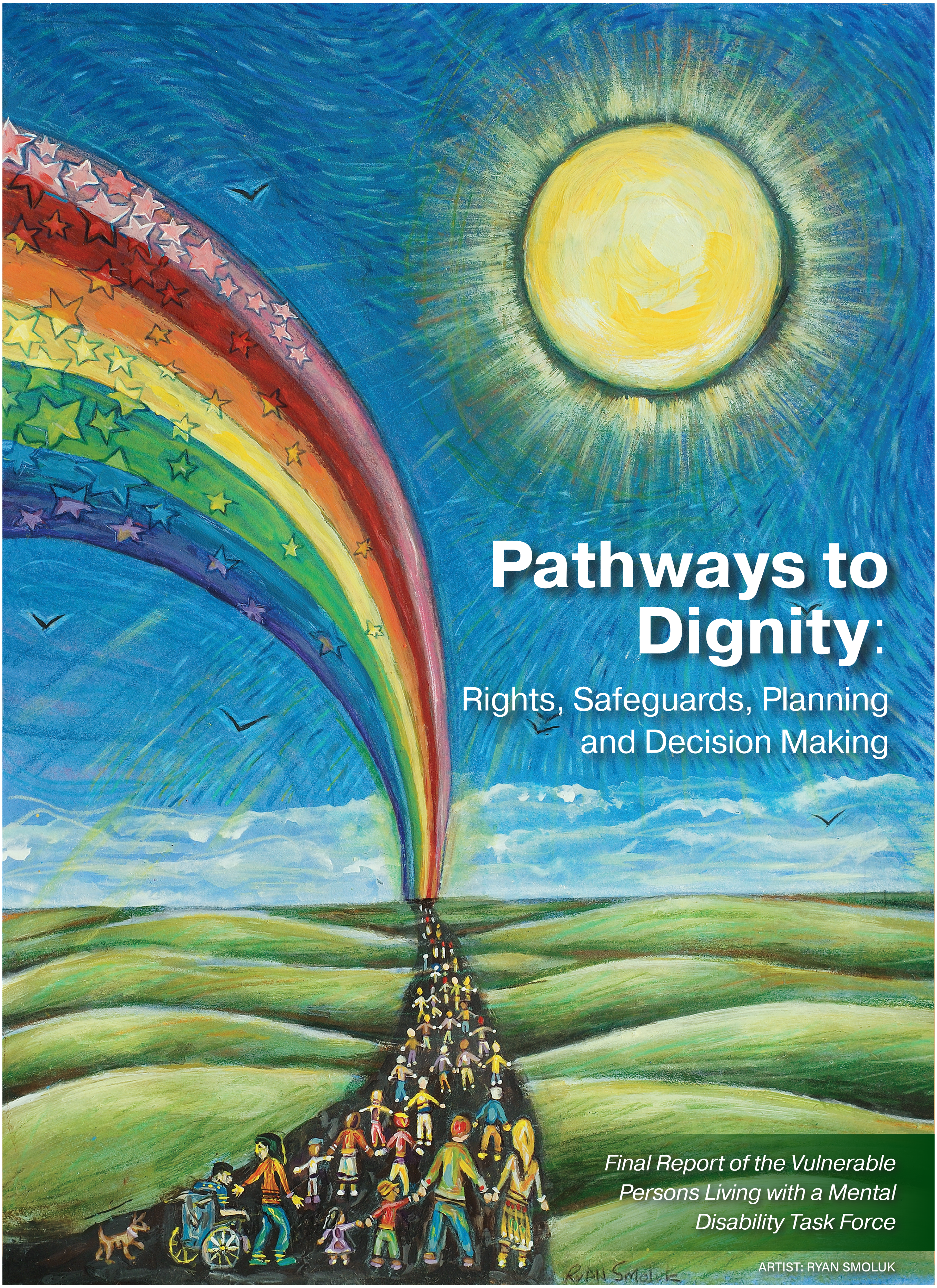

Pathways to Dignity:

Rights, Safeguards, Planning and Decision Making

Final Report of the Vulnerable Persons Living with a Mental Disability Task Force

ARTIST: RYAN SMOLUK

September 2021

Manitoba

Description of Art on Report Cover

Planning Alternative Tomorrows with Hope, known as The Path, is the name of the painting on the cover of the report. The artist, Ryan Smoluk, describes this art piece as follows:

> Everyone has a path and journey in life. When I approached this piece at 15 years old, I tried to express the need for people to walk with each other and share in each others journeys, regardless of difference. The rainbow symbolizes the diversity of everyone's path and yet the beauty that results when we all share in the same journey.

The cover art has been reprinted with permission of the artist.

This document is available in alternative formats on request. If you need to receive this document in a different format, please contact *Charissa.McIntosh@gov.mb.ca*.

Plain language explanations are used in this Report for each section, in boxes like this one. The full plain language summary is at page 72.

Contents

The **Pathways to Dignity: Rights, Safeguards, Planning and Decision Making** Report was created by a task force of nine members. These members were a dedicated, knowledgeable, insightful, respectful group of people who researched, studied and debated significant issues affecting the lives of people with an intellectual disability. We came to a consensus around 16 theme areas in a timely and efficient manner. Technical support was provided by Manitoba Families.

The task force members are:

- **Susan Boulter**
- **Kevin Johnson**
- **Scott Smith**
- **Margo Powell**
- **John Leggat**
- **Irene Hamilton**
- **Heidi Wurmann**
- **Janice Morley-Lecomte**
- **Dale Kendel**

Chair's Comments and Introduction

Chair's Comments
This report contains suggestions for the Minister of Families to improve all parts of the system for adults with intellectual disabilities. It took a lot of hard work from a lot of people. We hope this report talks about all the major issues we heard. We heard a lot of positive things, and some things that need to change. We are suggesting new ways of doing things that will make things better for adults with intellectual disabilities. Everyone will need to work together to make this happen. See Page 72 for the complete plain language version of this Report.

The Report of the Vulnerable Persons Act Task Force entitled **Pathways to Dignity: Rights, Safeguards, Planning and Decision Making** offers recommendations in 16 theme areas to the Minister of Families, Rochelle Squires.

The task force was initially set up by then Minister of Families Heather Stefanson in September 2020. The undertaking of such a serious task was accomplished thanks to the dedication, efforts, expertise and experience of the nine-member team listed on page 4.

The support and cooperation of Manitoba Families has been critically important and much appreciated. The contribution of a wealth of information from 138 individuals and organizations, representing a wide cross-section of the Manitoba population, has enlightened and given depth to the recommendations. We hope we have captured the passion, concern and emotion of all the contributors.

The **Pathways to Dignity** Report presents an exciting and transformative opportunity to update the act and policies to advance the rights and well-being of persons with intellectual disabilities in Manitoba. The overall theme of the report is about empowering communities, focusing on individuals and creating opportunities in a safer environment. The report features the use of plain language at the beginning of each section as well as a complete plain language version of the findings starting on page 72.

Individuals with lived experience, families and community agencies all desire positive change. We recognize that further consultation is required with Indigenous leadership to start a process of change around specific issues.

The implementation of the recommendations will require cooperation, leadership and a willingness to change some of our practices and policies. The goal is to reflect the original spirit of the act and build on its 25-year foundation.

The recommended changes offer innovative options that support the citizenship of individuals with an intellectual disability and create new opportunities for full participation in society. All of the proposed recommendations share a goal of creating legislation and practices that are consistent with contemporary human rights and a desire to ensure all Manitobans protected by the act are regarded as respected citizens.

We are recommending many changes. Each reflects a degree of urgency and a desire to do things better. Legislative revision, regulation changes and changes in operational procedures will be involved. Some recommendations can be implemented quickly, while others will take more time.

We must take a flexible approach that respects race, culture, sexual or gender expression, where people live and personal experience with barriers.

Collectively, implementation will be the responsibility of government, community, individuals and agencies working in partnership to support over 7500 adults with an intellectual disability in Manitoba.

The report of the task force puts Manitoba on **Pathways to Dignity: Rights, Safeguards, Planning and Decision Making**.

Respectfully submitted on behalf of task force members,

Dale H Kendel

Chair

THE ACT

ASSISTED DECISION MAKING

MONITORING PERFORMANCE — *ADVISORY COUNCIL*

STRENGTHENING COMMUNITY CAPACITY

APPEAL PROCESS AND RIGHTS RECOGNITION

TRANSITION TO ADULTHOOD — INDIVIDUAL PLANNING

HEARING PANELS

Individual & Family

COMMUNITY SERVICE WORKERS

THE VULNERABLE PERSONS COMMISSIONER

INDIGENOUS REPRESENTATION — *ABUSE AND PROTECTION*

SUBSTITUTE DECISION MAKING

PUBLIC GUARDIAN AND TRUSTEE

IMPROVEMENTS FOR FAMILIES

TRAINING AND EDUCATION

Executive Summary

The Vulnerable Persons Living with a Mental Disability Act came into force in 1996. At the time of its creation, it reflected a progressive approach based on best practices. The world has changed in the past 25 years, whereas the act has not. The understanding of disability has changed, and there is a recognition that adults with intellectual disabilities have a growing desire to be included in all parts of community life. Elements of the act and the system for adults with intellectual disabilities are no longer aligned, and it has been 14 years since government reviewed the system.

The Vulnerable Persons Living with a Mental Disability Task Force was created in September 2020 to review policies and practices around services for adults with intellectual disabilities, and provide a report and recommendations to the Minister of Families. Over the past nine months, the task force has worked diligently to explore the breadth of issues related to services for adults with intellectual disabilities. Through subcommittee work, research and consultations with community experts, the task force has touched on several major elements of the system and made recommendations related to each element. A wide cross-section of Manitobans, representing thousands of people connected to this work or affected by the act, has provided depth to our recommendations. For a full list of organizations, individuals and resources consulted, see Appendix B.

This report – **Pathways to Dignity: Rights, Safeguards, Planning and Decision Making** – addresses the services that directly impact the lives of thousands of Manitobans and their families. These services are delivered by many contributors, including different departments, multiple programs within the same department, community and service delivery agencies. They also touch on a wider array of individuals, programs and organizations in other sectors. Fundamentally, these services are about and for adults with intellectual disabilities.

Executive Summary

The Vulnerable Persons Living with a Mental Disability Act became law 25 years ago. At that time, the law did what people thought was the best. But since that time, ideas have changed. Today we think about people with intellectual disabilities differently, but the law has not changed.

In September 2020, the Minister of Families asked a group of people from the community (who we will call the task force in this document) to look at the Act, and at services that are offered for people with intellectual disabilities in Manitoba. The task force looked at a lot of things, and talked to a lot of people. We saw some good work, but there are also problems. We especially want to point out that we need to know more about the needs of Indigenous people.

This Report has suggestions for improving all different parts of the system. We think these suggestions will make the lives of people with intellectual disabilities better.

Members of the task force have witnessed the passion, dedication and expertise of individuals working in the system, the vast majority of whom have the best interests of the people they support in mind. However, the complexity of the system and the number of people and organizations involved creates challenges. The task force is concerned that the good work currently happening in individual offices and agencies is not occurring in a coherent manner that meets all the needs of adults with intellectual disabilities. Throughout its work, the task force has found evidence of gaps, inconsistencies and a lack of communication that diminishes the effectiveness of service delivery. Members also noted a disproportionate number of Indigenous people represented by the Public Guardian and Trustee as substitute decision makers, and that services for adults with intellectual disabilities do not respond well to the needs of Indigenous people. Indigenous people must be meaningfully consulted and be part of the change process.

> ***"…the Task Force has found evidence of gaps, inconsistencies, and a lack of communication that diminish the effectiveness of service delivery."***

In creating the **Pathways to Dignity: Rights, Safeguards, Planning and Decision Making** report, the task force has identified recommendations in 16 thematic areas. This report contains details on each of these recommendations. This represents only a portion of the full amount of information the task force reviewed.

The themes of the report cover:

- Establishing an advisory council
- Developing a comprehensive training strategy
- Recognizing and promoting assisted decision making
- Strengthening community capacity
- Seeking improvements for families
- Updating the principles of the act
- Establishing an appeal process
- Strengthening abuse and protection policies
- Monitoring performance of all substitute decision makers in a user-friendly manner
- Improving practices around transition to adulthood
- Consulting with Indigenous communities and leadership
- Clarifying the role of the vulnerable persons commissioner
- Improving hearing panel practices
- Improving individual planning practices
- Establishing a working group with the Public Guardian and Trustee to improve practices and discuss community issues

The task force believes that Manitoba is currently undergoing a significant shift in the role community plays in providing services to adults with intellectual disabilities. Where previously services were mostly directed in a top-down manner, the system currently reflects a greater role for community organizations. We believe this is a positive change, and many of our recommendations are aimed at supporting this shift.

Cooperation, leadership and planning are necessary to engage the appropriate people in the change process. By implementing these recommendations, Manitoba Families and other key stakeholders can transform the system in a way that leads to meaningful change in the lives of adults with intellectual disabilities.

Summary of Recommendations

The task force recommends the following:

1. Creation of an Advisory Council

Manitoba Families needs to create an advisory council to oversee the implementation of this report, and to generally oversee services under the act. The advisory council would be composed of:

- representatives from the department
- parents and family
- people with lived experience
- advocacy organizations
- service delivery agencies
- Indigenous organizations

The advisory council will be appointed by the Minister of Families. It should meet at least three times per year and receive specific updates on the implementation plan of this report (for additional detail see Appendix C).

2. Training and Education

a) Development of a Comprehensive Training Strategy

The department should work with all relevant parties to create a comprehensive, inclusive approach to training related to the act and services provided to adults with intellectual disabilities under the act. This would include outlining who is responsible for what, determining training expectations and setting minimum standards, as well as exploring innovative ways of offering training, among other issues. The training strategy must also cover the topics and audiences noted in the section on training.

b) Establishment of a Training Advisory Committee

The department should create a Training Advisory Committee reporting to an assistant deputy minister. This committee would meet quarterly to oversee the comprehensive training strategy. The committee should be co-chaired by the assistant deputy minister and Abilities Manitoba. Other members could be a representative of the Office of the Vulnerable Persons Commissioner, a community service worker representative, a parent of an adult receiving services, a person with lived experience and a representative of Red River College's Disability and Community Support program.

The Training Advisory Committee would:

- Approve the strategy for training related to the act in Manitoba.
- Ensure that training reaches all agencies and services contracted by Manitoba Families.
- Ensure all target groups are reached with training (e.g. families, individuals and substitute decision makers).
- Monitor implementation of the strategy and training plan and identify gaps or deficiencies.
- Conduct an annual review of accomplishments and deficiencies, and recommend actions for the next year.
- Inform the advisory council about the overall plan.

3. Assisted Decision Making

a) Assisted Decision Making

The department should work with a consortium of community agencies on an ongoing basis, with the initial goal of developing a pilot project to:

1. Assist individuals in having a community substitute decision maker appointed to replace the Public Guardian and Trustee.
2. Build support networks and assisted decision making so fewer individuals require a substitute decision maker.

b) Language

The term supported decision making should be replaced with assisted decision making.

c) Representation-Type Agreements

The department should engage in additional legal research and consultation with the community to determine:

i. how assisted decision making or related terms can best be defined in legislation to give the concept additional authority
ii. how a representation agreement or similar model can be incorporated into the act

4. Principles, Title and Wording of the Act

a) Updating Principles

i. Revisit the principles of the act to ensure they are consistent with other human rights and related legislation.
ii. Include a statement of rights of dignity, respect and independence, based on the United Nations Convention on the Rights of Persons with Disabilities as the first principle.
iii. Introduce a principle that decision making must be guided by the will, preferences, beliefs, desires and rights of the adult.

b) Wording, Title and Plain Language

i. Rename the legislation to eliminate the paternalistic term of vulnerable person and reflect that the act is for adults with intellectual disabilities, emphasizing their status as adults. Suggestions include:
    - The Adults Living with Intellectual Disabilities Act
    - The Adults Living with an Intellectual Disability Act: Rights, Safeguards, Planning and Alternate Decision Making
    - The My Voice, My Choice: Adult Disability Act
    - The Rights Protection and Promotion Act

ii. Rewrite the act in plain language to facilitate understanding and provide clarity.

c) Review Clause

Introduce a legislatively mandated review process with a set timeframe to evaluate and measure if the promise of the act is being realized and if it remains relevant. Work with the advisory council to determine an appropriate term for review.

5. Appeal Process and Rights Recognition

a) Rights Recognition

The department should work with community organizations to develop a neutral, safe space where families and individuals can raise questions or concerns about their rights being violated, and learn more about their options. This would need to be independent of government and service delivery agencies.

b) Appeals

The department should work with community organizations to develop a process for hearing appeals related to decisions made about adults with intellectual disabilities. This may include using existing mechanisms such as the Fair Practices Office, the Social Services Appeal Board, or considering other options such as working with advocacy services provided by Inclusion Winnipeg and other community organizations.

6. Abuse and Protection

a) Reporting Abuse

i. The department should consider a single contact point that could be used by anyone in Manitoba to report abuse of an adult with an intellectual disability, including building on existing systems such as Crime-Stoppers or creating a province-wide toll-free number. The department should determine timelines for responding based on the severity of the allegations, similar to the system for responding to allegations of child abuse.
ii. In consultation with police services, the department should create or revise guidelines for reporting abuse, including identifying when a matter should be referred to the police. This should build on and be integrated with existing processes, rather than being seen as an alternative system, in recognition of the fact that adults with intellectual disabilities have the same right to justice as all other adults.
iii. The department should work with community partners, funded agencies and families to share information about reporting abuse.
iv. For those allegations that do not meet the threshold of abuse or neglect, the department and community should work toward taking steps to address those concerns.

b) Investigations

i. The department should ensure that a specialized unit of trained investigators is able to lead investigations across Manitoba using standard guidelines. Investigations may include regional staff as needed, but should be led by the central unit.
ii. The department should create general guidelines on the process for investigations that can be shared publicly. These guidelines would outline the steps that are taken, the anticipated timelines, and what information will be communicated with whom.
iii. While respecting privacy considerations, the department should share results of investigations with the person who has made the formal allegation and the victim.
iv. When investigating abuse and interviewing victims, the department should consider the use of a single interview model such as the one used by Toba Centre for Children and Youth (investigator and social worker work collaboratively).

c) Definition

i. Review and revise the definition of abuse in the act to ensure that it aligns with best practices in other jurisdictions.
ii. Consider adding the concept of maltreatment to the act.

d) Abuse by People With Intellectual Disabilities

The department should work with partners to develop a response with appropriate guidelines and best practices for dealing with situations where adults with intellectual disabilities living in residential facilities are abusive towards one another.

e) High-Risk Situations

i. Manitoba Families should review caseloads to identify individuals who require increased supervision and oversight to reduce risk from neglect or abuse.
ii. In reviewing high-risk situations, the department should consider many factors and key determinants of risk, including poverty, isolation, risk of substance abuse and others. As an example, private home-shares were identified as an area with higher risk and low oversight by the department.
iii. The department should consider individuals who may require more support (e.g. children transitioning out of the Child and Family Services system) and make necessary adaptations to case management practices.

7. Monitoring Performance

a) Monitoring Substitute Decision Makers

i. Along with existing monitoring procedures, the Office of the Vulnerable Persons Commissioner should develop a process for conducting spot checks of a given number of substitute decision maker appointments per year (the task force suggests 20 per cent per year). This would concentrate on what is being done to advance the quality of life for the person, with the goal of building a profile of the individual and monitoring their life situation over time.
ii. Spot checks would also apply to all appointees, whether they are family, private or public guardian and trustee. In the case of the public guardian and trustee, the delegated community service worker would need to be involved.
iii. A summary of the experience with spot checks would be reported every six months to the advisory council. See Appendix D for additional questions that could be used as part of spot checks.

b) Delegation Agreements

The Office of the Vulnerable Persons Commissioner and Community Living disABILITY Services should consult with the Office of the Auditor General to determine whether existing risk assessment policies and actions taken are sufficient to protect adults with intellectual disabilities receiving services.

8. Transition to Adulthood

a) Common Transition Document

i. The department should complete revision of the document, Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional Needs from School to Community, within one year.
ii. The Bridging to Adulthood document should be used as a standardized guide for all parties when a child with intellectual disabilities is near the age of majority. This includes Child and Family Services agencies, Community Living disABILITY Services staff, Children's disABILITY Services staff, schools and families.
iii. A transitional map should be created for each person in transition, outlining the steps to be taken and the way to maintain support networks that have been developed with and for the person.

b) Children Leaving the Care of Child and Family Services

i. All Child and Family Services Authorities should adopt a common checklist of planning details for transitions.
ii. Mandatory transition planning meetings with Child and Family Services and Community Living disABILITY Services should begin at age 15.
iii. Quarterly notifications should be sent from Child and Family Services to Community Living disABILITY Services about children reaching the age of majority in the next period.

9. Indigenous Representation

i. The department should undertake consultations with Indigenous leadership and elders, social services agencies, people with lived experience and other parties to determine how Indigenous adults with intellectual disabilities are served by the act and in the broader system.
ii. All relevant parties should review their policies and practices, and amend them where needed, to ensure they are culturally sensitive and reflect the Truth and Reconciliation Commission's Calls to Action.
iii. The Advisory council should maintain a standing item on its agendas to report on Indigenous appointments, and address Indigenous matters and implementation of these recommendations.
iv. All hearing panels should begin with a treaty land acknowledgement.

10. Substitute Decision Making and the Role of the Office of the Vulnerable Persons Commissioner

a) Updating How the Commissioner Reports Information

While respecting the need to protect information, the commissioner's office should provide more information about how the commissioner came to decisions. This could include:

- Demonstrating how the commissioner determines that the appointment was a last resort, including the questions the commissioner asked to determine this, and hypothetical or anonymized examples of situations where a substitute decision maker was appointed (or not)
- Statistics about rejected applications, and situations where the decision differed from the application
- How frequently applications to vary, suspend or terminate substitute decision maker appointments are received
- Other material that would help the public better understand the decisions of the commissioner's office

b) The Commissioner's Role in Community

i. The commissioner's office should undertake a series of meetings with key stakeholders to better understand community perspectives and explain the role of the office.
ii. The commissioner should hold twice annual town halls with the public, specifically targeted at relevant stakeholders.
iii. The commissioner should meet periodically with family-based organizations such as the Family Advocacy Network or Continuity Care and consumer based organizations like People First Manitoba. The commissioner should ensure that at least one of the public town halls is targeted for families.
iv. The office should review and revise communications material it produces to determine any gaps.
v. The office should refresh and update its communications material so that it speaks to a 2021 audience.

c) Plain Language and Red Tape Review

i. The commissioner's office should review and revise all forms and information documents the office uses to ensure they are written in plain language.
ii. The commissioner's office should review all forms with a lens for red-tape reduction. Make the changes where possible or propose regulatory or legislative changes where necessary.
iii. The commissioner's office should develop a policy on waiving abuse registry checks in certain cases.

d) Proactive Approaches

The commissioner's office should support efforts to divert applications for substitute decision making where there are possible alternatives. This would involve working proactively with community partners and families at the outset of the process to determine whether a substitute decision making appointment is the appropriate path to take.

e) Monitoring

The task force also notes recommendations related to the role of the commissioner in monitoring substitute decision makers, which can be found in Section 7 (Monitoring Performance) and Section 14 (Improvements for Families).

11. Hearing Panels

Given its important role in the process, the task force felt it was necessary to include a section about the Vulnerable Persons Hearing Panel. However, specific recommendations related to the hearing panel are addressed in Section 2 (Training and Education), Section 9 (Indigenous Representation) and Section 10 (Role of the Office of the Vulnerable Persons Commissioner).

12. Individual Planning

a) Principles of Individual Planning

The principles of individual planning should be built into departmental policy:

- Knowing the person
- Listening to the person
- Connecting
- Designing supports

b) Separating Intake from Individual Planning

i. The department should clarify its approach to intake versus individual planning to ensure that the two are not treated as the same process.
ii. The department should ensure that the Supports Intensity Scale is not being used for individual planning, which is not its intended purpose.

c) Responsibility for Individual Planning

i. There should be greater clarity in the act about the role of the executive director in individual plans, as well as how this may be delegated.
ii. The executive director should recognize service delivery agencies as delegates for implementation of individual planning for persons under the act. This will require updating departmental policy and formalizing requirements through service purchase agreements with agencies.
iii. The department should work in partnership with service delivery agencies and other partners to develop options for training and education for individual planning. This training would be available to people under the act, service delivery agencies, families, support networks, substitute decision makers and Community Service Workers. This would involve addressing funding that agencies receive for training.
iv. The presence and participation of individuals, families and advocates should be assured in the individual planning process.

d) Department Oversight

i. The department should maintain a clear role in overseeing individual plans. This would include ensuring the plans are prepared, verifying that the plans adhere to guidelines and taking corrective action where necessary.
ii. The department should develop policy guidelines to outline its role.
iii. The department should explore the development of a monitoring process to ensure implementation and quality of individual plans.

13. Role of Community Service Workers

a) Role Clarity

i. The job description for community service workers should be shared publicly and in plain language format, particularly with individuals supported by Community Living disABILITY Services, families and agencies.
ii. The department should ensure that caseload sizes allow for meaningful contact with the individuals they support and the development of a trusting relationship. While different models and caseload sizes may be appropriate in different circumstances, the department should be guided by best practices and the need to ensure the best interests of supported individuals.
iii. While some difference in rural and urban casework is inevitable, the department should ensure consistency to the greatest extent possible, and that community service workers have the necessary resources to fulfill their role, including access to training.
iv. The results of the Service Transformation project should be shared within a year and expanded to other service providers as appropriate.

14. Improvements for Families

a) Support for Families

i. The Office of the Vulnerable Persons Commissioner should consult with family-focused groups such as the Family Advocacy Network, Continuity Care, Inclusion Winnipeg and others to implement family-friendly:
    - Approaches to information and forms
    - Procedures and questions in monitoring appointments
    - Training about options in decision making
    - Training about becoming a substitute decision maker

ii. When conducting spot checks with family substitute decision makers, the commissioner's office should build on its existing approach of educating into compliance when conducting spot checks. The goal would be to identify any issues and help the substitute decision maker work through them, except in cases of major violations that put the individual at risk of harm.

b) Transitions

Families should receive orientation from community service workers (or Children's disABILITY Services workers) about all the options that are available to their family regarding decision making — support networks, representation agreements (when available) and substitute decision making, as well as the role of the public guardian and trustee. The task force suggests using the Bridging to Adulthood resource as the basis for training.

c) Peer Support

i. An arrangement should be created with organizations like the Family Advocacy Network, Continuity Care, Inclusion Winnipeg or Innovative Life Options to develop and operate a peer support program with families about options in decision making, planning and protection issues.
ii. Peer support programs should be supported as part of government's approach to Strengthening Community Capacity (see Section 16 below).

d) Bonds and Sureties

The department should explore the issue of unintended consequences of the Bonds and Sureties requirement, and whether alternatives, such as group plans, may be used to reduce the burden related to bonds and sureties.

e) Additional Recommendations or Information

This report contains a number of additional recommendations and information that has impacts on families:

- Representation of families on the proposed advisory council (Section 1)
- Representation of families on the proposed Training Advisory Committee (Section 2)
- Benefits of rights recognition and an appeals process (Section 5)
- Training designed for families on the issues of transition (Section 8) and Abuse (Section 6)
- Targeted consultations with families by the Office of the Vulnerable Persons Commissioner (Section 10)
- Recent amendments to the act regarding the ten-year term renewals for family or friend substitute decision maker appointments (Section 10, footnote on page 49)

15. The Role of the Public Guardian and Trustee

a) Creation of a Working Group

i. A working group should be created with representation from the Public Guardian and Trustee, the Office of the Vulnerable Persons Commissioner, Community Living disABILITY Services, service delivery agencies and other relevant stakeholders.
ii. The working group should provide twice-yearly updates to the advisory council as proposed by the task force.
iii. The working group should focus on issues as they arise, with a particular focus at the beginning on the following:
    - Gathering stakeholder feedback
    - Supporting efforts to have an alternative for individuals who have the Public Guardian and Trustee as their substitute decision maker, either by replacement with a community substitute decision maker, or by relying on assisted decision making where appropriate
    - Providing feedback on efforts to improve and update training and education about the system for adults with intellectual disabilities
    - Considering how the values and principles that underpin the entire system for adults with intellectual disabilities can be aligned, and how those values and principles can be updated to reflect current human rights legislation
    - Exploring how to reduce the problem of siloed service delivery and miscommunication between parts of the system
    - Considering ongoing concerns around issues such as after-hours care and end-of-life care
    - Reviewing policies and practices on an ongoing basis to ensure they are coherent across the entire system and follow best practices

b) Legislative Review

Manitoba Finance should undertake a review of The Public Guardian and Trustee Act to ensure that it aligns with current human rights legislation (e.g., United Nations Convention on the Rights of Persons with Disabilities, the Canadian Charter of Rights and Freedoms, the Human Rights Code and The Accessibility for Manitobans Act), as well as other legislation dealing with adults with intellectual disabilities.

c) Review of Delegation Agreements

i. The Public Guardian and Trustee should work with Manitoba Families to review and revise the system of delegation to ensure that decision making support comes from the entity closest to the individual as possible.
ii. The Public Guardian and Trustee should develop stronger links to service delivery agencies. This may include having service delivery agencies as parties to delegation agreements.
iii. The Public Guardian and Trustee should consider how information is shared with service delivery agencies, with a view to increasing information-sharing to meet the principles of the act.

16. Strengthening Community Capacity

a) Governance and Funding

i. The department should set aside sufficient financial resources to fund ongoing projects related to supporting adults with intellectual disabilities.
ii. Government and community organizations should explore innovative approaches to funding and delivering projects including community-based funding, endowments or other government grants and social impact bonds, among others.

Background

Background

The Vulnerable Persons Living with a Mental Disability Act (the Act) is a Manitoba law that covers services for adults with intellectual disabilities. It became law in 1996, 25 years ago. Since then, the law has not been changed. In September 2020, the Minister of Families named a group of people from the community (who we will call the task force in this document) to look at the Act, and at services that are used by people with intellectual disabilities in Manitoba.

The task force learned a lot of things:

- *How people with intellectual disabilities are supported to make decisions*
- *What the vulnerable persons commissioner does and is responsible for*
- *What the Public Guardian and Trustee does and is responsible for*
- *How the act approaches protection and abuse*
- *The way the law is written and whether or not services are offered the way the law says they should*
- *How individual plans happen*
- *What community service workers do and what they are responsible for*

All of these things connect with each other. Even though the rest of this report looks at different issues, we think that all these parts have to work together.

The Vulnerable Persons Living with a Mental Disability Act is a Manitoba law that provides the authority and determines eligibility for services to adults with intellectual disabilities in the province. The act also:

- Creates the role of vulnerable persons commissioner
- Outlines the role of supported decision making
- Establishes the use of substitute decision makers, who are legally empowered to make some decisions on behalf of adults with intellectual disabilities
- Sets out requirements for individual planning for adults with intellectual disabilities under the act
- Outlines the process for investigating allegations of abuse of an adult with an intellectual disability

The act lists five principles:

- Adults with intellectual disabilities are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise.
- Adults with intellectual disabilities should be encouraged to make their own decisions.
- The adult with intellectual disability's support network should be encouraged to assist them in making decisions so as to enhance their independence and self-determination.
- Any assistance with decision making that is provided to an adult with an intellectual disability should be provided in a manner that 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.

- Substitute decision making should be invoked only as a last resort when an adult with an intellectual disability needs decisions to be made and is unable to make these decisions by themselves or with the involvement of members of their support network.

The act was proclaimed in 1996 and based on best practices of the time. In contrast to previous laws, which removed all legal decision making power from individuals when they were deemed to not have capacity, the act approaches decision making for adults with intellectual disabilities on a continuum. Individuals are assumed to have capacity unless demonstrated otherwise. The act also allows situations where people are deemed capable of making decisions in some areas but not in others. This allows a gradual, increasing degree of support in multiple areas, beginning with assistance from a group of trusted individuals in making decisions (supported decision making), up to the appointment of a substitute decision maker with legal authority.

In March 2019, community advocates from the disability sector brought together a group of stakeholders for a think tank session considering potential solutions to the shortcomings of the act and its administration. From this session, Community Living Manitoba and the Public Interest Law Centre produced a report with recommended changes to the act in August 2019.

In September 2020, the Honourable Heather Stefanson, then Minister of Families, announced the creation of a task force to provide recommendations on the way services for adults with intellectual disabilities are provided in Manitoba. The Terms of Reference established the scope and mandate of the task force (see Appendix A).

The task force was initially mandated to report by March 31, 2021. However, because of the COVID-19 pandemic, the task force was granted an extension to May 28, 2021.

The full task force met on a roughly monthly basis. Sub-committees met more frequently throughout the period of the task force's work, and brought in additional people to support their work.

The task force was not mandated to engage in widespread public consultations. However, the task force did engage thoroughly with all relevant major organizations in Manitoba, including government programs and staff, advocacy organizations, service delivery agencies, families and those with lived experience, and other related organizations. The task force also reviewed research, policy documents, scans, laws and various other documents. For a full list of resources consulted, see Appendix B.

In order to explore the full scope of the issues at hand, the task force created eight sub-committees to explore specific issues:

- Supported decision making
- Substitute decision making
- The role of the Office of the Vulnerable Persons Commissioner
- The role of the Public Guardian and Trustee
- Issues around protection and abuse
- The principles of the act and a review clause
- Individual planning issues
- The role of community service workers

These issues are interlocking, and the subcommittees found overlap in their work. A few examples help make this point:

- The role of community service workers touches on individual planning, abuse and the principles of the act, and those Workers also interact with the Office of the Vulnerable Persons Commissioner and the Public Guardian and Trustee.
- The Office of the Vulnerable Persons Commissioner is primarily linked to substitute decision making appointments, but their work has close connections to the Public Guardian and Trustee and community service workers, as well as having provisions for emergency changes or replacements to substitute decision maker appointments in cases of abuse. The commissioner is also clearly guided by the principles of the act.
- Individual planning engages community service workers and Manitoba Families, but strong individual planning can also help individuals live up to the principles of the act and assist in preventing abuse. The quality of individual plans also brings up questions of quality assurance and the role of various participants in ensuring that individual plans are strong and relevant.

In conducting its work and preparing this report, the task force had a strong desire to ensure that it took a holistic perspective. The sections below represent discrete topics, but they all build towards the larger goal of ensuring that adults with intellectual disabilities are encouraged and supported to live full, meaningful lives.

Findings By Topic

1. ADVISORY COUNCIL

The system for adults with intellectual disabilities is complex. A wide range of people and organizations interact with adults with intellectual disabilities, families and each other. One of the main observations of the task force is the significant amount of work that goes on each day to support adults with intellectual disabilities. Although this primarily occurs under the authority of The Vulnerable Persons Living with a Mental Disability Act, it touches on several other pieces of legislation, and multiple people and organizations.

The task force stresses that in conducting research for this report, its members have witnessed dedication, commitment, and a sincere passion for advancing the rights of adults with intellectual disabilities on the part of those who work in the system. However, the task force is concerned that collective good will and individual excellence do not add up to a system that meets all the needs of the population the act was meant to serve. Put simply, there are gaps, inconsistencies, and a lack of communication that diminish the effectiveness of service delivery.

Advisory Council

A lot of different people and organizations work with adults with intellectual disabilities. It's very important that all those people talk to each other, but that doesn't always happen. When people don't talk, it causes problems for everyone. To solve this problem, we are suggesting that the Minister of Families bring together a new group of people. These advisors would include people with different types of experience, including self-advocates. These advisors would also be responsible to keep track of all the work that is going on, and identifying where things could be better.

The task force feels there is a strong need for a body to provide oversight to the overall scope of the act and the multiple people working within it. This would ensure that different parts of the system are communicating with each other and that their work is being periodically overseen.

> ***"The task force feels that there is a strong need for a body to provide oversight to the overall scope of the Act and the multiple people working within it."***

Recommendation

1. Creation of an Advisory Council

Manitoba Families should create an advisory council to oversee the implementation of this report, and to generally oversee services under the act. The advisory council would be composed of representatives from the department, parents and family, people with lived experience, advocacy organizations, service delivery agencies and Indigenous organizations.

The advisory council would be appointed by the Minister of Families. It should meet at least three times per year and receive specific updates on the implementation plan of this report (for additional detail, see Appendix C).

2. TRAINING AND EDUCATION

As can be seen throughout this report, the task force was consistently informed that training is a pressing issue in the system. Training was the most common response when people were asked how to improve the implementation and understanding of the act. Good training ensures:

- The principles of the act are understood and followed
- Information is exchanged
- Skills are enhanced
- Reporting requirements are met
- Individual planning is meaningful and relevant
- Roles of all parties named in the act are clear.

The act is complex and has many parts. Training must be flexible to meet this complexity. There are a wide range of stakeholders with different needs and levels of knowledge. This too must be addressed when designing training. This may also necessitate a review of how service agencies are funded for training to ensure they can meet the expected training requirements.

The task force believes that training must cover the following:

- Introduction to the act
- The role of different participants in the system
- Related legislation, including The Public Guardian and Trustee Act, The Accessibility for Manitobans Act and human rights law
- Basic and advanced information about substitute decision making for different audiences; this would include:
  - What substitute decision making is
  - The process for applying
  - The requirements of substitute decision makers
- Basic and advanced information about assisted decision making (or supported decision making) for different audiences. This would include:
  - What a support network and assisted decision making are
  - The role of support networks and assisted decision makers
- The duty to report abuse and neglect, and the process for responding to allegations
- Basics of individual planning
- Transition from children's services to adult services
- Awareness of rights
- Awareness of Indigenous issues and cultural sensitivity
- Awareness of the diverse needs of adults with intellectual disabilities, including the impact and intersection of race, culture, Indigeneity, sexual or gender expression, experience of barriers, along with where they live in the province
- Safety for members of the Vulnerable Persons Hearing Panel
- Other matters as identified

Training and Education

Because the system is very complicated, there are a lot of things to learn about services for adults with intellectual disabilities. Everyone needs to learn: Community Services Workers, agency staff, families, self-advocates, people in the community, and other people. If people don't get the training they need, they won't learn what they need to know. We are recommending that government look at all the training it does to make sure it contains good information for everyone. We are also recommending that the Minister bring together another new group so that people can work together on training and make sure it is the best training possible.

Training would also need to be directed to different groups, including:

- Community service workers and other department staff
- Staff at the Public Guardian and Trustee’s Office
- Service delivery agency staff (including supervisors, direct service providers and respite staff)
- Board members of community agencies
- Home-share operators
- Parents, family, friends and others involved in support networks
- Adults with intellectual disabilities
- Staff in related systems (e.g. Children’s disABILITY Services and the Child and Family Services system)
- Substitute decision makers
- Vulnerable Persons Hearing Panel members
- Professionals who deal with adults with intellectual disabilities (e.g. bankers, lawyers and medical professionals)

Crucially, the task force feels it is essential that training be timely and ongoing. Delays in providing training after employees are hired means they do not have the tools they need to succeed, while a one-time approach to training leads to gaps. It is also important that staff demonstrate they have understood the training, particularly given the requirements in the Vulnerable Persons Living with a Mental Disability Regulation that a case cannot be referred to the Adult Abuse Registry Committee if the abuse occurred because of lack of training.

Training must be widely available and sensitive to the needs of different groups of people, including people who need training in different languages, as well as people in rural and remote locations. While technology and the increased use of virtual training is a positive development, not everyone has the same level of access to computers and reliable internet access.

Training currently exists to varying degrees. However, it is not provided consistently, does not target all the groups mentioned above, and critically, is not organized in a coherent way. The Community Living disABILITY Services Program offers a large amount of training, but this is not necessarily coordinated with training offered by the Office of the Vulnerable Persons Commissioner, or with service delivery agencies. Some populations, such as adults with intellectual disabilities, also seem underserved when it comes to training. Unless there is a coherent, province-wide approach to training, the task force believes the current approach will continue to lead to the issues identified in the rest of this report.

The task force also notes that training must be developed and delivered collaboratively. An overly rigid or top-down approach to training will struggle to reach all the people who need the training. The range of training and stakeholders mentioned above is large. Success will require working together.

Recommendations

1. Training and Education

a) Development of a Comprehensive Training Strategy

The department should work with all relevant parties to create a comprehensive, inclusive approach to training related to the act and services provided to adults with intellectual disabilities under the act. This would include outlining who is responsible for what, training expectations and minimum standards, as well as exploring innovative ways of offering training, among other issues. The training strategy must also cover the topics and audiences topics and audiences noted in this section.

b) Establishment of a Training Advisory Committee

The department should create a Training Advisory Committee, reporting to an assistant deputy minister. This committee would meet quarterly to oversee the comprehensive training strategy. The committee should be co-chaired by the assistant deputy minister and Abilities Manitoba. Other members could be a representative of the Office of the Vulnerable Persons Commissioner, a community service worker representative, a parent of an adult receiving services, a person with lived experience, and a representative of Red River College's Disability and Community Support program.

The Training Advisory Committee would:

- Approve the training strategy for training about the act in Manitoba.
- Ensure that training reaches all agencies and services contracted by Manitoba Families.
- Ensure that target groups are reached with training (e.g. families, individuals and substitute decision makers).
- Monitor implementation of the strategy and training plan and identify gaps or deficiencies.
- Conduct an annual review of accomplishments and deficiencies and recommend actions for the next year.
- Inform the advisory council about the overall plan.

3. SUPPORTED DECISION MAKING – ASSISTED DECISION MAKING

Supported decision making (hereafter referred to as assisted decision making to avoid confusion with substitute decision making) is a process by which people with disabilities rely on friends, family members and others to help them understand the situation and choices they face, so they can make their own decisions without needing a substitute decision maker.

Although considerable detail in the act is dedicated to substitute decision making, assisted decision making is more common, especially for individuals with greater capacity. This is natural and a reflection of reality: all people rely on assistance from others to varying degrees and people with intellectual disabilities are no exception. This assistance can range from major to minor issues. As one self-advocate stated: "My staff help me with day-to-day decisions like making supper, cleaning the house and eating healthy. I make my own choices, but they help me make the right choices." The Office of the Vulnerable Persons Commissioner estimates that roughly 30 per cent of Manitoba's known population of adults with intellectual disabilities have legally appointed substitute decision makers. This suggests that up to 70 per cent are making decisions independently or via assisted decision making.

Assisted decision making and support networks have some legal standing in the act, but in reality, the status of assisted decision making is more dependent on societal knowledge and acceptance than legislative requirements.

Supported or Assisted Decision Making
Everyone needs the help of others to make decisions in their life. For adults with intellectual disabilities, this is called "supported decision making." We like the term "assisted decision making" better, since it is less confusing.

Even though the law says assisted decision making should be happening, we don't think it is happening very much in real life. Not a lot of people know about assisted decision making. In some provinces, they have something called a "representation agreement," where an adult with an intellectual disability can decide who they would like to help them with decisions, without losing any of their rights. We think this could be a good example for Manitoba and we are suggesting that we learn more about it and how we may be able to use it here.

The importance of assisted decision making as a default way of supporting individuals is also reflected in the principles of the act. The five guiding principles state that:

- Persons with a disability are presumed to have capacity to make decisions affecting them, unless demonstrated otherwise.
- Persons with a disability should be encouraged to make their own decisions.
- A person's support network should be encouraged to assist in decision making.
- Assistance with decision making should be provided in a manner that respects privacy and dignity, and be the least restrictive and least intrusive form of assistance.
- Substitute decision making should be invoked only as a last resort.

Until the point of last resort, assisted decision making should be the primary support. While there is a need for formal substitute decision making powers in certain cases, the task force firmly believes these appointments should be made less often.

Training and Education

Discussions with a range of stakeholders at multiple levels demonstrate there is a significant lack of knowledge and understanding of the concept of assisted decision making. This has a major effect on the functionality of assisted decision making in practice. Truly functional assisted decision making requires that the individual, their family and friends, service delivery agency and community service worker all understand the nature of the arrangement and feel comfortable working within it.

Effective decision making that reflects an adult's needs and desires also requires wider societal knowledge, especially in certain sectors such as banking and law or the medical system. The task force heard examples of situations where an informal assisted decision making arrangement led to a formal substitute decision maker appointment because of a refusal from a bank or doctor to accept the decisions of the individual (and their support network). This will require concerted work that goes beyond government. However, government has a key role to play in addressing this issue.

Increasing reliance on assisted decision making

Part of the mandate given to the task force was to develop:

- A strategy to encourage assisted decision making as an alternative to substitute decision making
- A two-year action plan to reduce reliance on substitute decision makers

This is a fundamental issue. While the task force examined several elements related to the act, members believe that the best way to respect the principles of the act and improve the lives of adults with intellectual disabilities is to build support networks and assisted decision making, so the need for substitute decision making is reduced.

As noted above, regarding training and education, there is a lack of knowledge and understanding of assisted decision making and a lack of experience with it. Individuals may hesitate to become more fully engaged in a support network or as an assisted decision maker without a clearer sense of what it would mean in practice. The task force believes that government has a pivotal role to play in changing perceptions and increasing the use of assisted decision making, as well as addressing other needs identified by the community.

In Manitoba, there are few formal steps between being supported informally and having a substitute decision maker appointed. The 2019 report by Community Living Manitoba and the Public Interest Law Centre makes this point clearly: "…part of the reason for the overuse of substitute decision making is the lack of viable alternatives." While assisted decision making exists, and is mentioned in legislation, the concept is not well understood or implemented.

> ***"…part of the reason for the overuse of substitute decision making is the lack of viable alternatives."***
>
> ***-2019 Report by Community Living Manitoba and the Public Interest Law Centre***

A challenge in increasing use of assisted decision making is that it is an inherently informal process. Support networks of family, friends and community members are generally a natural development, rather than a formal structure. Nonetheless, the task force has seen ample evidence that assisted decision making can be enabled through targeted action.

The task force envisions a robust continuum of options, beginning with assisted decision making as the entry point for adults with intellectual disabilities who require some support in making decisions. The next tier of options could be representation agreements (see below). The final tier would be formal substitute decision making, which would be the exception. Ideally, many, or most, cases may be diverted to other options for support.

Options for Decision Making Supports

		First resort if support needed		**Last resort**
	Independent	**Informal Assisted Decision Making**	**Assisted Decision Making – (MB version of Representative Agreement from BC)**	**Substitute Decision Maker**
Formality	Default	Undocumented and informal	Documented and formalized – but does not require lawyer. Legitimizes the relationship that the person has with their designated supporter	Legal process
Screening	None needed	Natural supports - unscreened	Screening required	Review panel
Quantity & Types of People involved	n/a	Unpaid or paid supporters with the acknowledgement of the conflict of interest of paid supporters	Unpaid designated person or pair of persons	Unpaid appointed person or pair of persons
Timeline	Not limited by time	Not limited by time	Regular (annual?) renewal of appointment by person	Defined length of term with formal review at end of term
Authority	Person makes decisions without restriction or assistance	As identified by the person, may change day to day or decision to decision.	Designated by person for broad categories of decisions that they wish support with.	Appointed for specific decisions – i.e. health care, financial, legal, etc.
Guidance	Directed by the person	Directed by the person	Designated by the person and guided by the will, preference and rights of the person – active participation of the person	Appointed by the vulnerable persons commissioner and guided by the will, preference and rights of the person
Privacy	Person decides who they share information with	No formal release of information agreement	Could include a release of information agreement if signed by the person.	Requires release of information to substitute decision maker.
Legal Capacity	Person retains legal capacity	Person retains legal capacity	Person retains legal capacity	Person retains legal capacity

Assisted decision making would be a legislative option that relies on and builds informal support networks for individuals. Since the aim is to avoid overly formal or bureaucratic processes, this approach would rely on community leadership with government providing a supporting role. This approach would also need to be flexible to accommodate differences. Individuals without any family members are in a different situation than those with families. Assisted decision making should be equally available to both groups.

The task force believes that any new pilot project should have two main goals:

1. to assist individuals in having a community substitute decision maker appointed to replace the Public Guardian and Trustee
2. to build support networks and assisted decision making so more individuals no longer require a substitute decision maker

Existing work in Manitoba by enVision Community Living has demonstrated the viability of the first goal. There are also many international examples of successful projects to increase the use of assisted decision making. The task force does not believe that Manitoba needs to research these types of projects, as they have already been demonstrated in principle elsewhere. Rather, the focus should be on implementing lessons learned, through a project to reduce reliance on substitute decision making in favour of assisted decision making through education, training and demonstration.

This project must be co-led by both government and the community and will need adequate ongoing resources. It will also require a clear point for reporting and accountability. While the best forum for this work will need to be determined, the task force suggests that a number of core community organizations will need to be engaged.

Language

As this section has noted, the term in the act of supported decision making leads to confusion, particularly since it is very similar to substitute decision making. The task force believes that assisted decision making should be the preferred term going forward.

Representation-Type agreements

Representation agreements are documents signed by multiple parties that formalize an assisted decision making arrangement. Under such an agreement, an assisted decision maker may be allowed to receive information about the individual and help them make decisions but would not be able to make decisions on their behalf. The formality can vary. In some cases, the document may need to be prepared by a lawyer, but in general, these arrangements try and avoid legal intervention. The British Columbia model of representation agreements is held up as an international best practice for embedding assisted decision making in legislation (called supported decision making in British Columbia law). While Manitoba laws are somewhat different, the task force suggests that British Columbia (as well as some other provincial and territorial examples) offers lessons for Manitoba.

Recommendations

3. Assisted Decision Making

a) Assisted Decision Making

The department should work with a consortium of community agencies on an ongoing basis, with the initial goal of developing a pilot project to:

1. Assist individuals in having a community substitute decision maker appointed to replace the Public Guardian and Trustee.
2. Build support networks and assisted decision making so fewer individuals require a substitute decision maker.

b) Language

The term supported decision making should be replaced with assisted decision making.

c) Representation-Type Agreements

The department should engage in additional legal research and consultation with the community to determine:

- i. how assisted decision making or related terms can best be defined in legislation to give the concept additional weight
- ii. how a representation agreement or similar model can be incorporated into the act

4. PRINCIPLES, TITLE, AND WORDING OF THE ACT

Principles, Title, and Wording of the Act
The law is 25 years old. We think it needs to be changed so that it respects the human rights of people with intellectual disabilities. We also think the language of the law needs to change so that negative terms like "vulnerable person" aren't used anymore. We also think it's important that there are plain language versions available.

The Vulnerable Persons Living with a Mental Disability Act came into force in 1996 as a way to meet the needs of the distinct population of adults with intellectual disabilities, who were previously covered under The Mental Health Act. It brought in a regime that was considered progressive at the time, and is still in some respects unique across Canada.

Since the act was introduced, society's view of persons with intellectual disabilities and their rights and needs has continued to evolve. Manitobans with intellectual disabilities have established the confidence to advocate for their own independence and rights. Yet despite this, a significant percentage of this population continue to live with loneliness, isolation, poverty, and downgraded expectations compared to other citizens. As Inclusion Winnipeg noted in a submission to the task force: "The spirit and hope that was attached to the act at proclamation has, in a sense, been lost."

Although the task force was not mandated to engage in a comprehensive review of the Act, several aspects of the task force's work touched on the legislation. Several issues have been identified:

Updating the Principles

The principles outlined in the preamble provided a lens through which all the sections of the Act should be viewed. In some respects, they continue to reflect best practices, as noted by the 2019 report from Community Living Manitoba and the Public Interest Law Centre. However, as noted in more detail below, the task force found that the principles now require review and updating.

People with intellectual disabilities are people first, and entitled to the same rights as all other adults. This basic principle underpins all good practice when working with people with intellectual disabilities, and is reflected in Article 12.1 of the United Nations Convention on the Rights of Persons with Disabilities: "State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law." However, this is not stated in the principles of the act. The task force strongly believes that a people first principle should be clearly stated in the act. Similarly, decision making should be guided by the will, preferences and rights of individuals.

> ***"Article 12.1- State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law."***
>
> ***-United Nations Convention on the Rights of Persons with Disabilities***

Since the act was proclaimed, the United Nations Convention of the Rights of Persons with Disabilities was created, and has played a strong role in establishing international standards. As a signatory to the convention, Canada worked closely with the provinces and territories.

The act also co-exists with other legislation dealing with human rights, including the Canadian Charter of Rights and Freedoms, the Canadian Human Rights Code, the Manitoba Human Rights Code and The Accessibility for Manitobans Act. The task force believes that a review is necessary to ensure the act is aligned with those other laws.

Wording, Title and Plain Language

The act reflects the style of legislation written at the time of its creation. Some of the language is bureaucratic or vague, and the terminology is often outdated. Specifically, terms like vulnerable person have a negative connotation and portray adults with intellectual disabilities as vulnerable before they are anything else. This leads the task force to conclude that the title of the act needs to change. Although government will need to consult prior to any such change, the task force suggests that the name be simplified and updated (see recommendations for suggestions).

Additionally, certain terms such as supported decision making, support network or individual plan may need to be revisited to ensure they meet current best practices.

While the task force recognizes that legislation is written in a specific kind of language, the act should be reviewed to ensure clarity and precision. At the very least, it is important that families and individuals with intellectual disabilities have access to plain language descriptions of the act.

Review Clause

Currently, the act has no mandatory clause that would require a review in a set timeframe. Reviews of the legislation took place in 2007 (at the request of government) and 2019 (instigated by community organizations), but the resulting recommendations have not resulted in significant legislative changes.

Review clauses are common in modern legislative drafting, and are a useful way of ensuring that legislation does not sit unchanged for decades. While the act was best practice in 1996, the world has changed. Ensuring periodic review prevents this from occurring again.

In summary, the core of the act is still strong, and reflects elements of best practices. However, it is clearly outdated and in need of modernization, and updating to align with other legislation.

Recommendations

4. Principles, Title and Wording of the Act

a) Updating Principles

i. Revisit the principles of the act to ensure they are consistent with human rights and other related legislation.
ii. Include a statement of rights of dignity, respect and independence, based on the United Nations Convention on the Rights of Persons with Disabilities, as the first principle.
iii. Introduce a principle that decision making must be guided by the will, preferences, beliefs, desires and rights of the adult.

b) Wording, Title and Plain Language

i. Rename the legislation to eliminate the paternalistic term of vulnerable person and reflect that the act is for adults with intellectual disabilities, emphasizing their status as adults. Suggestions include:
    - The Adults Living with Intellectual Disabilities Act
    - The Adults Living with an Intellectual Disability Act: Rights, Safeguards, Planning and Alternate Decision Making
    - The My Voice, My Choice: Adult Disability Act
    - The Rights Protection and Promotion Act

ii. Rewrite the act in plain language to facilitate understanding and provide clarity.

c) Review Clause

i. Introduce a legislatively mandated review process with a set time frame to evaluate and measure if the promise of the act is being realized and if it remains relevant. Work with the advisory council to determine an appropriate term for review.

5. APPEAL PROCESS AND RIGHTS RECOGNITION

Adults with intellectual disabilities have the same rights as all other adults. This is a basic point that is recognized in the principles of the act, but needs to be reiterated. Either tacitly or explicitly, adults with intellectual disabilities are sometimes treated as though they do not have the same rights. In some situations, the act gives a substitute decision maker the final say in decisions about an individual. However, even in these cases, the rights, will and preferences of the individual should be respected.

The task force heard concerns, particularly from people with lived experience, that their rights are not being respected. This can include things such as being dismissed when raising concerns, or it can mean not knowing who to turn to when one's rights are violated. The task force feels that this is a significant issue. Whether or not violations of peoples' rights are common, every individual should feel like they have options and supports available to help them.

Appeal Process and Rights Recognition
We think it's important that people with intellectual disabilities know what to do when they don't agree with a decision that was made for them. There needs to be a safe place where people can go to talk about the problems they are seeing. Sometimes there also needs to be a way to get a second opinion about decisions. This is what's called an appeal process.

Rights Recognition Mechanism

Individuals need to know who they can talk to if they feel their rights have been violated. While adults with lived experience can reach out to their community service worker or service delivery agency, not every person feels comfortable raising such issues within the system, as they may fear repercussions. It is important that such individuals have access to a safe space to discuss concerns and learn about their options.

Appeals Process

People who support adults with intellectual disabilities, as well as those adults themselves, may disagree with decisions different participants in the system make. In these cases, it is not always clear what (if anything) can be done. The task force is concerned that families and their loved ones may feel as though they have no options. It is not obvious how and when decisions may be reviewed or appealed. In extreme cases, someone who feels a decision was wrong can seek to terminate or replace a substitute decision maker appointment, but in less urgent cases, the task force believes additional options are necessary.

Recommendations

5. Appeal Process and Rights Recognition

a) Rights Recognition

The department should work with community organizations to develop a neutral, safe space where families and individuals can raise questions or concerns about their rights being violated, and learn more about their options. This would need to be independent of government and service delivery agencies.

b) Appeals Process

The department should work with community organizations to develop a process for hearing appeals related to decisions made about adults with intellectual disabilities. This may include using existing mechanisms such as the Fair Practices Office, the Social Services Appeal Board, or considering other options such as working with the advocacy services provided by Inclusion Winnipeg and other community organizations.

6. ABUSE AND PROTECTION

A major component of the act concerns the protection of vulnerable adults. It defines the term abuse and sets out procedures for mandatory reporting, investigations and emergency intervention. This is a very important function and a primary purpose of the act, which reflects the fact that adults with intellectual disabilities are at greater risk of abuse than other adults, whether that abuse is verbal, physical, financial or other.

> ***Abuse and Protection***
>
> *The law talks a lot about abuse, including how to prevent abuse and what to do when it happens. But things don't always happen like the law says. People don't always know what to do when they see abuse. It's not clear what happens after someone reports abuse. The way the law is written means that a slap in the face might not be "abuse." We think the whole system needs to change how it handles abuse. We also think people need to be extra careful about abuse in risky situations.*

When abuse is alleged, cases go through a series of steps beginning in a review of the allegations. This can lead to a formal investigation by the department and may lead to referral to the Adult Abuse Registry. In 2019/20, Manitoba Families received 416 allegations of abuse, of which 198 were investigated, 218 were considered inconclusive, 56 were referred to police and six individuals were charged under the criminal code. Although it is technically possible to charge someone with offences under the act, this has occurred in only one case over the past three years.

The task force wishes to put a specific emphasis on protection and prevention. While having a process for investigating abuse after the fact is important, it is critical that efforts be made at all levels of the system to prevent abuse from happening in the first place.

The task force heard from a wide range of stakeholders and professionals. The feedback provided outlined a number of recommended changes to the legislation, provided valuable insight into existing training, reporting, and investigation and follow up related to the protection of adults with intellectual disabilities.

Training and Education

The way abuse is dealt with is inherently linked to training on a number of topics, including prevention, protection, reporting, investigating and determining consequences. Good training is essential for keeping adults with intellectual disabilities safe, which is reflected in the existing training on the duty to report. However, training can play a larger role than informing people about legislative requirements. A fully fleshed out training regime can help prevent abuse from happening in the first place by increasing information at multiple points in the system.

Currently, training is offered to department and agency staff on abuse issues. However, as with other areas of training around the act, there appears to be some discrepancy in the availability of training, as well as the populations that should be targeted. For instance, there is no specific training for families or individuals with lived experience about how to recognize and address abuse. This is crucial, as some adults with intellectual disabilities may not know what they can do if they feel they have been abused until it is explained to them in plain, straightforward language. There are also discrepancies in the availability of training for staff in rural locations. For additional detail, see Section 2 on Training and Education.

Reporting Abuse

While the duty to report is clearly set out in the act, the work of the task force demonstrates that there are questions around the process for reporting and potential improvements to be made. Among the concerns raised was the fact that there is no central location for reporting abuse of adults with intellectual disabilities. While all investigations involve the department on some level, it may not be obvious to many people who they should talk to when they suspect abuse has occurred.

The task force is also concerned that the process for investigating abuse under the act leads to the perception that adults with intellectual disabilities do not have access to the justice system and cannot report abuse to police. While this is not the case, the task force received questions about this from stakeholders. Complicating the matter is the fact that the criminal standard of proof is high.

Investigations

Following a report of abuse, the investigators' role is an essential one. The task force heard of discrepancies in how investigations are approached throughout the province. In particular, a team in Winnipeg is solely responsible for investigations in the city, whereas in rural Manitoba, community service workers are sometimes responsible for investigating in the same community and with the same people they work and share a community with. In some cases, agencies are asked to investigate themselves, which creates an evident conflict of interest.

The task force also heard about a lack of information on what happens after investigations, which leaves victims and families without important detail or follow-up. The 2019 report by Community Living Manitoba and the Public Interest Law Centre observes that: "Agencies and staff 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."

As the statistics cited earlier note, over half of the allegations made in 2019/20 did not lead to a formal investigation. The process can take months, and if the results are inconclusive or unsubstantiated, this is not necessarily communicated to the complainant or the alleged victim. The task force also notes that evidence from the Child and Family Services system demonstrates the value of using a single interview model, in which the victim is not forced to retell their story multiple times to different parties.

The task force stresses that adults with intellectual disabilities are adults first and foremost. They have the same access to the justice system as everyone else. The task force believes that in the future, the need for other streams of abuse reporting and investigation may not be necessary. However, in the current context, the ability of police to fully investigate abuse allegations needs to be supplemented by the work of Manitoba Families and other stakeholders. The existence of this supplementary system should not take away from the rights of adults with intellectual disabilities. Stakeholders in the justice system must also remain attuned to the needs of all people, including adults with intellectual disabilities.

Definition of Abuse

Manitoba is unique in having separate legislation to deal with adults with intellectual disabilities (covered by the act) and adults receiving services in health or geriatric day facilities (covered by The Protection for Persons in Care Act). The definition of abuse in the act is also different than that seen in some other jurisdictions.

Notably, Manitoba legislation requires that abuse or neglect be reasonably likely to cause serious physical or psychological harm. This means that a slap in the face is not necessarily considered abuse under the legal definition in the act, since it does not lead to lasting physical consequences. Such examples are at odds with common sense. The task force strongly believes that the act creates an overly strict test to prove that a person has been abused.

> ***"The task force strongly believes that the act creates an overly strict test to prove that a person has been abused."***

A number of other legislative examples exist that the task force believes are better suited to reality. As an example, Ontario regulations define abuse as:

> "Action or behaviour that causes or is likely to cause physical injury or psychological harm or both to a person with a developmental disability, or results or is likely to result in significant loss or destruction of their property, and includes neglect."

Abuse by Adults with Intellectual Disabilities

A reality of the system is that abuse is sometimes perpetrated by adults with intellectual disabilities. The task force heard that these situations can be challenging to deal with, and while they should be treated differently than abuse by other parties, they still require common solutions and discussion.

High-Risk Situations

Adults with intellectual disabilities live in a number of different types of settings, ranging from their family home, to independent living, to home-shares or other residential placements. The task force notes that some service types such as private home-shares may require more time from staff for case management, as they are not connected to an agency that could provide oversight and additional resources. The lack of connection, particularly if coupled with a lack of family or close friends, may result in increased risks for the individual.

There are 464 private home-share situations across the province. Community service workers and/or residential licensing staff have full responsibility for oversight of these placements, including:

- Developing and monitoring person centered plan
- Providing quality assurance oversight
- Providing guidance to home-share providers around assisted decision making
- Monitoring potential instances of abuse or neglect and monitoring overall well-being
- There is a requirement to see people in these placements only once per year

While the task force did not hear examples of significant problems with private home-shares, the limited contact and oversight inherently creates risks. Community service workers are placed in the difficult situation of having to provide oversight without necessarily having the time to do so adequately. Agency-operated home-shares provide more oversight and regular contact.

Recommendations

6. Abuse and Protection

a) Reporting Abuse

i. The department should consider a single contact point that could be used by anyone in Manitoba to report abuse of an adult with intellectual disabilities, including building on existing systems such as Crime-Stoppers or creating a province-wide toll-free number. The department should determine timelines for responding based on the severity of the allegations, similar to the system for responding to allegations of child abuse.
ii. In consultation with police services, the department should create or revise guidelines for reporting abuse, including identifying when a matter should be referred to the police. This should build on and be integrated with existing processes, rather than being seen as an alternative system, in recognition of the fact that adults with intellectual disabilities have the same right to justice as all other adults.
iii. The department should work with community partners, funded agencies and families to share information about reporting abuse.
iv. For those allegations that do not meet the threshold of abuse or neglect, the department and community will work toward taking steps to address those concerns.

b) Investigations

i. The department should ensure that a specialized unit of trained investigators is able to lead investigations across Manitoba, using standard guidelines. Investigations may include regional staff as needed, but should be led by the central unit.
ii. The department should create general guidelines on the process for investigations that can be shared publicly. These guidelines would outline the steps that are taken, the anticipated timelines and what information will be communicated with whom.
iii. While respecting privacy considerations, the department should share results of investigations with the person who has made the formal allegation and the victim.
iv. When investigating abuse and interviewing victims, the department should consider using a single interview model such as the one used by Toba Centre for Children and Youth (investigator and social worker work collaboratively).

c) Definition

i. Review and revise the definition of abuse in the act to ensure that it aligns with best practice in other jurisdictions.
ii. Consider adding the concept of maltreatment to the act.

d) Abuse by People with Intellectual Disabilities

The department should work with partners to develop appropriate guidelines and best practices for dealing with situations where adults with intellectual disabilities living in residential facilities are abusive towards one another.

e) High-Risk Situations

i. Manitoba Families should review caseloads to identify individuals who require increased supervision and oversight to reduce risk from neglect or abuse.
ii. In reviewing high-risk situations, the department should consider many factors and key determinants of risk, including poverty, isolation, risk of substance abuse and others. As an example, private home-shares were identified as an area with higher risk and low oversight by the department.
iii. The department should consider individuals who may require more support (e.g. children transitioning out of the Child and Family Services system) and make necessary adaptations to case management practices.

7. MONITORING PERFORMANCE

Performance in the system for adults with intellectual disabilities has several components. Depending on what is being evaluated, performance can mean different things. It could refer to the performance of individuals working in the system, or it could refer to positive outcomes for adults with intellectual disabilities. However, whichever part of the system is being examined, there are two fundamental questions that capture the essential issues of performance measurement:

- Does the action meet existing legal, regulatory or policy requirements?
- Does the action respect the spirit of the act (e.g. empowering adults with intellectual disabilities to live full lives, in keeping with the principles of the act)?

On the first question, while there are always improvements that can be identified, for the most part, participants in the system for adults with intellectual disabilities are respecting their obligations.

Making Sure the Right Things Happens

The task force looked at how we can tell when the system is doing well. One of the ways we do this is by looking at what each part of the system is doing. One thing we are worried about is the connection between people with intellectual disabilities and the Public Guardian and Trustee. Sometimes there can be many steps required and too many people involved to connect to a person's worker and get help. That makes contact difficult. We are recommending that the government look at how the connection between the person and the caseworker can be stronger.

On the second question, the task force is less convinced. There is considerable focus on following the rules, without necessarily thinking through or reimagining whether the rules are the best way of meeting the principles of the act. The task force sincerely believes that this is not the result of bad faith on the part of any particular participants. Different participants are busy doing what the act requires of them. However, the action of all the parties does not necessarily add up to a system that respects the spirit of the act. The task force heard many examples of people's experiences differing from the intent of the act.

Monitoring Substitute Decision Makers

An important part of protecting the rights of individuals is the Office of the Vulnerable Persons Commissioner's monitoring of the performance of substitute decision makers. Monitoring ensures financial assets are not misused, that debts and bills are paid, health and wellness decisions are informed and timely, and the person's desires and preferences are considered.

As Section 15 on the Public Guardian and Trustee notes, the act creates different requirements for reporting, depending on whether the substitute decision maker is a family or friend or the Public Guardian and Trustee. When the appointment is with the Public Guardian and Trustee, there is no annual accounting. Although both types of appointments are subject to a full review on application for renewal, this leaves a period of up to five years during which the vulnerable persons commissioner has no contact with either the individual or the Public Guardian and Trustee.

The task force heard concerns from many community advocacy groups, such as Continuity Care and Community Living Manitoba, about the lack of relationship between the person subject to a substitute decision making appointment and the Public Guardian and Trustee. Family and friends who act as substitute decision makers for individuals are under more scrutiny. An unequal practice exists.

> ***"Family and friends who act as substitute decision makers for individuals are under more scrutiny. An unequal practice exists."***

Even in the case of family member and friend substitute decision makers, the yearly reporting to the vulnerable persons commissioner is an annual accounting. The commissioner's office does not conduct an evaluation of other types of decision making except on renewal of an appointment. Although requirements are more robust for family members and friends, here again, there is arguably a gap in performance measurement and monitoring.

Delegation Agreements

The use of delegation agreements by the Public Guardian and Trustee, where substitute decision making responsibility for some decisions is delegated to community service workers, also raises questions about performance measurement. As is discussed in Section 13 on community service workers, those workers no longer have a substantial role in case management, as this function now largely rests with service delivery agencies. This creates three layers between the individual and the person legally responsible for making decisions on their behalf (the Public Guardian and Trustee), and four layers between the individual and the person who decides on the suitability of their substitute decision maker (the vulnerable persons commissioner). While some level of distance between the vulnerable persons commissioner and individuals with substitute decision makers is to be expected, it creates challenges for evaluating how well services respect the will, rights and preferences of the person. The task force also heard a number of instances where communication concerns due to the multiple layers resulted in delayed and lost opportunities, and unmet needs for individuals.

The task force suggests that a new approach needs to be taken to monitoring, to build on the existing system in a way that allows all parties to focus on the spirit of the act, rather than relying on legal and policy requirements as a check-box.

Spot checks may be used by the department as a way of reviewing practices involving individual planning, abuse training, and understanding of policies of the department. It is meant to be used as a non-punitive measure and education tool for improvement as needed.

Recommendations

7. Monitoring Performance

a) Monitoring Substitute Decision Makers

i. Along with existing monitoring procedures, the Office of the Vulnerable Persons Commissioner should develop a process for conducting spot checks of a given number of substitute decision maker appointments per year (the task force suggests 20 per cent per year). This would concentrate on what is being done to advance the quality of life for the person, with the goal of building a profile of the individual and monitoring their life situation over time.

ii. Spot checks would also apply to all appointees, whether family/private or Public Guardian and Trustee. In the case of the Public Guardian and Trustee, the delegated community service worker would need to be involved.

iii. A summary of the experience with spot checks would be reported every six months to the advisory council. See Appendix D for additional questions that could be used as part of the spot checks.

b) Delegation Agreements

The Office of the Vulnerable Persons Commissioner and Community Living disABILITY Services should consult with the Office of the Auditor General to determine whether existing risk assessment policies and actions taken are sufficient to protect adults with intellectual disabilities receiving services.

8. TRANSITION TO ADULTHOOD

Children with intellectual disabilities enter the adult services system through several channels. Some come into contact through the education and Children's disABILITY Services systems. Others are children in the care of Child and Family Services agencies. The transition from adolescence to adulthood is one of the most important and challenging periods of a person's life, especially for someone with an intellectual disability. The task force found that there are two distinctly different experiences, depending on the individual's living arrangements before age 18.

Transition to Adulthood

When you turn 18, you become an adult with rights and new responsibilities. Youth with intellectual disabilities enter the system for adults in different ways. For some youth, they enter the system for adults with the help of their parents and family.

Other youth are being taken care of by Child and Family Services and don't always have family support. Schools and the government are also involved. Different parts of the system don't always share information, and that makes the switch to adult services even harder. That's especially true for youth leaving Child and Family Services care, and Indigenous youth. We are recommending that everyone work together to make sure youth are getting the support they need when they turn 18.

1. Children with Intellectual Disabilities Living at Home with Parents:

These children, when they reach their 18th birthday, have rights and can make decisions about their own lives, independent of parents and family. Families indicated that this is a period of change for the individual and for the supporting family. Adjustments are needed from all sides. The individual's needs vary based on their capacity, their desire to be independent and seek support, and their families' perception of what they can do and the desire to protect them.

Support services offered by Children's disABILITY Services stop at age 18 and the young adult with an intellectual disability is transferred to Community Living disABILITY Services. As a result, the existing worker is no longer part of the family support team. If the Children's disABILITY Services worker has been with the family for some time, this can be a loss of significant support. Planning for transition is critical and should be undertaken with care, ideally starting at age 15.

The information reviewed by the task force did not find a single protocol that is consistently used to guide transition from children's to adult services. However, one document was frequently mentioned, Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional needs from School to Community. Manitoba Families indicates that this document is currently being revised, although work was delayed by the COVID-19 response.

2. Children with Intellectual Disabilities who are in the Care of Child and Family Services

These children have a different transition, although all of the same transition elements apply. An age of majority policy from Community Living disABILITY Services outlines the planning process that starts at age 15.

At 18, the individual has the right to make their own decisions and may decline services from the government. Given their experiences, the person may not want to continue being connected to an agency or group care. If they decline services with no informal (family or friend) supports, the individual may struggle to manage their newfound independence, and be at increased risk of homelessness.

Individuals can choose to continue with the support of an agency, in which case the planning process is somewhat different. Child and Family Services workers are meant to help plan transition from age 15 where it is clear that the individual is in need of ongoing support. Annual reviews should take place, and efforts should be made to connect support networks for the individual. Child and Family Services policy supports the development of support networks at an early stage in the person's life. If this is not done vigorously and maintained, the networks tend to disappear.

A warm handoff to adult disability services takes place at age 18 and the services of Manitoba Families can continue through various mechanisms, including Agreements with Young Adults (Support beyond termination of guardianship) up to the age of 21, Employment and Income Assistance benefits and any other financial arrangement deemed appropriate.

On turning 18, the individual will be faced with decisions about finances, handling money, medical issues, living arrangements, and may not be able to act alone. If the individual has no support network or person willing to step in, community service workers may apply for a substitute decision maker appointment of the Public Guardian and Trustee.

The task force observed inconsistency in how children with intellectual disabilities and their families are prepared for transition as they reach the age of majority. The task force also heard of challenges when families who have always exercised decision making power over their children must transition to a world in which their adult child has the same rights as all adults.

> ***"The task force observes inconsistency in how children with intellectual disabilities and their families are prepared for transition as they reach the age of majority."***

Children with Intellectual Disabilities Aging Out of Child and Family Services care

The task force was particularly struck by the challenges children with intellectual disabilities who are exiting the care of Child and Family Services face. Members of the Vulnerable Persons Hearing Panel advised the task force that they often see young adults exiting Child and Family Services care in need of support, with no connections in their life. In those situations, a recommendation that the Public Guardian and Trustee be appointed the substitute decision maker is made, because of a lack of other options.

The Office of the Manitoba Advocate for Children and Youth told the task force that it receives periodic requests to intervene and complaints about youth receiving inadequate transitional supports from Child and Family Services care to Community Living disABILITY Services. This includes refusal to accept referrals because of disagreements over eligibility, and lack of resources and placement. The 2019-20 annual report of the Manitoba Advocate for Children and Youth speaks to transition planning issues, support services and planning for transitions from Child and Family Services to Adult services.

Indigenous Children with Intellectual Disabilities

The task force also learned that Indigenous youth represent a disproportionate number of people who leave Child and Family Services care only to result in the appointment of the Public Guardian and Trustee as their substitute decision maker. Although there are limits to the data, the department is able to report that, of Community Living DisABILITY Services participants who have the Public Guardian and Trustee as their substitute decision maker and have First Nations Treaty Status, 51 per cent were referred from a Child and Family Services Agency. See Section 9 on Indigenous Representation for additional discussion of this issue.

Recommendations

8. Transition to Adulthood

a) Common Transition Document

- i. The department should complete revisions on the document, Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional Needs from School to Community, within one year.
- ii. The Bridging to Adulthood document should be used as a standardized guide for all parties when a child with intellectual disabilities is near the age of majority. This includes Child and Family Services agencies, Community Living disABILITY Services staff, Children's disABILITY Services staff, schools and families.
- iii. A transitional map should be created for each person in transition, outlining the steps to be taken and the way to maintain support networks that have been developed with and for the person.

b) Children Leaving the Care of Child and Family Services

- i. All Child and Family Services Authorities should adopt a common checklist of planning details for transitions.
- ii. Mandatory transition planning meetings with Child and Family Services and Community Living disABILITY Services should begin at age 15.
- iii. Quarterly notifications should be sent from Child and Family Services to Community Living disABILITY Services about children reaching the age of majority in the next period.

9. INDIGENOUS REPRESENTATION

According to the 2016 census, individuals with Aboriginal[1] identity comprise 18 per cent of the population of Manitoba. Yet, they are disproportionately represented in high need areas of child poverty (50 per cent) and children in care (90 per cent).

The final report of the Truth and Reconciliation Commission outlines the generational effect of residential schools on survivors and descendants. It is expected that many Indigenous children, especially those with intellectual disabilities, grow into adulthood with the need for additional supports.

Indigenous Representation

There are a lot of Indigenous people who get disability services. We think government needs to do better to learn what their needs are. We are asking that government work with Indigenous people to learn what they need. We are also asking that different parts of the system look at the work they are doing to make sure they are doing what Indigenous people need. We also think Indigenous people need to have a place to make decisions about the system.

The Office of the Vulnerable Persons Commissioner does not keep demographic information about the Indigenous identity of the 2,101 people with substitute decision maker appointees. As a result, it is not known how many of the 956 private substitute decision maker and 182 shared appointments are for Indigenous people. However, the Public Guardian and Trustee does keep demographic information on the individuals for which it is appointed. The Public Guardian and Trustee has identified it has 334 appointments for Indigenous people (roughly 28 per cent of its substitute decision maker caseload). However, this may be underreported. There are limitations to the information available, as the Public Guardian and Trustee reports based on Treaty Status, which does not account for Metis or Inuit individuals, and may not capture all First Nations individuals.

In any case, even with significant gaps in the data, the overrepresentation of Indigenous people is evident in the system for adults with intellectual disabilities.

Indigenous adults, their families and their support network are often challenged by the bureaucratic process to become a formal substitute decision maker. The appointment process does not provide a comforting and familiar circle. The task force believes a strong Indigenous presence throughout, and consistent informed training for all parties will increase sensitivity and improve the process for all. This will also provide much-needed consideration for those adults with intellectual disabilities who are Indigenous. The task force also believes Indigenous customs should be respected and included wherever possible.

It is important to note that Indigenous peoples are not one homogeneous group with shared experiences, viewpoints, heritage and language. First Nations, Metis, and Inuit individuals will have different views of how the people with intellectual disabilities in their communities should be supported. Issues related to Indigenous adults with intellectual disabilities were a recurring and consistent theme. The need to address the needs of Indigenous people with disabilities is also reflected in Article 22.1 of the United Nations Declaration on the Rights of Indigenous People.

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[1] The term Aboriginal is used in the census.

> ***"Article 22.1 Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration."***
>
> ***-United Nations Declaration on the Rights of Indigenous People***

Representation and Consultation

While government employees and service delivery agencies may have other opportunities to learn about and take action on reconciliation with Indigenous people, the task force does not believe that the needs of Indigenous people have been specifically explored or addressed in the system for adults with intellectual disabilities.

In Section 1 (Advisory Council), the task force recommends the appointment of at least one Indigenous person on the council.

The principle of nothing about us without us is enshrined within the disability community and is doubly relevant when addressing the needs of Indigenous people. Ultimately, all parties, including the Community Living disABILITY Services Program, the Office of the Vulnerable Persons Commissioner, the Public Guardian and Trustee, and service delivery agencies should make a concerted effort to reach out to Indigenous people and groups to bring their perspectives into the system. Special efforts should be made to acknowledge Indigenous history, needs and challenges. This will require outreach to experts and elders.

Without seeking to overly influence the direction of further consultations, the task force believes certain questions and topics may be a helpful starting point:

- What gaps exist in current government policy around services for Indigenous adults with intellectual disabilities?
- Why are Indigenous people more likely to have the Public Guardian and Trustee as their substitute decision maker?
- How can Indigenous-specific assisted decision making be developed?
- How can Indigenous peoples and customs be included in the process of applications and hearings?

Recommendations

9. Indigenous Representation

i. The department should undertake consultations with Indigenous leadership and elders, social services agencies, people with lived experience and other parties to determine how Indigenous adults with intellectual disabilities are served by the act and in the broader system.
ii. All relevant parties should review their policies and practices, and amend them where needed, to ensure they are culturally sensitive and reflect the Truth and Reconciliation Commission's calls to action.
iii. The advisory council should maintain a standing item on its agendas to report on Indigenous appointments, and address Indigenous matters and implementation of these recommendations.
iv. All hearing panels should begin with a treaty land acknowledgement.

10. SUBSTITUTE DECISION MAKING AND THE ROLE OF THE OFFICE OF THE VULNERABLE PERSONS COMMISSIONER

The act establishes substitute decision making, as well as the Office of the Vulnerable Persons Commissioner. A substitute decision maker is a person appointed by the vulnerable persons' commissioner to make decisions for a "person with significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour and manifested prior to the age of 18 years."

Substitute decision making is regarded as a last resort measure, as outlined in the principles of the act. A substitute decision maker has the legal authority to make decisions for the person in those specific areas in which they have been given power by the commissioner.

As of March 31, 2020, there are 2,101 substitute decision maker appointments of which 963 are with the Public Guardian and Trustee, 956 are for family or friends and 182 are shared arrangements.

All proposed substitute decision makers and, if applicable, each alternate (other than those for Public Guardian and Trustee) must have criminal record checks, child abuse registry check and adult abuse registry checks. Applications include:

- Statements attesting to applicants' suitability and capacity
- Information about the adults' financial situation
- Copies of physicians' opinions of disability
- School reports

Substitute Decision Making and the Role of the Office of the Vulnerable Persons Commissioner

When someone can't make their own decisions, the law lets government decide who will make decisions for them. This is called a substitute decision maker. The person who decides who gets to be a substitute decision maker is called the vulnerable persons commissioner. The decision to name a substitute decision maker is only supposed to happen when there are no other options. We are worried that the decision sometimes happens even though there are other choices. We want more information to be shared to make sure that naming a substitute decision maker is actually the only option. We also think people in the community should know who the Commissioner is and what they do. We also think information from the Commissioner should be available in plain language.

The application package can be quite voluminous and preparing it can be daunting. Conversely, some application packages can be rather slim when not much is known about the adult and no one has stepped forward to act as substitute decision maker. If the adult has a sizeable portfolio or income, the applicants may have to get a bond or surety, which can be costly.

The commissioner's office reviews the packages for completeness and determines if the requirements of the act are met. If complete, they are sent to the commissioner for referral to a hearing. If the commissioner agrees with the recommendation, they sign the referral. Then the coordinator contacts panel members and all parties to set up the hearing. The coordinator also sends copies or electronic copies to the panel members to review before the hearing. Because of delays related to the COVID-19 pandemic, this process can currently take up to ten months. A more typical timeline for scheduling an initial hearing is two months.

All applicants must go through the hearing process, even in cases where everyone in the vulnerable person's life believes the appointment is in their best interests[2]. Once the hearing has been held, the coordinator and panel immediately write up the recommendation report. It is important to note that the panel only recommends the minimum powers needed to assist the adult, and does not recommend any powers not requested. Appointments should also only be in place for the length of time needed. The coordinator forwards the report to the commissioner, who typically sends out the appointment documents within two weeks.

After an appointment is made, the office remains involved through annual reporting and periodic reappointment applications. The Office also deals with requests to vary, terminate or name emergency appointees.

Since the appointment of a substitute decision maker reassigns the individual's ability to make decisions in some areas to another person, the commissioner plays a very important role in the lives of adults with intellectual disabilities. The office also plays a primary role in providing information about substitute decision making and monitoring substitute decision makers.

Perception Around Last Resort

A major issue related to the Office of the Vulnerable Persons Commissioner and to the commissioner, is the difference between how the office is seen in the community, versus how the office sees itself. The most pressing example of this difference is related to how the commissioner decides to appoint a substitute decision maker. The act requires that the appointment of a substitute decision maker must be a last resort, the last step on a continuum of options meant to support vulnerable people.

There is a sense among community advocates that substitute decision makers are not always a last resort. The 2019 report by Community Living Manitoba and the Public Interest Law Centre explicitly states that "In practice, substitute decision making is invoked not as a last resort, but as a routine part of planning for people with intellectual disabilities." This perception is also noted by a submission to the task force, which observed that "In today's world, this decision [to appoint a substitute decision maker] seems to have become somewhat automatic when children turn eighteen years of age." Abilities Manitoba agreed, noting in their submission that "[It is] not clear that there is an active and robust effort to ensure that there is no other option than appointing a substitute decision maker."

The Office of the Vulnerable Persons Commissioner does not share this perspective, noting that the commissioner is always guided by the principles of the act, the most important of which is that a substitute decision maker appointment be the last resort.

The difference in perception may partly be related to the fact that the details of each hearing are not public. When considering whether the commissioner uses substitute decision maker appointments as a last resort, it is difficult to move beyond anecdotal evidence to better understand what last resort looked like in each case. It is also not currently possible to evaluate cases at the aggregate level, as the details of each case are unique to the situation at hand.

Interaction of Adults with Intellectual Disabilities and The Mental Health Act

It is commonly understood by those in the community that The Vulnerable Persons Living with a Mental Disability Act and The Mental Health Act deal with separate populations, and are mutually exclusive. However, this is not entirely true. While there is relatively little overlap between the two acts, it is possible

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[2] During the creation of this Report, the Legislative Assembly of Manitoba passed amendments to the act that will give the commissioner the discretion to forego a hearing in cases where there are no concerns, and allow appointment renewals of up to ten years where the family is the substitute decision maker. These amendments have received royal assent but have not yet been proclaimed.

for an adult with an intellectual disability who has never had a substitute decision maker to be subject to a committeeship order under The Mental Health Act. A substitute decision maker appointment under The Vulnerable Persons Living with a Mental Disability Act can replace a pre-existing Committee appointment issued under Part 8 of The Mental Health Act if the Committee appointment was issued without a court order. However, a Committee appointment cannot be replaced by a substitute decision maker appointment where it was made by the Court of Queen's Bench or where the individual is a patient in a psychiatric facility (Part 9).

These situations are rare, and are most likely to occur later in life, as adults begin to experience issues such as dementia that are unrelated to their intellectual disability. Although these situations may not be common, the task force strongly feels there needs to be a greater awareness of the potential overlap, as the intent of The Vulnerable Persons Living with a Mental Disability Act is to create a separate set of options for adults with intellectual disabilities.

The Commissioner's Role in Community

Given the office's small staff complement and the need to process and decide on substitute decision maker applications, the majority of the office's work concentrates on dealing with actual applications. However, this comes at the cost of reduced visibility.

Some of the submissions note that the Office of Vulnerable Persons Commissioner lacks visibility in the community. For instance, the submission to the task force from Continuity Care recommends that "The commissioner needs to have more of a presence… their role should include more outreach and consultation."

> ***"The Commissioner needs to have more of a presence… their role should include more outreach and consultation."***
>
> ***-Continuity Care***

The commissioner's office is also not necessarily seen as having a leadership role in providing training. Training around the act is led by multiple parties, including community agencies, approved volunteers and staff from Community Living disABILITY Services. While the office is involved in substitute decision making provision training, it is not the primary or most visible source of training on the ct.

The task force also believes that the commissioner needs to provide education to the legal system on the office's functions and the purpose of substitute decision making under the act. As the commissioner makes quasi-judicial decisions, it is important that the rest of the judicial and legal sector understand the office's role.

Clarity of Information

There was a sense from some respondents that the material used by the office, particularly the forms and documents used by applicants, needed to be reviewed for plain language. Some members of the Vulnerable Persons Hearing Panel stated that the forms should be rewritten with a plain language edit to make things easier for families. As one member commented: "The forms are not well designed."

Role of the Commissioner

Some submissions preferred a very different role for the office. Abilities Manitoba, for instance, argued that "The vulnerable persons' commissioner should be mandated to work … in a protection and supportive role rather than solely an administrative one."

In keeping with the Terms of Reference for the task force, the sub-committee had chosen to leave aside discussions that would fundamentally change the role of the office. However, the minister may wish to consider how other parties in the system could play this role, as there is an identified need for a proactive approach that engages with families before they enter the substitute decision maker system.

Recommendations

10. The Office of the Vulnerable Persons Commissioner and Substitute Decision Making

a) Updating How the Commissioner Reports Information

While respecting the need to protect information, the commissioner's office should provide more information about how the commissioner came to decisions. This could include:

- Demonstrating how the commissioner determines that the appointment is a last resort, including the questions the commissioner asked to determine this, and hypothetical or anonymized examples of situations where a substitute decision maker was appointed (or not)
- Statistics about rejected applications, and situations where the decision differed from the application
- How frequently applications to vary, suspend or terminate substitute decision maker appointments are received
- Other material that would help the public better understand the decisions of the commissioner's office

b) The Commissioner's Role in Community

i. The commissioner's office should undertake a series of meetings with key stakeholders to better understand community perspectives and explain the role of the office.
ii. The commissioner should hold twice annual town halls with the public, specifically targeted at relevant stakeholders.
iii. The commissioner should meet periodically with family-based organizations such as the Family Advocacy Network or Continuity Care and consumer based organizations like People First Manitoba. The commissioner should ensure that at least one of the public town halls is targeted for families.
iv. The office should review and revise the communications material it produces, to determine any gaps.
v. The office should refresh and update its communications material so it speaks to a 2021 audience.

c) Plain Language and Red Tape Review

i. The commissioner's office should review and revise all forms and information documents the office uses to ensure they are written in plain language.
ii. The commissioner's office should review all forms with a lens for red-tape reduction. Make the changes where possible or propose regulatory or legislative changes where necessary.
iii. The commissioner's office should develop a policy on waiving abuse registry checks in certain cases.

d) Proactive Approaches

The commissioner's office should support efforts to divert applications for substitute decision making where there are possible alternatives. This would involve working proactively with community partners and families at the outset of the process to determine whether a substitute decision making appointment is the appropriate path to take.

e) Monitoring

The task force also notes recommendations related to the role of the commissioner in monitoring substitute decision makers, which can be found in Section 7 (Monitoring Performance) and Section 14 (Improvements for Families).

11. HEARING PANELS

Prior to the appointment of a substitute decision maker, the act requires that a panel be held before members of the Vulnerable Persons Hearing Panel. The act lays out a process for the appointment of panel members and it lays out the hearing process.

Sections 34 to 45 of the act outline:

- The minimum number of panel member appointments (20)
- The composition of the three person panel roster for each hearing
- Remuneration of panel members
- Duty of the panel
- Criteria for appointment
- Ineligibility in specific cases (also known as conflict of interest)
- Representation at hearings
- Evidence
- The recommendation process

Hearing Panels

When someone asks to be a substitute decision maker, they talk to a group called the "Vulnerable Persons Hearing Panel" in a formal hearing. This group helps the vulnerable persons commissioner decide if there needs to be a substitute decision maker. We believe that the "Hearing Panel" needs to use plain language and find ways to make the meetings less stressful. We also think there should be a way of making sure everyone who goes to a hearing panel feels safe while they are there.

Family members and advocacy groups provided the task force with viewpoints on the hearing panels and the hearing process. On behalf of the task force, the department solicited feedback (in the form of a survey) from hearing panel members. Eleven of the 30 appointees responded. Panel members felt the process provided an important learning opportunity for families, who often came to hearings with incomplete understanding of the powers and responsibilities they were seeking.

The Office of the Vulnerable Persons Commissioner holds training for new panel members and once yearly meetings with available panel members. During the initial meeting, members are given a handbook to use as a guide for hearing preparation. The hearing panel follows an established script for questions, some of which may not be relevant to the person for whom the hearing is being held.

Overall, members reported the Office of the Vulnerable Persons Commissioner as being "very responsive to the needs of the hearing panel". Panel members particularly expressed strong support for the coordinator who arranges and attends hearing panels, as well as ensuring decisions are prepared. Some members were apprehensive of the reliance on one person for these services and wondered about succession planning.

User Friendly Language and Family Awareness

Members of the hearing panel noted that they frequently find situations where families or friends learn about the role of a substitute decision maker through the hearing panel itself. This raises some concerns, as the applicant would have gone through several steps before going to a hearing. They also reported hearing from applicants who found the documentation confusing and not user friendly. As is noted in Section 10 on the role of the Office of the Vulnerable Persons Commissioner, the number of forms and the complexity of those documents are ongoing issues. It is the task force's assessment that this is the case with hearing panels as well.

Safety

Panel members also expressed concerns about personal safety during meetings: some files clearly indicate the adult has a tendency to act out frustration in violent or unpleasant ways. One panel member related a hearing during which the adult physically assaulted a fellow panel member and caused some property damage to the site. This required the summoning of a security guard while the panel members barricaded themselves inside the hearing room. The panel members were not debriefed afterwards, and no apparent changes were made to the hearing process.

Indigenous Representation

As noted in Section 9 on Indigenous Representation, Indigenous people represent a significant portion of those with substitute decision maker appointments, and hearings are sometimes held in First Nations communities. Hearing panel members themselves expressed concerns about adequate representation of Indigenous people and cultural awareness during hearings. The task force agrees, and notes that the Office of the Vulnerable Persons Commissioner, hearing panel members and community service workers would benefit from sensitivity training, particularly related to dealing with Indigenous individuals.

Recommendations

Given its important role in the process, the task force felt it was necessary to include a section about the Vulnerable Persons Hearing Panel. However, specific recommendations related to the hearing panel are addressed in Sections 2 (Training and Education), Section 9 (Indigenous Representation) and Section 10 (Role of the Office of the Vulnerable Persons Commissioner).

12. INDIVIDUAL PLANNING

Individual planning is generally understood as the creation of a document in writing (amended from time to time) that states the goals for an individual set by the individual, with support from family, friends and support staff. When properly done, individual plans are a key part of a person's life, and are used as a way of mapping and achieving goals for the individual.

The principles of individual planning are as follows:

> **Knowing the person**-This involves knowing an individual as a person. Who are they in terms of their history, experience, personality, gifts and challenges? What are their aspirations and their dreams?
>
> **Listening to the Person**- This involves establishing an authentic relationship based on trust and sincere interest. It may involve conversation or learning about the individual's style of communication and creating time, space and formats capturing what a person has to say.
>
> **Connecting**- This work includes exploring with a person the kind and quality of connection that is meaningful to that person.
>
> **Designing Support-** This involves designing a plan of support that is driven by the supported person. It goes well beyond the traditional understanding of support as supervision and basic care.

Individual Planning

Every person who gets services from Community Living disABILITY Services is supposed to have an individual plan. These plans are a way of knowing what a person's goals are, and helping to figure out how they will reach those goals. Sometimes an individual plan is also called a support plan or person-centered plan. A good individual plan depends on knowing and listening to the person, and making sure the person participates in all planning. Individual planning happens now, but we are worried that it doesn't work that well. If the person doesn't get to decide what is in their plan and how it is created and kept up to date, we know it probably won't work. We are recommending the government look at how individual planning happens to make sure these plans work for people.

At a minimum, the individual planning model requires that support be driven by the needs, priorities and aspirations of the person, as opposed to slotting people into pre-existing service slots or placements. The focus is on developing services and supports that facilitate social inclusion (community presence and participation), social capital (connection to family and friends), self-determination (choice and control) and well-being (safety and security).

Individual planning is mentioned in sections 11 and 12 of the act, which sets out the obligation to develop an individual plan for every person receiving support. It explicitly places this responsibility in the hands of the executive director, as well as granting the executive director the ability to review and vary plans. In practice, this function is delegated to Community Living disABILITY Services staff, guided by policy and working closely with service delivery agencies.

The overriding question that guided the task force's review was whether or not the act leads to consistent and vigorous individual planning for vulnerable persons. Overall, the task force has identified issues related to the bureaucratization of planning, a focus on intake procedures, and a need to adapt to the reality of modern service delivery.

Bureaucratization

With the introduction of the act, the department assumed a compliance role related to individual planning, as it was now required under the act. Since 1996, every person receiving service and support has had to have an individual plan that is written, shared with the person, reviewed with the service delivery agency, and monitored (continuous and systematic assessment) by the department. This situation has produced a dilemma in terms of the capacity of the system to develop and deliver personalized individual planning. As Inclusion Winnipeg succinctly summarized in their submission to the task force, "Individual plans have become bureaucratized under the auspices of person-centered planning."

The tendency of large systems is to shape requirements to make them fit more easily into the current way of operating. In situations of reduced staff capacity, the individual planning requirement is often melded with the intake procedure, rather than remaining a separate process. Over time, the language used in policy around individual planning has retained a focus on individual planning as a separate and robust process, but the practice has changed. In short, the task force believes that individual planning has largely been reduced to a compliance procedure, and has become an exercise in box-checking as opposed to a robust tool for individuals, families and agencies.

Focus on Intake

The task force believes the department has focused on an intake procedure, the Supports Intensity Scale, as a substitute for true individual planning.

The Supports Intensity Scale is an assessment to determine what supports an individual needs to complete various tasks or to accommodate medical or behavioural challenges. Community Living disABILITY Services has a centralized team of trained facilitators who administer the Supports Intensity Scale assessment through an interview. Through discussion and consensus with the individual, their friends and family, and possibly other members of the support network who know the person well, the facilitator completes the Supports Intensity Scale assessment form. The outcome of the assessment is the support budget level an individual is assigned for Community Living disABILITY Services support.

> ***"The task force believes the department has focused on an intake procedure, the Supports Intensity Scale, as a substitute for true individual planning."***

In 2015, Community Living disABILITY Services moved to the Supports Intensity Scale as their needs-based assessment intake and budget allocation process. Over time, this process has assumed the function of individual planning. Although the Supports Intensity Scale claims to develop a person-centred plan as part of its needs assessment process, it is not a personalized individual planning process. It is an intake procedure and support budget assessment process, developed to provide systems with a process that would control and contain cost and make management more predictable and efficient. In reviewing the process for individual planning, the task force was not convinced that the Supports Intensity Scale needs assessment and budget allocation process fulfill the requirement for an individual plan under the act.

Person-Centred Versus Individual Planning

Community Living disABILITY Services policy suggests that the use of person-centred planning fulfils the need for individual planning. In the opinion of the task force, there needs to be clarification about differences between person-centred planning and individual planning.

Person-centred planning is a commitment and community-based planning approach. It was not developed for, nor is it appropriate for, compliance-based system-wide planning directed by professionals. It is focused on individuals and their experiences, rather than whether specific actions meet the compliance requirements of a plan.

Good person-centred planning is a voluntary and organic expression of passion for social justice, focused on supporting growth in valued community roles. Person-centred planning can be messy, confusing and slow. It is about exploring life in the community and discovering the distinctive ways that services can play a necessary part in supporting individuals. Bureaucratizing person-centred planning risks taking attention away from the human experience of living together well with a disability.

Individual planning is consistent with the principles and values of person-centred planning, but differs significantly in that it is professionalized and compliance-focused. It often integrates useful person-centred tools in planning for individuals. Clarification of the differences between the two approaches would benefit implementation of individual planning.

Person-centred planning also takes resources and the proper skill set to do properly. Ongoing issues related to staff shortages, unrealistic caseloads, and a focus on compliance create barriers for the ability of the department to undertake true person-centred planning. Person-centred training is an effective way to build the skills needed to assist people to plan well, however training needs in service agencies currently outweigh funding for training, creating an additional challenge.

In summary, while person-centred planning is noted in departmental policy and is generally in line with the department's approach to individual planning, there needs to be a recognition that it is distinct from both individual planning and intake processes. The department also needs to revisit its role in person-centred planning, given its issues with capacity and the large role service delivery agencies play in the lives of individuals.

Service Delivery Agencies and Individual Planning

Lost in the current individual planning process is the importance and role of service delivery agencies. The agencies are those most connected with, and responsible for, the quality of life of the people they support. Quality of life is not adequately measured by looking at existing legislation, departmental policies and practices, monitoring, or the intake process. Quality of life and quality of support will be established by the efforts and ability of agencies to plan and deliver effective services to persons they support.

It is imperative that individual planning be based on listening and knowing the person, and establishing an authentic relationship based on trust and sincere interest. Reliable and quality individual planning must focus on the person's choice and control, their presence and participation in community life, their ability to develop relationships, and their personal safety and security. Agencies are the locations in the system where people become known and the possibility to organize support around their aspirations is most possible.

The task force believes that the approach to individual planning and person-centred planning needs to be fundamentally rethought. While there is much ongoing good work happening in the field between departmental and agency staff, the role of the department is significantly affected by capacity issues. This leads to a reliance on formalized procedures and a check-box exercise in individual planning.

The risk is that this makes individual planning sporadic and compliance driven. Under the current approach, an individual plan of some description may be developed, shared with the agency, kept on file and reviewed annually. However, this does not constitute effective personalized individual support, and may be of little or no use to individuals, their families or the agency. For the sake of all parties, especially individuals with intellectual disabilities, the task force suggests that the approach to individual planning be reimagined and reinvigorated.

Recommendations

12. Individual Planning

a) Principles of Individual Planning

The principles of individual planning should be built into departmental policy:

- Knowing the person
- Listening to the person
- Connecting
- Designing supports

b) Separating Intake from Individual Planning

i. The department should clarify its approach to intake versus individual planning to ensure that the two are not treated as the same process.
ii. The department should ensure that the Supports Intensity Scale is not being used for individual planning, which is not its intended purpose.

c) Responsibility for Individual Planning

i. There should be greater clarity in the act about the role of the executive director in individual plans, as well as how this may be delegated.
ii. The executive director should recognize service delivery agencies as delegates for implementation of individual planning for people under the act. This may include updating departmental policy and formalizing requirements through service purchase agreements with agencies.
iii. The department should work in partnership with service delivery agencies and other partners to develop options for training and education for individual planning. This training would be available to people under the act, service delivery agencies, families, support networks, substitute decision makers and community service workers. This would involve addressing the funding that agencies receive for training.
iv. The presence and participation of individuals, families and advocates should be assured in the individual planning process.

d) Department oversight

i. The department should maintain a clear role in overseeing individual plans. This would include ensuring the plans are prepared, verifying that the plans adhere to guidelines and taking corrective action where necessary.
ii. The department should develop policy guidelines to outline its role.
iii. The department should explore the development of a monitoring process to ensure implementation and quality of individual plans.

13. ROLE OF COMMUNITY SERVICE WORKERS

Community service workers are key, front-line Manitoba Families staff who work with adults with intellectual disabilities. They are responsible for:

- Referral and intake
- Crisis and/or protection services
- Assessment (including risk assessment)
- Case planning, counselling and providing support services, including financial management
- Service monitoring and evaluation
- Service termination

In principle, community service workers are the departmental staff with the greatest level of contact with the individuals who the department supports. They are responsible for a distinct caseload and are the primary face of Manitoba Families for many adults with intellectual disabilities and their families.

The task force notes that the role of community service workers has changed over time. When the act was first introduced, community service workers seemingly had more time to connect with all or most of the people on their caseloads and establish relationships with families, agencies and supported individuals. They were responsible for and often were involved in individual planning, abuse investigations and providing needed supports around substitute decision making and supported decision making. The task force also heard of varied levels of involvement with community service workers and an overall lack of consistency in people's experiences.

Role of Community Service Workers

Community service workers are the people in the Department of Families who work most closely with adults with intellectual disabilities. Sometimes we refer to these people as workers. They have a very important job in the system. But the way they do their job has changed a lot since 1996, when the law was made. Community service workers used to have more time to connect with individuals. We heard a lot of complaints that people don't even meet their worker. We are recommending that the department change the way community service workers do their jobs, and make sure everyone understands what those workers do.

While community service workers continue to have very important functions related to the act, their ability to robustly fulfill those expectations has diminished as caseloads, vacancies and turnover have increased. The demographics of people accessing services have also changed. Today, it appears to be far too difficult for community service workers to achieve that level of involvement. By way of example, the task force heard of reduced contact between community service workers and the people on their caseloads, to the point where individuals, families, hearing panel members and staff all reported situations in which community service workers do not know and may not have met the individual. Over time, some agencies have taken on some of those functions. Things look significantly different compared to 25 years ago, and it is critical that case management be relevant to the present day realities. Moreover, there have been significant shifts in case management capacity, and changes are required to reflect what is needed in our current reality.

Research on best practices in case management notes a few key findings:

- The relationship between case manager and individual is fundamental to success.
- Caseloads must allow meaningful contact with supported individuals.
- People need access to familiar people at all times.

While community service workers are important to providing services to adults with intellectual disabilities, the changing nature of the job has led to a number of issues.

Training and Education

As has been repeatedly noted in other areas of the task force's work, for the act to influence quality supports and services for people with an intellectual disability, it is essential that families, supported individuals and support services have a solid understanding of the values and intent of the act. Community service workers are often pivotal in helping supported individuals and families understand the act. Information received by the task force suggests that the current level of education and training is inadequate to ensure that the act is a living, breathing tool that provides a daily positive influence in the lives of the people it is intended to impact.

Specifically, the task force notes gaps in terms of training and education for community service workers and those in related positions. Among the issues noted are the lack of ongoing training, differences in rural and urban settings, and lack of knowledge about the act in related systems (such as Children's disABILITY Services and the Child and Family Services system).

Role Clarity

A number of people who contributed to the work of the task force have identified a lack of clarity around the role of community service workers as well as difficulty accessing their workers. This is likely due to high turnover, heavy caseloads, and demographic changes in people accessing Community Living disABILITY Services since the act came into force in 1996. There are also differences in the role community service workers play, depending on their caseload and location. A consistent theme among community service workers the task force interviewed was the feeling that their caseloads were too high for them to develop meaningful connections with the individuals they support . A similar theme exists for individuals who do not know who their worker is. As self-advocate Kevin Johnson noted, "My worker has changed so much. I wish there was more consistency so my community service workers could get to know me. It's pretty hard to talk about personal things with someone you don't know." The task force highlights the importance of relationships in providing good case management.

> ***"My worker has changed so much. I wish there was more consistency so my community service workers could get to know me. It's pretty hard to talk about personal things with someone you don't know."***
>
> ***-Kevin Johnson, Self-Advocate***

Departmental Review

To address the changing nature of the role of community service workers, the department is already engaged in work to launch a Service Transformation project whose objective is to refocus the role of community service workers, quality assurance, standards compliance and transition case management responsibilities to agency staff. The goal is to address consistent and continued quality service delivery and sustainability. The task force believes this is an important project, the results of which should be communicated to all relevant stakeholders.

Recommendations

13. Role of Community Service Workers

a) Role Clarity

i. The job description for community service workers should be shared publicly and in plain language format, particularly with individuals supported by Community Living disABILITY Services, families and agencies.

ii. The department should ensure that caseload sizes allow for meaningful contact with individuals they support and the development of a trusting relationship. While different models and caseload sizes may be appropriate in different circumstances, the department should be guided by best practices and the need to ensure the best interests of supported individuals.

iii. While some difference in rural and urban casework is inevitable, the department should ensure consistency to the greatest extent possible. It should ensure community service workers have the necessary resources to fulfil their role, including access to training.

iv. The results of the Service Transformation project should be shared within a year and expanded to other service providers as appropriate.

14. IMPROVEMENTS FOR FAMILIES

A consistent theme that the task force encountered was the difficulties faced by families seeking to support their family member with an intellectual disability. Whether this occurred in the transition to adulthood, in understanding assisted decision making, seeking a substitute decision maker appointment, or reporting on those appointments, the task force strongly believes that all parts of the system can work together to improve things for families.

Issues for Families and the Office of the Vulnerable Persons Commissioner

Sometimes, family members express to hearing panel members a deep resentment that the panel members (whom they do not know) are weighing their eligibility and capacity to care for their family member. This appears especially painful for parents or siblings who have cared for their loved one for decades. Families also have said they resent having to make travel arrangements for themselves and the person with an intellectual disability, and missing work for hearings. Lessons learned during the COVID-19 pandemic, including the usefulness of virtual meetings, should continue to be explored as options.

Improvements for Families

We talked to families of adults with intellectual disabilities and heard about problems in the system. When a family asks to be a substitute decision maker, they have to fill out a lot of complicated forms and go through a lot of work. The Public Guardian and Trustee doesn't have to do all the same work. We are recommending that things should be easier for families. This could mean making forms and documents simpler and easier to understand. It could also mean changing some of the work families need to do. We are also recommending that the department start doing random checks with all substitute decision makers, to make sure that they are doing what's best for the person.

Comments that families receive also suggest that some people find the documentation associated with a substitute decision maker application (particularly a substitute decision maker for property) to be unclear and overly burdensome. This can be a disincentive for a family member or friend to apply to be a substitute decision maker, and may increase reliance on the Public Guardian and Trustee to become the substitute decision maker.

The reporting requirements placed on families are also a source of concern, particularly when compared with the requirements for the Public Guardian and Trustee. As noted in Section 7 on Monitoring Performance, the Public Guardian and Trustee can go up to five years without any interaction or review by the Office of the Vulnerable Persons Commissioner. In that section, the task force recommended that the commissioner's office conduct spot checks of all substitute decision maker appointments to explore what is being done to advance the condition of the person. This process will need to respect the fact that families may perceive an audit as a stressful and negative experience. The task force believes in the concept of spot checks as a strong way of monitoring the system, but recognizes that the commissioner's office will need to take particular care when using such a model to review family substitute decision makers. The purpose of these spot checks is not to be punitive or to scare appointees, and monitoring is about more than financial reviews. It is about interactions with the individual, improving quality of life, and knowing the individual and their will and preferences.

Transitions

As noted in Section 8 on Transition to Adulthood, the period of transitioning to adulthood can be a challenging time for both young adults with intellectual disabilities and their families. Along with changes in their caseworker, there is also a legal transition and the possibility of needing to seek an appointment as a substitute decision maker. Families can feel overwhelmed, and it is not clear to the task force that the system is set up to support them. Although some of these issues are already addressed above, the task force believes there needs to be a specific family friendly lens brought to this issue. Training should also be available to families, using the Bridging to Adulthood document as its basis.

Peer Support

Organizations such as the Family Advocacy Network already bring together families of individuals with intellectual disabilities. While this network does good work to connect families, the task force believes there is a need for more intensive peer support to assist families in dealing with transition and with the ongoing experience of supporting their loved one.

An example could include a one-on-one Peer Support Program offered to families who have a family member with an intellectual disability in Manitoba. The support program would match families with a peer, who can provide:

- Non-judgmental understanding
- An empathetic ear
- Information about topics like:
  - Assisted decision making
  - Substitute decision making
  - The hearing panel process
  - Transition planning
  - Questions about the act
  - Others

Peers could share first-hand experience, information and resources. Through this type of program, families will gain confidence and awareness of issues, be able to ask questions and get assistance with planning.

Bonds and Sureties

Members of the community also raised concerns about the bonds and surety requirements, which require that substitute decision makers provide personal or commercial bonds (depending on the amount) equivalent to the assets of the adult with an intellectual disability.

The commissioner's office notes that this regulatory requirement is a key element in protecting individuals from financial abuse. Currently, 210 substitute decision makers for personal property (or 24 per cent) have bonds in place. In the last decade, the commissioner's office has found 15 cases of financial mismanagement. Four cases were referred to Manitoba Prosecutions; however, only two of those had a bond in place.

Members of the community note that the bonds and sureties requirement creates additional burden for families, and can act as a disincentive not only for applying to be a substitute decision maker, but also affects the family's approach to Registered Disability Savings Plans. In some cases, the task force heard that families are not using the Savings Plan to its full extent because the increased value would trigger the bond requirement. Continuity Care reports that "some substitute decision makers are choosing not to contribute to their family member's Registered Disability Savings Plan because of this." The task force is concerned that regulatory requirements for bonds under the act are having an unintentional effect on Registered Disability Savings Plans, which are a crucial support for people with intellectual disabilities in some cases.

Recommendations

14. Improvements for Families

a) Support for Families

i. The Office of the Vulnerable Persons Commissioner should consult with family-focused groups such as the Family Advocacy Network, Continuity Care, Inclusion Winnipeg and others to implement family-friendly:
    - Approaches to information and forms
    - Procedures and questions in monitoring appointments
    - Training about options in decision making
    - Training about becoming a substitute decision maker

ii. When conducting spot checks with family substitute decision makers, the commissioner's office should build on its existing approach of educating into compliance. The goal would be to identify any issues and help the substitute decision maker work through them, except in cases of major violations that put the individual at risk of harm.

b) Transitions

i. Families should receive orientation from community service workers (or Children's disABILITY Services workers) about all the options that are available to their family regarding decision making - support networks, representation agreements (when available), and substitute decision making, as well as the role of the Public Guardian and Trustee. The task force suggests using the Bridging to Adulthood resource as the basis for training.

c) Peer Support

i. An arrangement should be created with organizations like the Family Advocacy Network, Continuity Care, Inclusion Winnipeg, or Innovative Life Options to develop and operate a peer support program with families about options in decision making, planning and protection issues.
ii. Peer support programs should be supported as part of government's approach to Strengthening Community Capacity (see Section 16 below).

d) Bonds and Sureties

The department should explore the issue of unintended consequences of the Bonds and Sureties requirement, and whether alternatives, such as group plans, may be used to reduce the burden related to bonds and sureties.

e) Additional recommendations or information

This report contains a number of additional recommendations and information that has impacts on families:

- Representation of families on the proposed advisory council (Section 1)
- Representation of families on the proposed Training Advisory Committee (Section 2)
- Benefits of rights recognition and an appeals process (Section 5)
- Training designed for families on the issues of transition (Section 8) and Abuse (Section 6)
- Targeted consultations with families by the Office of the Vulnerable Persons Commissioner (Section 10)
- Recent amendments to the act regarding the ten-year term renewals for family or friend substitute decision maker appointments (Section 10, footnote on page 49)

15. THE ROLE OF THE PUBLIC GUARDIAN AND TRUSTEE

The Public Guardian and Trustee is the office responsible for operating as the substitute decision maker where there are no family members or friends ready or able to take on that role. As of March 31, 2020 there were 963 adults with intellectual disabilities who had the Public Guardian and Trustee as their substitute decision maker, representing roughly 46 per cent of the total number of individuals with substitute decision makers.

In many cases, individuals who have the Public Guardian and Trustee as their substitute decision maker are those with the fewest connections and the least-developed support networks. It is fair to say that no one involved with the system for adults with intellectual disabilities is seeking to increase the Public Guardian and Trustee's caseload. Its role is viewed as a necessary last resort. It exists as a backstop, but the need for the Public Guardian and Trustee's services is a sign of an ongoing gap in connections for the people they support.

The Role of the Public Guardian and Trustee

When no one else can be the substitute decision maker, the Public Guardian and Trustee steps in. They are the last resort, and that's an important role. We heard questions about some of the ways the Public Guardian and Trustee works. One thing we really noticed was that the Public Guardian and Trustee doesn't have a lot of contact with the people they are making decisions for. We think it's important that the Public Guardian and Trustee talk with the person and their community service workers and agencies to make sure that everyone is working together to get the best result for the person.

Difference in Treatment

The Public Guardian and Trustee is not subject to the same reporting requirements as other substitute decision makers. Specifically, family and friend substitute decision makers for property are required to provide an annual accounting, which the Public Guardian and Trustee is not.

This is primarily because of the fact that the Public Guardian and Trustee is an arm's length body accountable to the provincial government. If any financial wrongdoing occurs with specific appointments, this is dealt with through the regular risk management and accountability processes of government. The Public Guardian and Trustee is also in a somewhat different position as the default appointee. If a family or friend substitute decision maker needs to be replaced, the Public Guardian and Trustee is the last resort replacement. If there were problems found with an appointment, this would have to be dealt with internally at the Public Guardian and Trustee Office.

The Public Guardian and Trustee also goes through the same review process as other appointees when the term of the agreement expires. However, this leaves a five-year period during which there is no verification or follow-up on the appropriateness of decisions made by the substitute decision maker (the Public Guardian and Trustee).

On the face of it, the task force believes there is room for greater reporting and accountability. The task force heard examples of situations where decisions made by the Public Guardian and Trustee about adults with intellectual disabilities on their caseload were inordinately delayed, not fully communicated or simply made without any consultation with the person.

The task force heard examples of how these decisions have a significant impact on peoples' lives and it is clear there are issues that need resolution. These issues are persistent, and those who raised them noted these had been ongoing for a number of years. The task force believes that the Public Guardian and Trustee must work closely with all stakeholders to reduce concerns and improve outcomes for the individuals for whom it is the substitute decision maker.

Delegation

Given the caseloads of Public Guardian and Trustee adult services administrators, the practice for several years has been for the Public Guardian and Trustee to delegate responsibilities for adults they support to community service workers from Manitoba Families. This is done because community service workers are presumed to have more direct knowledge of the individuals and their needs. However, this is often no longer the case in practice. Changes in the way Manitoba Families operates mean that community service workers may have no more contact with adults with intellectual disabilities than adult services administrators. This calls into question the effectiveness of proxy delegation to community service workers.

In reality, service delivery agencies are often the parties with the greatest knowledge of and interaction with individuals. They are the most likely to be able to speak to the will and preferences of individuals. While Manitoba Families will always have an important role to play, the current reality calls for a new way to ensure the will, preferences and rights of the individual are known and honoured by the proxy.

> ***"…the current reality calls for a new way to ensure the will, preferences and rights of the individual are known and honoured…"***

Relationships

In providing services for adults with intellectual disabilities, the Community Living disABILITY Program works closely with service delivery agencies, families, the Office of the Vulnerable Persons Commissioner and the Public Guardian and Trustee. However, the Public Guardian and Trustee works primarily through delegation agreements with community service workers in Manitoba Families.

In contrast to community service workers, adult services administrators with the Public Guardian and Trustee do not have significant contact with the agencies responsible for supporting people. This creates challenges for making decisions based on the will, preferences and rights of the person. It also creates barriers to communication, which limits opportunities and experiences in which people can take part. This was noted by several individuals in multiple sectors who provided information to the task force. It is clear to the task force that there should be greater alignment between the Public Guardian and Trustee and other parties who work with the individuals they serve. The ability of stakeholders to work together and communicate effectively on behalf of people, is critical to the outcomes of the individuals served by the Public Guardian and Trustee. Ultimately, the aim is to move processes as close to the individual with as little red tape as possible.

Principles of the Act

Services for people with disabilities are governed by a range of human rights legislation, including the United Nations Convention on the Rights of Persons with Disabilities, the Canadian Charter of Rights and Freedoms, the Human Rights Code and The Accessibility for Manitobans Act. The Vulnerable Persons Living with a Mental Disability Act currently includes a set of principles, and the task force has recommended that these be reviewed and updated.

By contrast, The Public Guardian and Trustee Act is heavily focused on the powers of the Public Guardian and Trustee. It does not contain a statement of values or principles or make reference to other documents related to the rights of adults with intellectual disabilities. At best, this creates an apparent lack of connection between the principles underpinning both acts. In any case, it is clear that there stands to be greater alignment between the various acts that deal with similar populations.

As the legal decision maker of last resort, the Public Guardian and Trustee plays a primary role in the system. Its role is neither easy nor simple, and there will likely always be a need for it. That said, the task force heard significant concerns about the differences in how individuals were treated. The experiences of people represented by the Public Guardian and Trustee would be improved if all stakeholders worked together to ensure the best interests of the individual were met in a timely and effective way. This requires creative solutions and openness to change. The task force feels there should be greater collaboration among all parties in the system, and the Public Guardian and Trustee has an important role to play in ongoing discussions.

Recommendations

15. Public Guardian and Trustee

a) Creation of a Working Group

i. A working group should be created with representation from the Public Guardian and Trustee, the Office of the Vulnerable Persons Commissioner, Community Living disABILITY Services, service delivery agencies, and other relevant stakeholders.

ii. The working group should provide twice-yearly updates to the advisory council being proposed by the task force.

iii. The working group would solicit feedback from the stakeholder group to identify issues and themes with a particular focus at the beginning on the following:

- Gathering stakeholder feedback
- Supporting efforts to have an alternative for individuals who have the Public Guardian and Trustee as their substitute decision maker, either by replacement with a community substitute decision maker, or by relying on assisted decision making where appropriate
- Providing feedback on efforts to improve and update training and education about the system for adults with intellectual disabilities
- Considering how the values and principles that underpin the entire system for adults with intellectual disabilities can be aligned, and how those values and principles can be updated to reflect current human rights legislation
- Exploring how to reduce the problem of siloed service delivery and miscommunication between parts of the system
- Considering ongoing concerns for improving the quality of life for the individual, particularly around issues such as financial, after-hours care and end-of-life care
- Reviewing policies and practices on an ongoing basis to ensure that they are coherent across the entire system and following best practices

b) Legislative Review

Manitoba Finance should undertake a review of The Public Guardian and Trustee Act to ensure that it aligns with current human rights legislation (United Nations Convention on the Rights of Persons with Disabilities, the Canadian Charter of Rights and Freedoms, the Human Rights Code and The Accessibility for Manitobans Act), as well as other legislation dealing with adults with intellectual disabilities.

c) Review of Delegation Agreements

i. The Public Guardian and Trustee should work with Manitoba Families to review and revise the system of delegation to ensure that decision making support comes from the entity closest to the individual as possible.

ii. The Public Guardian and Trustee should work in partnership with service delivery agencies. This may include having service delivery agencies as parties to delegation agreements.

iii. The Public Guardian and Trustee should consider how information is shared with service delivery agencies, with a view to increasing information-sharing to meet the principles of the act.

16. STRENGTHENING COMMUNITY CAPACITY

Strengthening Community Capacity
A lot of what we looked at focuses on government. But there's a lot of work going on the in the community to help people with intellectual disabilities. Community organizations are finding new ways of doing things and interesting ways of helping families and people. This might mean helping people navigate the system, or better understand their rights. We think the government should support this work, and make sure there is funding to support interesting new ideas.

The majority of this report focuses on actions that government should take, whether on its own or in collaboration with community organizations. However, there is a range of work ongoing at the community level to help Manitobans with intellectual disabilities live full, meaningful lives. In preparing this report, and in discussion with key community stakeholders and families, the task force has identified a number of functions that have been suggested, are being considered, or are developing in an ad-hoc way. These include:

- Matching people to advocates to increase relationships and connections in people's lives and build support networks. This could be pursued by a coalition of agencies. Some of this work could be done by agencies as part of their Service Purchase Agreement with the department.
- Playing a role in proxy decisions and enabling agencies to be proxy through a new agreement with Community Living disABILITY Services and the Public Guardian and Trustee.
- Acting as a service navigator for people looking for services. This could build on existing work by Abilities Manitoba and Innovative Life Options.
- Providing education and resources on assisted decision making. The Family Advocacy Network, Abilities Manitoba and Inclusion Winnipeg are potential participants.
- Acting as a resource for substitute decision makers, which could include Inclusion Winnipeg, and Continuity Care. This would build on the existing work of the Office of the Vulnerable Persons Commissioner.
- Acting as a watchdog on issues of protection, including providing confidential advice, and a safe space to discuss concerns, as well as advocating for people. Abilities Manitoba and Inclusion Winnipeg may be able to play this role.
- Hosting a rights restrictions committee to review concerns, with inclusion from People First Manitoba and community agencies.
- Developing peer support networks and resources (see Section 14, Improvements for Families).

In some cases, these roles could be taken on by existing organizations with additional funding. In others, the community will need to work together to determine how these ideas can be developed.

The task force stresses that government cannot, and should not, lead everything. The above functions will develop organically through the leadership and passion of community organizations. That said, the task force believes that government can play a strong role to underpin this work with ongoing support. Community Living Manitoba noted as much in its submission to the task force: "The community may be a major component of the solution, but intervention is likely required to assist and jump-start the change." The department has recently signalled its support for funding community-led initiatives through endowments for accessibility projects and employment supports. This type of permanent funding rewards community innovation while ensuring stability.

Recommendations

16. Strengthening Community Capacity

a) Governance and Funding

- i. The department should set aside sufficient financial resources to fund ongoing projects related to supporting adults with intellectual disabilities.
- ii. Government and community organizations should explore innovative approaches to funding and delivering projects including community-based funding, endowments or other government grants, and social impact bonds, among others.

CONCLUSION

Manitobans with intellectual disabilities receive services from many different people and organizations: the Community Living disABILITY Services Program and community service workers, the Office of the Vulnerable Persons Commissioner, the Public Guardian and Trustee, service delivery agencies and others. They may also be assisted by friends and family, as well as community advocates. As this report demonstrates, it is a complex system.

It is not a system that works cohesively towards the same goal or one that fully respects the spirit of The Vulnerable Persons Living with a Mental Disability Act. Strong practices exist, and there is no shortage of commitment and passion in the system, but all of the people and organizations involved are not always working together. The recommendations of the task force are all aimed at correcting this situation, so the effort of those in the system leads to meaningful results for adults with intellectual disabilities.

Conclusion
The system for adults with intellectual disabilities is complicated. There is good work happening, but people don't always work together. We think our recommendations will make things better. In the future, people will need to work together better, and the government will need to let community take the lead. By doing that, we think Manitoba will be able to do what's best for adults with intellectual disabilities.

In order to successfully implement these recommendations, government will need to work collaboratively with community organizations and individuals. The task force believes that Manitoba is on the cusp of a major shift to community-led development. Government will always play an important role, but will need to create space for community led activity, and be prepared to support that work without leading it.

In the 25 years since the act came into force, the thinking around services for adults with intellectual disabilities has evolved. The task force believes that the recommendations of this report will set the course for the next 25 years and put Manitoba on the Pathways to Dignity.

PLAIN LANGUAGE SUMMARY

Chair's Comments

This report contains suggestions for the minister of Families to improve all parts of the system for adults with intellectual disabilities. It took a lot of hard work from a lot of people. We hope this report talks about all the major issues we heard. We heard a lot of positive things, and some things that need to change. We are suggesting new ways of doing things that will make things better for adults with intellectual disabilities. Everyone will need to work together to make this happen.

Executive summary

The Vulnerable Persons Living with a Mental Disability Act became law 25 years ago. At that time, the law did what people thought was best. But since that time, ideas have changed. Today we think about people with intellectual disabilities differently, but the law has not changed.

In September 2020, the Minister of Families asked a group of people from the community (who we will call the task force in this document) to look at the act, and at services that are offered for people with intellectual disabilities in Manitoba. The task force looked at a lot of things, and talked to a lot of people. We saw some good work, but there are also problems. We especially want to point out that we need to know more about the needs of Indigenous people.

This report contains suggestions for improving many different parts of the system. We think these suggestions will make the lives of people with intellectual disabilities better.

Background

The Vulnerable Persons Living with a Mental Disability Act is a Manitoba law that covers services for adults with intellectual disabilities. It became law in 1996, 25 years ago. Since then, the law has not been changed. In September 2020, the Minister of Families named a group of people from the community (who we will call the task force in this document) to look at the act, and at services that are used by people with intellectual disabilities in Manitoba.

The task force learned a lot of things:

- How people with intellectual disabilities are supported to make decisions
- What the vulnerable persons commissioner does and is responsible for
- What the Public Guardian and Trustee does and is responsible for
- How the act approaches protection and abuse
- The way the law is written and whether or not services are offered the way the law says they should be
- How individual plans happen
- What community service workers do and what they are responsible for

All of these things connect with each other. Even though the rest of this report looks at different issues, we think that all these parts have to work together.

Advisory Council

A lot of different people and organizations work with adults with intellectual disabilities. It's very important that all those people talk to each other, but that doesn't always happen. When people don't talk, it causes problems for everyone. To solve this problem, we are suggesting that the Minister of Families bring together a new group of people. These advisors would include people with different types of experience, including self-advocates. These advisors would also be responsible for keeping track of all the work that is going on, and identifying where things could be better.

Training and Education

Because the system is very complicated, there are a lot of things to learn about services for adults with intellectual disabilities. Everyone needs to learn: community service workers, agency staff, families, self-advocates, people in the community and other people. If people don't get the training they need, they won't learn what they need to know. We are recommending that government look at all the training it does to make sure it contains good information for everyone. We are also recommending that the minister bring together another new group, so people can work together on training and make sure it is the best training possible.

Supported Decision-Making – Assisted Decision Making

Everyone needs the help of others to make decisions in their lives. For adults with intellectual disabilities, this is called supported decision making. We like the term assisted decision making better, since it is less confusing.

Even though the law says assisted decision making should be happening, we don't think it is happening very much in real life. Not a lot of people know about assisted decision making. In some provinces, they have something called a representation agreement, where an adult with an intellectual disability can decide who they would like to help them with decisions, without losing any of their rights. We think this could be a good example for Manitoba and we are suggesting that we learn more about it and how we may be able to use it here.

Principles, Title, and Wording of the Act

The law is 25 years old. We think it needs to be changed so that it respects the human rights of people with intellectual disabilities. We also think the language of the law needs to change so that negative terms like vulnerable person aren't used anymore. We also think it's important that there are plain language versions available.

Appeal Process and Rights Recognition

We think it's important that people with intellectual disabilities know what to do when they don't agree with a decision that was made for them. There needs to be a safe place where people can go to talk about the problems they are seeing. Sometimes, there also needs to be a way to get a second opinion about decisions. This is what's called an appeal process.

Abuse and Protection

The law talks a lot about abuse, including how to prevent abuse and what to do when it happens. But things don't always happen like the law says. People don't always know what to do when they see abuse. It's not clear what happens after someone reports abuse. The way the law is written means that a slap in the face might not be abuse. We think the whole system needs to change how it handles abuse. We also think people need to be extra careful about abuse in risky situations.

Making Sure the Right Things Happen

The task force looked at how we can tell when the system is doing well. One of the ways we do this is by looking at what each part of the system is doing. One thing we are worried about is the connection between people with intellectual disabilities and the Public Guardian and Trustee. Sometimes there can be many steps required and too many people involved to connect to a person's worker and get help. That makes contact difficult. We are recommending that the government look at how the connection between the person and the caseworker can be stronger.

Transition to Adulthood

When you turn 18, you become an adult with rights and new responsibilities. Youth with intellectual disabilities enter the system for adults in different ways. For some youth, they enter the system for adults with the help of their parents and family.

Other youth are being taken care of by Child and Family Services and don’t always have family support. Schools and the government are also involved. Different parts of the system don’t always share information, and that makes the switch to adult services even harder. That’s especially true for youth leaving Child and Family Services care, and Indigenous youth. We are recommending that everyone work together to make sure youth are getting the support they need when they turn 18.

Indigenous Representation

There are a lot of Indigenous people who get disability services. We think government needs to do better to learn what their needs are. We are asking that government work with Indigenous people to learn what they need. We are also asking that different parts of the system look at the work they are doing to make sure they are doing what Indigenous people need. We also think Indigenous people need to have a place to make decisions about the system.

Substitute Decision Making and the role of the Office of the Vulnerable Persons Commissioner

When someone can’t make their own decisions, the law lets government decide who will make decisions for them. This is called a substitute decision maker. The person who decides who gets to be a substitute decision maker is called the vulnerable persons commissioner. The decision to name a substitute decision maker is only supposed to happen when there are no other options. We are worried that the decision sometimes happens even though there are other choices. We want more information to be shared to make sure naming a substitute decision maker is actually the only option. We also think people in the community should know who the commissioner is and what they do. We also think information from the commissioner should be available in plain language.

Hearing Panels

When someone asks to be a substitute decision maker, they talk to a group called the Vulnerable Persons Hearing Panel In a formal hearing. This group helps the vulnerable persons commissioner decide if there needs to be a substitute decision maker. We believe that the hearing panel needs to use plain language and find ways to make the meetings less stressful. We also think there should be a way of making sure everyone who goes to a hearing panel feels safe while they are there.

Individual Planning

Every person who gets services from Community Living disABILITY Services is supposed to have an individual plan. These plans are a way of knowing what a person’s goals are, and helping to figure out how they will reach those goals. Sometimes an individual plan is also called a support plan or person-centred plan. A good individual plan depends on knowing and listening to the person, and making sure the person participates in all planning. Individual planning happens now, but we are worried that it doesn’t work that well. If the person doesn’t get to decide what is in their plan and how it is created and kept up to date, we know it probably won’t work. We are recommending the government look at how individual planning happens to make sure these plans work for people.

Role of Community Service Workers

Community service workers are the people in the department called Manitoba Families who work most closely with adults with intellectual disabilities. Sometimes we refer to these people as workers. They have a very important job in the system. But the way they do their job has changed a lot since 1996, when the law was made. Community service workers used to have more time to connect with individuals. We heard a lot of complaints that people don't even meet their worker. We are recommending that the department change the way community service workers do their jobs, and make sure everyone understands what those workers do.

Improvements for Families

We talked to families of adults with intellectual disabilities and heard about problems in the system. When a family asks to be a substitute decision maker, they have to fill out a lot of complicated forms and go through a lot of work. The Public Guardian and Trustee doesn't have to do all the same work. We are recommending that things should be easier for families. This could mean making forms and documents simpler and easier to understand. It could also mean changing some of the work families need to do. We are also recommending that the department start doing random checks with all substitute decision makers, to make sure that they are doing what's best for the person.

The role of the Public Guardian and Trustee

When no one else can be the substitute decision maker, the Public Guardian and Trustee steps in. They are the last resort, and that's an important role. We heard questions about some of the ways the Public Guardian and Trustee works. One thing we really noticed was that the Public Guardian and Trustee doesn't have a lot of contact with the people they are making decisions for. We think it's important that the Public Guardian and Trustee talk with the person and their community service workers and agencies to make sure everyone is working together to get the best result for the person.

Strengthening Community Capacity

A lot of what we looked at focuses on government. But there's a lot of work going on in the community to help people with intellectual disabilities. Community organizations are finding new ways of doing things and interesting ways of helping families and people. This might mean helping people navigate the system, or better understand their rights. We think the government should support this work, and make sure there is funding to support interesting new ideas.

Conclusion

The system for adults with intellectual disabilities is complicated. There is good work happening, but people don't always work together. We think our recommendations will make things better. In the future, people will need to work together better, and the government will need to let the community take the lead. By doing that, we think Manitoba will be able to do what's best for adults with intellectual disabilities.

APPENDICES

Appendix A – Terms of Reference for the Task Force

September 9, 2020

Terms of Reference – Vulnerable Persons Living with a Mental Disability Task Force

Background

The Vulnerable Persons Living with a Mental Disability Act is a Manitoba law that provides authority and determines eligibility for services to adults with intellectual disabilities in the province. The law also:

- Creates the role of vulnerable persons commissioner
- Outlines the role of supported decision making
- Establishes the use of substitute decision makers, who are legally empowered to make decisions on behalf of vulnerable persons
- Sets out requirements for individual planning for vulnerable people under the act
- Outlines the process for investigating allegations of abuse of a vulnerable person

The act lists five principles:

- Vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise.
- Vulnerable persons should be encouraged to make their own decisions.
- 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.
- 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.
- 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.

The act was proclaimed in 1996 and based on best practices of the time. In contrast to previous laws, which removed all legal decision making power from individuals when they were deemed to not have capacity, the act approaches decision making for adults with intellectual disabilities on a continuum. Individuals are assumed to have capacity unless demonstrated otherwise. The act also allows situations where people are deemed capable of making decisions in some areas but not in others. This allows a gradual, increasing degree of support in multiple areas, beginning with assistance from a group of trusted individuals in making decisions (supported decision making), up to the appointment of a substitute decision maker with legal authority.

In March 2019, community advocates from the disability sector brought together a group of stakeholders for a think tank session considering "potential solutions to the shortcomings of the act and its administration." From this session, Community Living Manitoba and the Public Interest Law Centre produced a report with recommended changes to the act in August 2019.

To respond to the concerns raised by community advocates, the Honourable Heather Stefanson, Minister of Families, has created a task force to provide recommendations on the way services for adults with intellectual disabilities are provided in Manitoba. These Terms of Reference establish the scope and mandate of the task force.

Scope and Deliverables

The task force is a time limited project that will provide recommendations on key elements of the supports and services available to adults with intellectual disabilities.

In Scope

The task force will be empowered to develop:

- A strategy to encourage supported decision making as an alternative to substitute decision making
- A two-year action plan to reduce reliance on substitute decision makers

The task force will also be empowered to create sub-groups to examine the following specific issues and make recommendations on:

- The community engagement and education role of the Office of the Vulnerable Persons Commissioner
- The role of community service workers
- Issues around the legal definition of abuse, as well as the process of investigating, verifying, and the penalty for substantiated cases of abuse
- The role of the Adult Abuse Registry
- Issues around supported decision making
- Individual planning issues
- The role of the Public Guardian and Trustee

Out of Scope

The task force is not empowered to explore the following issues:

- Comprehensive legislative review of the act
- Changing the role of the vulnerable persons commissioner
- The level of funding for supports to adults with intellectual disabilities
- Eligibility criteria for provincial disability services
- Services on reserves

Deliverables

By March 31, 2021, the task force will provide the minister with:

- Recommendations for improving services and supports for adults with intellectual disabilities
- An action plan for implementing the recommendations

Consultations

The task force has been created to bring together community experts to share their perspectives and experience on key elements of service provision. The task force is not expected to engage in wide-scale consultations, or reproduce consultations that have already occurred.

However, the task force may find it necessary to engage in targeted consultations on specific questions, and may organize meetings for that purpose.

No additional budget will be provided for consultations, although the task force may rely on department resources for this purpose.

Membership

The task force will include the following members:

- **Dale Kendel,** Former executive director of Community Living Manitoba (chair)
- **Margo Powell**, Executive Director, Abilities Manitoba
- **Scott Smith**, Director, Pulford Community Living Services
- **Irene Hamilton**, Former Provincial Ombudsman
- **Susan Boulter**, Member of the Vulnerable Persons Hearing Panel roster
- **Heidi Wurmann**, Assistant Deputy Minister, Corporate Services, Manitoba Families
- **Janice Morley-Lecomte**, Member of the Legislative Assembly for Seine River
- **Kevin Johnson**, First President, People First Manitoba
- **John Leggat**, Chief Executive Officer, St. Amant
- Honorary member: **Jessica Croy** (self-advocate), Special Advisor to the Minister on Disability Issues

Dale Kendel will serve as Chair of the Vulnerable Persons Living with a Mental Disability task force. He will be responsible for:

- Acting in an impartial and non-partisan manner
- Guiding meetings according to the agenda and time available
- Encouraging the balanced analysis of all relevant issues and questions for a variety of perspectives
- Ensuring that all members participate in discussions and decision making
- Determining when consensus is reached
- Assessing real or perceived conflict of interest of any members, and recording in writing any declared conflict of interest
- Verifying that minutes of the meetings are accurately recorded
- Monitoring the work of the task force with a view to keeping it on track to meet timelines
- Submitting a final report to the minister on behalf of the task force

Task force members will be responsible for:

- Participating in meetings and proposing agenda items
- Carrying out tasks agreed upon at meetings
- Appreciating and advancing, in a balanced and fair way, the views and interests pertaining to persons with intellectual disabilities, the sectors affected by the act, as well as other relevant stakeholders

Consensus

The task force will attempt to seek consensus among its members on the recommendations made to the minister. Consensus means substantial agreement of members, without persistent opposition by a process taking into account the views of all members.

Timeline and Meetings

The task force will meet on a monthly basis from September 2020 to April 2021. Additional meetings may be scheduled if needed.

Sub-group meetings may occur as needed. The chair will be responsible for ensuring that sub-group work respects the reporting deadline for the task force.

Final report to be delivered to the minister by **March 31, 2021**.

Upon receiving the task force recommendations, the minister will review and respond to them by **Fall 2021**.

Resources and Remuneration

The chair will facilitate meetings. Government staff will provide impartial administration, research, writing and coordination support, including assistance in preparing the final report to the minister.

Participation and attendance at meetings are important to ensure the steady progress and success of the task force. Meetings will be scheduled in advance to allow for proper planning and attendance of members. It is anticipated that work by task force members will take place between meetings (e.g., review and approval of documents by email).

Reimbursement **for up to 10 task force meetings**, each lasting less than three hours will be as follows:

- The chairperson will be remunerated $256 per meeting, for a maximum of $2,560.
- Members will be remunerated $146 per meeting, for a maximum of $1,460.
- Members for whom participation is part of their regular work as members of the legislative assembly or government employees will not be eligible for remuneration.

Parking and other transportation costs will be covered, subject to the provision of receipts and in line with the Government of Manitoba General Manual of Administration.

Should the task force decide to establish a subcommittee to support its work, it will need to ensure subcommittee participation is voluntary and free from any financial compensation or reduce the number of task force meetings to compensate subcommittee members accordingly.

All meetings will be accessible to participants experiencing barriers. Members will be required to identify to the chair any specific accessibility supports that will be required for full participation in meetings.

Appendix B – Resources and Individuals Consulted

In conducting the research for this report, the task force and subcommittee members consulted with the following individuals and groups. Topics discussed covered the range of issues addressed in this report. Where additional clarification was needed, the task force followed up by email, in some cases several times. The task force is grateful to all those who took the time to provide information.

Manitoba government organizations/staff

- Office of the Vulnerable Persons Commissioner
- Public Guardian and Trustee
- Community Living disABILITY Programs staff
    - Protection Unit
    - Focus group of Community Service Workers
    - Staff responsible for training
    - Senior Management
- Members of the Vulnerable Persons Hearing Panel
- Members of the Adult Abuse Registry Committee

Manitoba government organizations/staff

- Winnipeg Police Service
- RCMP
- Red River College - Disability and Community Support Program
- Manitoba Advocate for Children and Youth
- Child and Family Services Authorities

Community organizations

- Community Living Manitoba
- Abilities Manitoba
- Family Advocacy Network
- People First Manitoba
- Downs Syndrome Manitoba
- Continuity Care
- Inclusion Winnipeg
- Life’s Journey
- Innovative Life Options
- Winnipeg Indigenous Executive Circle

Individuals

- Jessica Croy
- Rose Flaig
- Gail Scheer
- Tardiff Family

The task force also consulted the following documents:

Policy Documents

- Community Living disABILITY Services
  - Management of Personal Funds (2019)
  - Support Plan Policy (2019)
  - Person Centred Individual Planning (2016)
  - Reporting Process and Documentation Requirements for Allegations and Investigations of Abuse/Neglect of a Vulnerable Person (2017)
  - Delegation of Authority Agreement with The Public Trustee of Manitoba (2009)
- Children's disABILITY Services
  - Bridging to Adulthood: A Protocol for Transitioning Students with Exceptional needs from School to Community
- Child and Family Services
  - Age of Majority Framework (Winnipeg Child and Family Services)
  - Transitional Planning Mapping Template (Winnipeg Child and Family Services)
  - Leading Practice Guidelines for supporting youth to transition at age 18 (Child and Family Services General Authority)

Research prepared by the department for the task force

- Best Practices for Enabling Supported Decision making: Review of International Law
- Supported Decision making: The Situation in Canadian Law
- Comparison of Power of Attorney, commiteeship, and substitute decision making
- Reimagining the Role of Community Service Workers in Supporting People with Disabilities

Jurisdictional Scans

- Legal definition of abuse
- Inclusion of review clauses
- Principles of adult guardianship legislation
- Public reviews of provincial disability programs in Canada

Laws

- The Vulnerable Persons Living with a Mental Disability Act
- The Public Guardian and Trustee Act
- The Mental Health Act
- The Powers of Attorney Act
- The Human Rights Code
- The Accessibility for Manitobans Act
- United Nations Convention on the Rights of Persons with Disabilities
- Canadian Charter of Rights and Freedoms
- The Canadian Human Rights Act

Other documents

- Report on the Examination of the Implementation and Impact of The Vulnerable Persons Living with a Mental Disability Act (2007)
- The Future of the VPA: Recommended Amendments to the *Vulnerable Persons Living with a Mental Disability Act* (2019)
- IRIS: Implementing Equal Access to Legal Capacity in Canada: Experience, Evidence and Legal Imperative Summary Report (April 2019)
- IDEA 12 – Good and Promising Practice Guide
- A Personal Guide to the Act, 2013
- A Family Guide to the Act,
- An Agency Guide to the Act
- Manitoba Families - Annual Report 2019-20
- Public Guardian and Trustee of Manitoba - Annual Report 2019-20
- Manitoba Advocate for Children and Youth – Annual Report 2019-20
- A Guide to Understanding the Protection for Persons in Care Act, Government of Alberta (July 2010)
- Building on Abilities (BOA) Supports Intensity Scale Guide for Service Providers and Agencies (February 2017)
- Contemporary Issues in Disability- Conceptual Frameworks- Red River College
- Persons with Developmental Disabilities Central Alberta Community Board - ***Person-Centred Planning Approaches – A literature review*** (May 2001)
- People First Manitoba – ***The Right to Live in Community***
- Abilities Manitoba – ***Leading Practices Guidelines***
- Discussion Paper – Changes to Legislation Affecting Manitobans Living with a Mental Disability (1991)
- Examining Legislation Affecting Adult Manitobans Living with a Mental Disability as Vulnerable Persons (1991)

Appendix C – Details of Proposed Advisory Council

Composition:

The advisory council would be composed of

- assistant deputy minister (co- chair)
- Representative of the minister (co- chair)
- Representative of parents of disabled person(s)
- Representative of advocacy organizations
- Representative of services agencies
- Representative of People First
- Representative of Indigenous People

As appointed by the minister responsible for the act

Frequency of Meetings:

The council will meet at least three times a year—June (annual return date) October (business planning for next fiscal year) and February (previous annual year statistics)

Duties:

The council will review a report from the vulnerable persons commissioner on the:

- Number of people currently under substitute decision maker appointments during the fiscal year
- Findings of spot checks and reviews
- Status of backlogs
- Impact of the amendment and changes
- Number of renewals of substitute decision makers
- Efforts to find assisted decision makers to replace substitute decision makers
- Number of hearing panels conducted and the disposition of the recommendations
- Number of monitoring reports requested and received from family/ private and Public Guardian and Trustee
- Progress of Indigenous Relations and related recommendations
- Emerging issues
- Administrative changes to make the website, processes and forms more user friendly

The council will review additional information, as needed, related to:

- The Training Advisory Committee on implementation of the comprehensive training plan and online training
- Individual planning
- Abuse issues, the number of investigations and disposition, deficiencies and plans
- Current practices for transition to adulthood, the number of people involved and the status of the working relationship with Child and Family Services and Community Living disABILITY Services
- The assisted decision making pilot project
- The Public Guardian and Trustee working group

The council may also meet with advocacy groups and have presentations as it desires or as requested by the minister.

Appendix D – Questions for Spot Checks

A. Personal information

1. Name of person for whom you are substitute decision maker:____________________________

2. Your relationship to that person:____

3. Length of time you have been appointed as substitute decision maker: ______________________

4. Tell us about the individual and how they are doing in the community?______________________

____

5. How often do you have contact with the appointed community service worker:________________

6. Do you have power to oversee health issues : Yes ☐ No ☐

   If yes, have you made any health decisions in the last year? Yes ☐ No ☐

7. Do you have power to oversee living arrangements? Yes ☐ No ☐

   If yes, have you made any decisions about living arrangements in the last year? Yes ☐ No ☐

8. Do you have power to consent to community activities? Yes ☐ No ☐

   *If yes, what have you had to consent to in the last year?*______________________________

9. Did you participate in the development of an individual plan for the person? Yes ☐ No ☐

   If yes, does it reflect the will and preferences of the person? Yes ☐ No ☐

B. Financial information

Please complete this section if you have power to make financial decisions.

1. Is there a financial plan for the person? Yes ☐ No ☐

2. What expenditures have been made to improve the person's quality of life?____________________

____

3. Do you have long-term plans for special or unexpected expenses? Yes ☐ No ☐

   *If yes, please provide details*____

____

4. Did the person's income tax return get filed? Yes ☐ No ☐

Manitoba