

A Family Guide to the

VULNERABLE PERSONS ACT



You've got to think about the big things while you're doing the small things, so that all the small things go in the right direction.

- Alvin Toffler

Who is a Vulnerable Person? Q & A — Vulnerable Persons 2. The Five Guiding Principles to the Act An Example - Denise's Story Q & A — Guiding Principles Notes & Quotes Think About Talk About — Guiding Principles 3. Support Services An Example of Day Time Supports - Bradley's Story Supported Decision Making Think About Talk About — Decision Making Notes & Ouotes **Individual Planning** Person Centered Planning An Example of Person Centered Planning Q & A — Support Services Think About Talk About — Planning Notes & Quotes **Substitute Decision Making** The Process Q & A — Substitute Decision Making Think About Talk About — Decision Making Notes & Ouotes

Protection from Abuse or Neglect

Safeguarding Against Abuse

Q & A — Safeguarding Against Abuse

Think About Talk About — Abuse

Think About Talk About —Feelings

One Family's Story

Notes & Quotes

Contacts and Acknowledgements

The Everything Else Page

A New Understanding

Notes & Ouotes

Notes & Quotes

Glossary

(A)

(B)

(C)

(D)

(E)

(F)

Background

How to Use this Book

The Vulnerable Persons Act

WHAT'S INSIDE

1

10

14

17

20

21

22

29

33-35

36-39

42-43

40

44

45

46

50

11-13

2-3

4-6

7

15

16

23

24 25

26

30

41

47

48

49

51

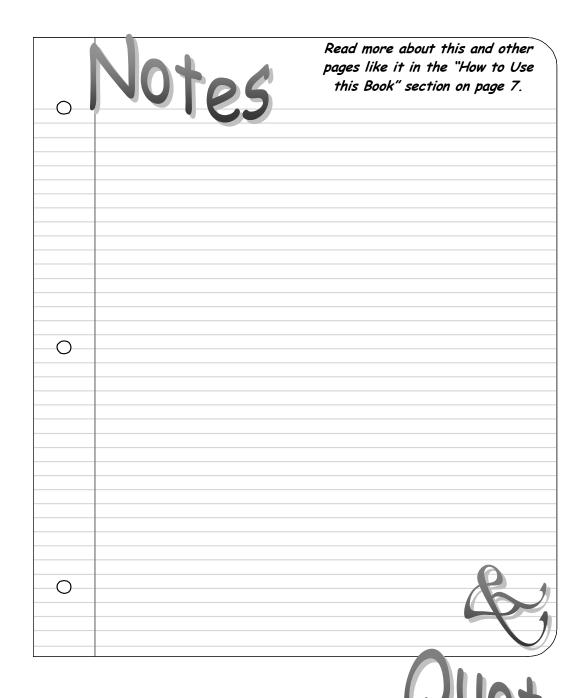
54

52-53

27-28

31-32

18-19



Our mind, once stretched by a new idea, never regains its original dimensions.

- Oliver Wendell Holmes

(A) BACKGROUND

In order to understand the importance of the Vulnerable Persons Living with a Mental Disability Act, we have to look at what came before. Prior to October 1996, we in Manitoba were legislatively instructed to see people with intellectual disabilities as incompetent and unable to make their own decisions. Even if our sons or daughters were able to make decisions, they were not allowed to do so. Services were designed for the "disabled" with little or no attention to the uniqueness of each person.

It was only a short 50 years ago when the only referral for our sons and daughters was to Manitoba institutions. We were told to turn our children over to these large structures and assured that it was the kindest place for them to live and ultimately die. We were given no hope and consequently had few expectations.

Some of us resisted these traditional attitudes and chose to raise our children at home. If they did live with us, they were bussed to special schools, special programs, special doctors and we felt isolated and frustrated. As adults, our sons and daughters had no say in where they lived, who they lived with or the kind of supports that were offered to them. Many of us fought and won small victories only to move on to the next stage of life to start the fight again.

BACKGROUND CONTINUED

The Vulnerable Persons Act is a breath of fresh air! It brings us words like "choice, rights, empowerment, enabling, and planning." It inspires and challenges services. It provides them with a different direction in which to work, and us with a framework of hope. It is what we have fought for all these years. It provides the right for people to choose who they want to be, where they want to live, and how they want their lives to unfold. It states clearly "vulnerable persons are presumed to have capacity." Our adult sons and daughters no longer have to prove what they can do. Rather, this legislation begins by announcing that Manitobans must presume that people with disabilities have skills and abilities.

Changing people's attitudes and values can be difficult. Families, government workers, service providers, and other systems are still in a process of learning what this legislation really means for people with disabilities. We are all challenged to ensure that our actions reflect the spirit of the Vulnerable Persons Act.

We must remain vigilant and patient. It is critical that we, as parents, have a thorough understanding of what the Vulnerable Persons Act means for our sons and daughters, families, and communities, so that we can be part of that ongoing learning. Our informed voices <u>can</u> make a difference.

(C) GLOSSARY OF TERMS

The Association for Community

Living-Manitoba Inc.(ACL-MB) — a provincial organization dedicated to the full

inclusion in the community of persons of all ages who

live with an intellectual disability.

Commissioner — the senior provincial civil servant who is responsible

for the Substitute Decision Making portion of the

Vulnerable Persons Act.

Community Services Worker (CSW) — the case worker hired by the Department of Family

Services and Housing who coordinates the provision of services to people with intellectual disabilities and their

families.

Day Services — agencies that provide a range (e.g. workshops,

supported employment) of day services for people with intellectual disabilities and are funded by the Dept. of

Family Services

Emergency Intervention — the protection portion of the Act gives the

Department of Family Services the ability to provide

interim support.

Executive Director — senior staff designate of the Department of Family

Services

Family Services — a department of the provincial government that

administers the government's social services agenda.

IQ — the Intelligence Quotient is a test that measures a

person's intelligence against the average.

GLOSSARY OF TERMS CONTINUED

Least Restrictive — an environment that provides opportunities for

people to learn and make decisions with a minimum of

restrictions.

Life Management Skills — includes activities of daily living such as bathing,

dressing, eating plus instrumental activities such as managing money, housework, taking medications, shopping, preparing meals, using the telephone.

MAP — a person-centered planning process

Minister — the Minister of Family Services and Housing

Minister of Family Services — the elected member of the current provincial

government who is responsible for the Department of

Family Services and Housing.

PATH — a person-centered planning process

Person Centered Plan — is a planning process which centers around the needs

and desires of an individual rather than the service or

system that supports the individual

Public Trustee — an office of the Provincial government that oversees

and makes decisions for Manitobans who are deemed unable to manage their own affairs. A small fee is

charged for this service.

Service Providers — agencies that provide services to people with

intellectual disabilities, funded by the provincial government, such as residential, employment, day

programs.

GLOSSARY OF TERMS CONTINUED

Substitute Decision Maker (SDM) — the person appointed by the Commissioner to make

decisions for a vulnerable person that the person cannot make him/herself, with or without the help of

a support network.

Support Network — a small group of family and/or friends of a vulnerable

person who provides support and assistance.

Supported Employment Agency — an agency that helps an individual identify their skills

and abilities, find a job, get training and receive ongoing

support as needed.

Supported Decision Making — a process of assisting a vulnerable person to make

decisions on their own by providing information, advice

and support.

Transition Planning — a planning process that assists in the transition from

school to employment programs.

Vulnerable Person — according to the act, an adult over 18 who has a

mental disability and who needs help with personal care

or property and money management.

Vulnerable Persons Act (VPA) — an act passed by the Manitoba legislature in 1996 as

The Vulnerable Persons Living with a Mental Disability Act.

Work or Job Related Plan — an individual plan that relates only to the employment

services that a person might receive.

(B) HOW TO USE THIS BOOK

This book will provide families with an understanding of the principles and spirit of the legislation. The **five guiding principles** are important to keep in mind as you read through this guide.

The intention of this book is to provide families with an overview of the Vulnerable Persons Act. If you read through it, and answer the questions, you will end up with a basic understanding of the Act and how it might impact your family. This is not a book that can answer all of your questions and indeed it may create even more. We suggest you note them in the Notes & Quotes pages located throughout this book and then contact the Association for Community Living-Manitoba or any one listed at the back of this book. The answers to the frequently asked questions are based on our experience, discussions with professionals and other families, and other written material. There are no clear right answers for many issues that arise; therefore, many of our answers are based on our values/principles. After gathering information your answers may vary depending on your experiences and value base.

In some sections, you will read the legislation as it was written, and then you will read it in corresponding everyday language.

We also use stories to show how the Act impacts vulnerable people and their families. The "Think About/Talk About" sections are just that, a way of helping you to think of the Act in terms of your situation.

This book goes through the Guiding Principles and the three main parts of the Act — Support Services, Protection from Abuse, and Substitute Decision Making. Questions in each section have been answered as factually as possible and at times are a reflection of the interpretation of the authors. This legislation doesn't give black and white interpretations to every situation but challenges us as families to think about and talk about our own circumstances, and come to our own understanding using the guiding principles as the foundation.

The Vulnerable Person's Act is young legislation — it is still new to everyone. We are all learning. It is important to ask questions.

(D) THE VULNERABLE PERSONS ACT



What we see depends mainly on what we look for.

John Lubbock

1. WHO IS A VULNERABLE PERSON?

According to The Vulnerable Persons Act a vulnerable person is defined as:

- An **adult** over 18 who has a
- Mental disability
 (lower IQ, needing help in daily living, and having the disability before the age of 18)
- And who needs help with personal care or property and money management

In order for your family member to fall within this Act, all three of the above must be in place.

This Act doesn't include people with a mental illness unless they have a dual diagnosis. That means they have a mental disability as defined above and a mental illness.

It's understood that the vulnerable person in your life might be a sister, uncle, friend. However, the vulnerable person in this book is referred to as son or daughter (son/daughter).



- 1. What if my child has never had an IQ test or life skills assessment? If an organization or school is referring your son/daughter to adult services, they will organize and fund whatever testing is necessary to ensure acceptance. If you are calling the Department of Family Services on your own (self-referring), Family Services will make those arrangements. The official word from the Department is that they will fund the process of testing.
- 2. I have resisted IQ tests throughout the school years, why do I have to have one now? The VPA uses an IQ measurement as one of the three basic standards in defining a person's eligibility or access to the Act. Many families have never been comfortable with the IQ test as an accurate measurement of a child's abilities and needs. Some have refused to have their son/daughter tested over the years. The reality is that it is required in order to access adult services and qualify under the VPA. Legislation always provides some definition or clarifies its target population. As families we have learned to pick and choose our battles and in terms of this specific issue, we will need to compromise if we are looking for services or for status under the Act.
- 3. My daughter's disability happened when she was 19 years old when she was in a vehicle collision, why doesn't she fall under this act? The Act states that the disability must have occurred prior to the age of 18. This means that your adult child will not fall under this specific legislation. That does not mean that her needs are not similar or even the same as individuals who do fall under the Act. It is simply a reflection of the definition of who qualifies. There may be other legislation, policies or services that relate more specifically to your daughter. Check with the Department of Family Services, the Department of Health or a medical service provider.

2. THE FIVE GUIDING PRINCIPLES TO THE ACT



We shall require a substantially new manner of thinking if mankind is to survive.

- Albert Einstein

2. THE FIVE GUIDING PRINCIPLES TO THE ACT

	Here's how it is written in the Act:	
1.	WHEREAS Manitobans recognize that vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise;	·····
2.	AND WHEREAS it is recognized that vulnerable persons should be encouraged to make their own decisions;	
3.	AND WHEREAS it is recognized that the vulnerable person's support network should be encouraged to assist the vulnerable person in making decisions so as to enhance his or her independence and self-determination;	
4.	AND WHEREAS it is recognized that any assistance with decision making that is provided to a vulnerable person should be provided in a manner which respects the privacy and dignity of the person and should be the least restrictive and least intrusive form of assistance that is appropriate in the circumstances;	·····
5.	AND WHEREAS it is recognized that substitute decision making should be invoked only as a last resort when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself or with the involvement of members of his or her support network;	

THE FIVE GUIDING PRINCIPLES TO THE ACT

—		And now in everyday language:
>	1.	The legislation tells us that vulnerable people are presumed able to make their own decisions.
······	2.	Your son/daughter is encouraged to make his/her own choices.
	3.	If your son/daughter needs help to make a choice, the legislation encourages friends, family, and service providers to help him/her understand the choices to make an informed decision.
······	4.	Any help provided must be respectful of your son/daughter's privacy and dignity as an adult.
······	5.	There may be a decision that your son/daughter is unable to make, even with help. As a last resort a substitute decision maker can be identified.

An Example of the Guiding principles at Work

Denise's Story — Denise is a 30-year-old woman who lives in a house with two roommates. Although she does not speak, use sign language, read or write, Denise is able to communicate well with those who know her. There is always a staff person there to support Denise with her day-to-day needs. Denise has reconnected with a few family members who are now involved in her life. Her life has unfolded in a more fulfilling way in the past six years.

	BEFORE VPA	AFTER VPA
Guiding Principle 1	Denise followed the routine of the group home.	Denise plans her day choosing from a variety of things to do.
Guiding Principle 2	One of Denise's staff reminds her of what she will be doing today.	One of Denise's staff encourages her to think about what she wants to do today.
Guiding Principle 3	Denise and the other group home members go on an annual trip to Grand Beach for a week.	Denise meets with her support network and they help her think through possible vacation options and plans.
Guiding Principle 4	Some of Denise's staff slip into a parent/child role when dealing with her.	Denise's support staff and network treat her as an adult.
Guiding Principle 5	As a <u>first</u> resort, Denise's decisions are made for her.	As a <u>last</u> resort an SDM is identified when Denise has a decision to make and is unable to make it, even with support.



- 1. My son just turned 18 and he makes decision I don't agree with. Can he do that? Yes, the first guiding principle of the VPA states clearly that a person is presumed capable of making decisions on their own. Guiding principles 2,3 and 4 encourage strong support and assistance be provided to individuals as they learn to make their own decisions. Only as a last resort does guiding principle 5 allow for a substitute decision maker to be identified to make decisions for them. We must remember that this is good news for our sons/daughters and families. It recognizes that our sons/daughters have rights and abilities, something many of us have fought long and hard for.
- 2. How do I let my daughter make her own decisions when I see her making such bad choices? This is one of the difficulties that we as family members experience as our children grow and become adults. It is our time to learn to let go and recognize that our sons/daughters may make decisions that we think are "bad." In the larger scheme of things it might help if we asked ourselves "how big an issue is this really?" For example, is the situation life threatening, an unmade bed, or money spent frivolously... or somewhere in the middle? The vast majority of decisions that any of us make each day are not life or death but rather the ongoing opportunities to succeed, fail and try again. This is an integral part of learning and for the most part, fairly harmless. It is important that people with disabilities have good support, advice and information as they learn to make their own decisions. And it is equally as important that we get better at standing back and encouraging them to make those decisions on their own.
- 3. I heard that a year ago my son was hurt and no one told me. When I questioned the support worker I was advised that he requested I not be told. Can they do this? As difficult as it is to sometimes acknowledge, our adult sons/daughters with disabilities now have access to the same rights and privacies as any other Manitoban.

Notes.	
0	

Quotes

I am only one, but I am one.
I cannot do everything, but I can do something.
And I will not let what I cannot do
interfere with what I can do.
— Edward Everett Hale



- How does your son/daughter make choices in life?
- ▼ Is your son/daughter supported to make choices?
 - ♥ How does that happen?
- ♥ What is your role as a parent in your son/daughter's decision making?

3. SUPPORT SERVICES



Call it a clan, call it a network, call it a tribe, call it a family.

Whatever you call it, whoever you are, you need one.

- Jane Howard

3(a) - Support Services

The minister may make grants or payments Your son or daughter may choose from a to, purchase services from, or enter into agreements with, persons or organizations to provide support services for vulnerable persons under such terms and conditions as the minister considers appropriate.

Here's how it is written in the Act: And now in everyday language:

variety of housing options and supports, and a variety of daytime options and supports.

What are Housing Options & Supports?

Your son/daughter may choose to live in a house and hire a support person as needed. He/she may need and prefer a place to live with 24-hour staff. There are many options — he/she may choose to live in a home with foster care support, in a home with other people with disabilities, in the family home or . . .

What are Daytime Options & Supports?

Your son/daughter may choose from a range of day services. Services to assist in starting a business, career planning, or job training may be possible. There are also day supports to access a variety of social, recreational, or volunteer opportunities, available either in segregated settings (workshops) or in the community.

SOMETHING TO THINK ABOUT: When your son/daughter is considering support services it is important to find services that fit his/her skills, talents, and interests.

An Example of Creative Day Time Support

п

П

п

п

п

П

п

"

11

п

ш

п

п

п

ш

11

п

11

п

п

п

п

П

п

п

П

п

П

"

П

п

| | | | |

п

п

П

ш

П

п

ш

п

ш

П

П

п

ш

п

П

п

п

BRADLEY'S STORY — Bradley is a young man with significant physical and developmental needs. While he was growing up his parents worried about what he would do every day when he was no longer in school. When Bradley was close to finishing school, the school contacted his parents and asked them to participate in transition planning. After some discussion, it was decided that Bradley should approach a supported employment agency who would then apply for the funding for a full-time support person.

When Bradley finished school, the agency had funding in place for him. The agency consulted with Bradley and other significant people in his life to determine what he wanted to do, what he didn't want to do, and to find out what support he might need. They developed a plan for him, which includes working three days a week at a major corporation to shred documents, sort mail, and make deliveries.

He enjoys the people he works with and they very much enjoy him. He also has access to many downtown lunch break activities such as eating out, concerts, and shopping. Twice a week he has physiotherapy and swimming.

Bradley's plan is flexible enough to allow for physical and medical needs but also has a consistency that helps him feel comfortable. Everyone agreed to a regular review of the plan. As Bradley uses a wheelchair, all his daily transportation is provided.

This arrangement has worked successfully now for several years.

3(b) - Supported Decision Making

Here's how it is written in the Act: And now in everyday language:

"Supported decision making" refers to the "..... process whereby a vulnerable person is enabled to make and communicate decisions with respect to personal care for his or her property and in which advice, support or assistance is provided to the vulnerable person by members of his or her support network.

The process of supported decision making encourages your son/daughter's support network to provide assistance for him/her to make decisions.

Supported decision making is giving advice and encouragement, and sharing information that enables your son/daughter to make a decision.

The word "enabling" used in this legislation means opening up possibilities and opportunities.



- What support does your son/daughter need to make a decision?
- ❤ How can you support your son/daughter to make decisions?
 - ♥ Who else can your son/daughter turn to for support in decision making?

0		
0		
		8
	ciously give other are liberated fro	ote

As people permission to do the same. As we are liberated from our own fear, our presence automatically liberates others. Nelson Mandela

3(c) - Individual Planning

Here's how it's written in the act: And now in everyday language:

- 1. The executive director shall develop an ····· 1. individual plan for every vulnerable person who receives support under this Part.
- 2. The executive director may review an 2. People change this plan can be individual plan and vary it, or determine that the person for whom support services were provided is no longer a vulnerable person.
- reasonable steps to ensure that the vulnerable person and his or her substitute decision maker or committee if any, have an opportunity to participate in the development of, and are informed of any decision respecting, the individual plan.

- An individual plan is a person centered plan developed for every person under the Act.
- reviewed at times to be sure it is up to date.
- Everyone important in your son/ daughter's life — family, friends, service providers — will be part of the planning.

Person Centered Planning

Person centered planning is a creative and hopeful process. It is not just another way of doing a service plan, but represents a different way of thinking and is very results oriented.

A meeting is held that focuses on your son or daughter. Participants who attend are invited because they have a special relationship with your son/daughter and usually include: parents, siblings, extended family members, friends, and others who are part of your son/daughter's life. Staff members may also be asked to participate. An objective person is asked to facilitate the session to ensure that the dreams and wishes of your son/daughter and contributions from all participants are heard and documented. A person centered plan is an excellent way to help build a team or support network around your son/daughter and to provide the team with some direction.

There are several person centered planning tools. (You may have heard the word PATH or MAP.)
The process is the same regardless of which tool is used.

You know it's personcentered planning if:

- ✓ listening and learning continues
- √ family members and friends are full partners
- ✓ your son or daughter is at the center of the process
- √ hopeful action happens
- ✓ the focus is on developing capacities

Parts of this reprinted
with permission from
Jack Pearpoint/Inclusion Press

An Example of Person Centered Planning

JEFF'S STORY — Jeff is a 22 year-old-man who has recently moved into an apartment on his own. He utilizes the support of a staff person 15 hours a week to help with life management skills. Jeff has a small group of involved family and friends who are also an active part of his life. Jeff, his support network, and service providers gathered in his living room for a PATH. He invited everyone to help him plan for the next year.

They started by talking about hopes and dreams — something to aim for even if they are not practical. This part of the PATH is intended to brainstorm all kinds of possibilities. Everyone was excited about Jeff's dream to combine his love of travel and of hiking — an around the world trip of the best hiking locations on the planet. A mansion with a roller coaster, a cook and a maid were also dreams of Jeff's.

While these dreams seemed ridiculous at first — dreams often do — it was important to keep them in mind for the next step, identifying positive and possible goals to meet during the next year. The plan that was decided on that day included several weekend hiking trips with family, and one big trip to hike in the mountains with friends. Jeff was motivated to save money for those trips, his support network would help him to find a day service to see which would help him find a job and get the training he would need.

Jeff's dream of owning a mansion was a little out of his price range, but he planned to ride the roller coaster at the fair during the summer, take a cooking class at the community centre, and hire a cleaning service once every two months.

Everyone at the meeting had a role to play in helping Jeff meet his goals. They would check in from time to time to be sure that things were moving along, and agreed to meet in one year to review the past year, celebrate it, and plan for the next.

This was person-centered planning because everyone listened and respected Jeff's dreams and focused on developing capacities. Hopeful actions occurred too.



- 1. My daughter is 15 years old. Is it too early to begin planning? Absolutely not. The more time that you have to create the dream and plan for the future, the better. Talk with the school and let them know that you are beginning to think about your daughter's coming of age. Be persistent and assertive. The Department of Education has an information package called "Manitoba Transition Planning Process Support Guidelines for Students with Special Needs Reaching Age 16." Contact your school or call the Department directly for your copy.
- 2. My son is 18 years old but we have not done any transitional planning yet. Is it too late to do transitional planning and if not how do I start? It is never too late for planning; in fact planning will happen throughout our sons/daughters' lives. Most schools are becoming more aware of how important a transitional plan is. Some schools are still not facilitating the planning for adulthood, which leaves the job to us. Contact your local Department of Family Services office or ACL Manitoba for assistance. You will find phone numbers at the back of this book.
- 3. The VPA talks about services but how can we access them on behalf of our daughter? Contact your local Department of Family Services office to get more information about supports/services in your area. Read the 'person centered planning' portion of this book. It will help you understand the kind of planning that you might want to have to help get you started. There are many families and professionals around the province that you can turn to who have been through it. Remember, just because a specific type of service is not available in your community doesn't mean that it's out of reach for your family. New services are being developed on an ongoing basis in response to a demand created by families just like yours.



- 4. Everyone seems to have more services than my daughter. Why is this?

 In Manitoba, children are entitled to services adults are not. As families we need to get very good at being assertive, persistent and advocate for what our sons/daughters need and want. Speak to other families and find out the processes that they used. Work together with your local Association for Community Living or contact ACL Manitoba for more information. Ultimately don't be intimidated about asking and then asking again. Remember...the squeaky wheel . . .
- 5. My son doesn't have a support network. How can I help create one? A support network can be formal or informal. The first step may be sitting down with your son and family to identify all the people (family members and friends) who are part of your lives. Then take a look at that list and think about who are the trusted, responsible individuals that you and your son might turn to for support. Consider inviting those people for dessert or a barbecue and discussing the concept of "community" and "support." Reach out to other families who have support networks in place for advice. There are organizations that may be able to help you. Some of them are listed at the back of this book. Don't be afraid or embarrassed to ask. You may be surprised at the positive responses you will receive.
- 6. My daughter wants to move out but my CSW tells me that there is not enough money to make this happen. What can we do? What's important for us to understand is that a lack of government resources doesn't have to stop us from being innovative. Another reality that we as families need to recognize is that for most of us, government will not meet all of our needs. Whether they should or not is another book entirely. This does not mean you should stop advocating for government resources. Rather this may be a perfect opportunity to connect with other families and community to develop new and creative options. There are a number of families around the province who have balanced resources and support needs in very interesting ways. Do some research
- 7. Whose job is it to initiate a person centered plan? Sometimes service providers do. Sometimes the Department of Family Services staff do. Sometimes families do. Anyone can initiate a planning process anytime they feel that it is needed. There are many trained facilitators around the province who would be able to help. Contact a number at the back of this book if you need more information.



- What are your son/daughter's hopes and dreams?
 - How did he/she and the support network identify these dreams?
- Who are the important people to your son/daughter?
 Are these people an active part of your son/daughter's planning?
- Does your son/daughter have a plan that includes goals for the future?
 - How does the support network help your son/daughter to meet these goals?

Notes	
	_(

4. SUBSTITUTE DECISION MAKING (SDM)



Remember that the challenges are not there to stop you. The challenges are there to help you grow.

- Ralph S. Marston, Jr.

Substitute Decision Making (SDM)

Let's suppose your family has thought about and talked about what best meets the needs of your son/daughter and everyone agrees that an SDM is required. It is natural to feel some "nervousness" about the process so this section will address what to expect and how to be prepared. Frequently asked questions and answers that follow address many of the concerns and requirements. Remember, you don't have to feel alone in this process. There are people to contact for support.

Substitute Decision Making — The Process

What is an SDM

(Substitute Decision Maker)?

When there is a decision to be made that your son/daughter is unable to make even with help, a *substitute decision maker* is appointed <u>as a last resort</u>.

This person or persons then have the authority and responsibility to make the decision for your son/daughter.

Who can be an SDM?

A family member or friend of your son/daughter may be appointed and more than one person may be appointed. These persons must be adults who are willing, suitable and able to be a substitute decision maker for your son/daughter. If no one else is available, the Public Trustee is appointed as substitute decision maker as a last resort.

Service providers may not be appointed as substitute decision makers if they provide your son/daughter with services for which they are paid.

There are two areas in which a substitute decision maker may be appointed;

1-SDM for Personal Care

This means matters concerning where to live, health care (like medication or surgery), education or training, where to work, leisure and recreation, etc.

2-SDM for Property

This means matters concerning depositing, investing, paying bills, signing leases, major purchases, business decisions, etc. The SDM is required to keep a record of all transactions and provide regular reports to the Commissioner detailing the management of your son/daughter's property.

The substitute decision-maker has the responsibility to encourage your son/daughter to participate in the decision making process and to take into account his/her wishes, values, and beliefs.

Substitute Decision Making — The Process Continued

How will it happen?

Anyone can apply to initiate the process of appointing a substitute decision-maker. Your Community Services Worker can assist in this process. Once an application is made there is a preliminary exploration. This will determine if your son/daughter is a vulnerable person as defined in the Act and to determine if there is a decision to be made. This preliminary work could include gathering records or arranging for assessments if recent ones are not available.

An application to become an SDM requires a recent criminal records check from your local police department and a child abuse registry check from the Family Services office in your area. Once the application is completed a hearing will be convened.

The hearing panel

Three people make up a panel. Panel members are appointed by the Minister of Family Services and can be relatives of vulnerable people, lawyers, and community members. Hearings can take place in every community of the province.

Who is present at the hearing?

At least seven days in advance of a hearing notice will be given as to the date, time, place, and purpose of the hearing. Notice will be given to the vulnerable person, the applicant, the proposed SDM(s), the person's nearest relative(s), and anyone else the vulnerable person or the Commissioner considers appropriate — service providers for residential, educational, occupational, and recreational areas could be included in this list. Anyone who wishes to attend but is not able to do so in person, may participate through a telephone conference call.

Substitute Decision Making — The Process Continued

What happens at the hearing?

Hearings can be held anywhere as long as the meeting space offers privacy and will accommodate the number of people likely to attend. Family Services board rooms, leisure centres, agency meeting rooms are a few likely places.

With the exception of formal opening and closing remarks read by the presiding panel member, the hearing process is an informal one. Hearings last on average of one hour.

Everyone in attendance is encouraged to participate. Panel members will ask questions about the written information and about the vulnerable person's life in general. They will want to know what has precipitated the application. Other questions might centre around how your son/daughter handles money, does their shopping, spends their day, what recreation or leisure activities they enjoy, who their support network is, etc.

It is an opportunity for people to share the abilities and needs of the vulnerable person, in this case your son/daughter. The panel members listen to what people in attendance say and, together with the written material, make recommendations as to

- whether there is a decision to be made that the vulnerable person could not make with or without a support network
- who should be appointed
- which powers could be granted for the SDM, and for how long.

How is the decision made?

The Commissioner reads the information and the panel's recommendations, listens to the recorded hearing and makes his decision whether or not to approve the application for a substitute decision maker. Notification of decisions reached takes approximately two weeks.

Any decision that is made by the Commissioner can be appealed to the Court of Queen's Bench by anyone who was given notice to attend and spoke at a hearing, and disagrees with the decision.



- 1. Where can I get more information about being a substitute decision maker?

 Contact the Department of Family Services and ask about the "Guidebook for Substitute Decision Makers from the Manitoba Government". It is a fairly easy to read document that addresses every aspect of what is involved once a person is identified and confirmed to be the SDM for someone. The Department can also help answer any questions you have about the application or hearing panel process.
- 2. Can a parent initiate the SDM process? Yes you can. The first thing you must do is to ensure that your son/daughter is a vulnerable person as defined in the Act. If there is a decision to be made and you are fairly sure that your son/daughter can not make it even with support, then you can initiate the process.
- 3. My 21-year-old son lives with my husband and I and we do all his banking. Do I need to apply for SDM status? This is one of those questions where there is no specific right answer. It is true that in the eyes of the legislation (and therefore the law) your son is considered capable of making his own decision if there is no SDM in place. Given that your son is living at home and supported by your family there may be no urgent need to gain official SDM status. In time, when he moves out that situation may change depending on his ability to manage his own money related decisions. You should be aware that a situation might arise where a signature is required and you son is unable to understand the implications. A bank manager for example may ask if he is able to understand what he is signing and if not, may question the validity of his signature. Or you may go away for several months in the winter and he may not be able to manage his finances in your absence or have someone to help him. These examples and others that may arise might make it necessary to apply for a short term SDM to address the specific issues. It is critical for us to remember that what we need most is thoughtful planning and having the information to take steps if and when needed.



- 4. Is an SDM the same as a trustee identified in a will? No. In order to prepare your will and estate you will need to speak to a lawyer and probably an accountant. The trustee that you identify in your will plays a completely different role than a Substitute Decision Maker.
- 5. We know that our son needs an SDM for personal care. How do we decide who would be best for this? Other families have found that it is wise to find a person who is closer in age to your son, like a sibling, other relative or friend. The reasons for this are obvious. If your son needs an SDM today, it may be that he will require one at some point in the future. Aging parents may be unable to continue doing this. It is also important that the SDM be someone who is trustworthy and respectful and able to communicate with your son to understand his wishes and needs.
- 6. We've decided that our daughter needs an SDM. Who do we call? The most direct way to initiate the process is to contact your local Department of Family Services and ask to speak to someone who can help you do this. There is a fairly lengthy form that will need to be filled out to assist the hearing panel in making their recommendations.
- 7. The form sounds overwhelming. Where can I go to get help? Once again we suggest that whenever possible, families connect with other families. They may be your best source of expertise and information. There are also organizations/ services that can assist you including the Department of Family Services, ACL Manitoba, other services in your community, etc.



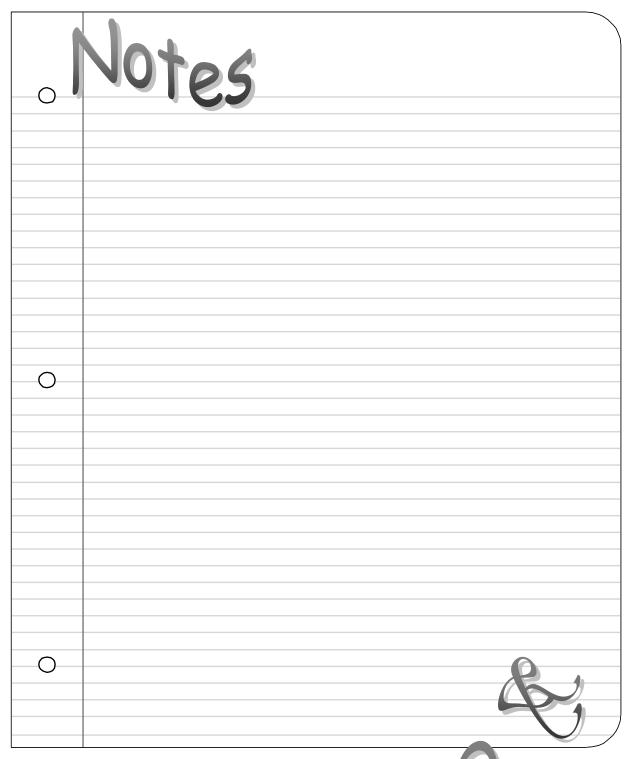
- 8. If I don't get SDM status, what will happen if there is an emergency? The Act does allow for a short-term SDM to be invoked quickly in an emergency situation. This process does not require a hearing panel. It would be done through the Department of Family Services who is empowered to step in quickly if needed. Some parents are beginning to anticipate possible situations by discussing options with doctors and other professionals. This will ensure that an emergency plan is in place. A good rule of thumb is . . . be prepared!
- 9. Do I need a lawyer present at the hearing panel? This decision is entirely yours. If it makes you feel more comfortable and you have a lawyer that you trust then go ahead. However it's important for you to know that most families do not have legal counsel. Remember the hearing is not a formal legal process. It is an informal community forum that was created to facilitate the SDM portion of this Act. Whether you decide to invite your lawyer or not, don't be reluctant to include people from your family or son/daughter's support network to be part of this process.
- 10. Why do I as a family member need a criminal record check and an abuse registry check? It is true that every SDM in the province must have a formal criminal record check. Some parents feel angry and resentful that they are asked to 'prove' that they are good choices to fulfill this role. It does sound diminishing and offensive but we must remember that it was included in the Act to protect our sons/daughters, not to offend us. It's hard to believe that family members might not be the right choice to speak on behalf of vulnerable family members, but in a very few situations this is the case. We must not take this personally and realize that it is ultimately for the protection of our children.



11. My son will turn 18 years old next month. I was told I should apply for SDM status to protect and keep him safe. Should I? First, you need to remember that when an SDM is invoked your son loses his right to make decisions in some areas. That in it self should cause us to think deeply about whether this "last resort guiding principle" is needed. If safeguarding and protection is the issue, pay attention to some of the ways that specifically will help safeguard your son. Most people working and involved in the community living movement have come to understand that the best way to keep vulnerable people safe is by establishing a network of people around them. We know that isolation is a contributing factor when people fall into harm's way. Continually surrounding our sons/daughters with people, family and friends will ensure that they are not isolated. Work on getting a support network up and functioning. It is important for us to ensure that good people are involved in our sons/daughters' lives. One of our roles may be to continue advocating for our son/daughter to have appropriate supports. We need to feel confident that the agency providing supports is capable and respectful. We need to establish good communicative relationships with that agency and specific support staff. These are the safeguards that minimize the risks involved in living each day for all of us.



- What kind of decisions is my son/daughter making?
 - What are the decisions that my son/daughter needs assistance with?
- Discuss with your family the decisions your son/daughter makes that challenge your comfort zone.



Mistakes are the portals for discovery. — James Joyce

5. PROTECTION FROM ABUSE or NEGLECT



"Injustice anywhere is a threat to justice everywhere. We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly."

- Martin Luther King, Jr.

Protection from Abuse or Neglect

The Vulnerable Persons Act requires by law that service providers and substitute decision makers, must report abuse or neglect, or suspicion of abuse or neglect of the vulnerable persons they support. They make this report to the Department of Family services. Family members, friends, and the public are encouraged to report any suspicion as well but are not required by law to do so.

It is important to note that you need only report your knowledge or suspicions — Family Services will investigate and determine whether or not there has been abuse or neglect. There are many ways to report abuse or suspected abuse — to service providers, to Family Services, or directly to the police.

What is Abuse?

Abuse is about someone misusing their power over someone else. Abuse may be intentional or non-intentional, and can be a combination of actions.

Any act of abuse causes harm to the victim. It is important to recognize the range of actions that are considered abusive.

There are five types of abuse:

- 1. Physical
- 2. Sexual
- 3. Mental
- 4. Emotional
- 5. Financial

What is neglect?

Neglect is failing to provide basic needs. It can be either intentional or non-intentional. Even if the service provider does not understand the needs of the individual, if they fail to provide them they are being neglectful.

One Family's Story

"My son has been acting odd. I can't put my finger on any one thing in particular - it's just that he's normally so easygoing and affectionate, but now he's acting shy, even with his family. We all think that this is strange. He doesn't talk much, but from his actions, I think something must be wrong. When I brought it up with the staff at the house where he lives they just brushed me off. Now what do I do? I don't want to be labeled a troublesome mother, but still, I'm worried."

Remember you are a <u>committed family member</u> showing personal interest and **not** someone being "troublesome." You communicated to your son's service providers but did not feel your concerns were addressed. Speak with them again and ask other members of your son's support network to be there with you. You may go elsewhere with your concerns — other service providers, Family Services, or contact the police directly. Under the Act, your concerns of abuse must be investigated by Family Services.

Safeguarding Against Abuse

This portion of the Act can evoke fearful emotions. It is frightening to think about our sons and daughters needing protection from abuse. These emotions should not be ignored nor should they be used as an excuse to overprotect even though that might be our first instinct. This page provides us with some of the positive and proactive ways to create safeguards around our vulnerable sons and daughters. If we deal with our fears with good solid planning, a lot of our anxieties can be alleviated and our sons and daughters **WILL** live safer lives.

- 1. Personal Interest and Commitment Be involved in your son/daughter's life. Know the people hired to support them, know their friends. Let everyone know that you are there to support your son/daughter.
- Support Network Other family members and friends are an important part of your son/daughter's life. Act as a team. Collective support is powerful.

Being part of a community, with support of the people around you, is the best safeguard against abuse.

- 3. <u>Communication</u> Talk to your son/daughter, and, more importantly, listen. Listen to their words, and observe their actions, expressions, and moods. Communicate with others in their support network and share your experiences. Talk with your son/daughter's service providers to be sure that everyone is sharing information.
- 4. Education Know the Vulnerable Persons Act and how it applies to your son/daughter and your family. Ask questions. Be sure that your son/daughter's service providers also know about this legislation and how they must act under the law. Teach people around you about the VPA so that they know what is law in Manitoba.



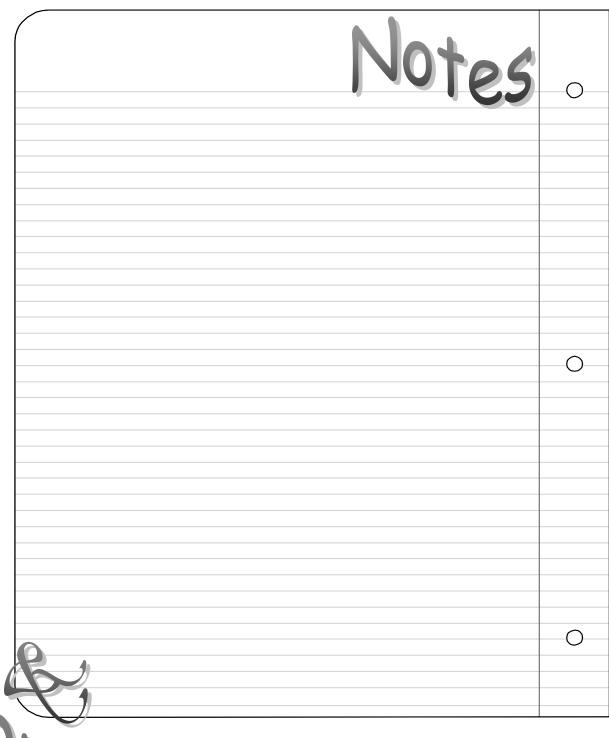
- 1. What if my son or daughter is still in harm's way? Will I be notified?" As an adult, your son/daughter has the same rights to privacy that anyone else has. No one has the right to take away that privacy. Under the Act you know that Family Services must investigate every allegation of abuse and deal with it appropriately.
- 2. How does Family Services investigate abuse allegations? How do I know that it will be taken care of appropriately?" Someone from Family Services investigates by:
 - communicating with the vulnerable person to help determine what happened
 - entering any facility to speak with the vulnerable person and review any information important to the investigation.
 - interviewing any other people who might be involved or have relevant knowledge.
 - obtaining any information or records important to the investigation.
- 3. What if my son/daughter was abused or is still in harm's way?" To protect your son/daughter from being abused or to protect him/her from more abuse, Family Services can:
 - arrange for other support services
 - contact the RCMP or your local police about possible criminal actions
 - intervene immediately if there is risk to your son/daughter
 - apply for an emergency SDM if needed, to ensure the safety and well being of the vulnerable person

REMEMBER: You may be your son/daughter's best advocate. Make certain your questions are asked and answered in a way that you are satisfied.



- Abuse can be so subtle. Spend some time with members of your family talking about what the word "abuse" means to you.
- What actions might affect my son/daughter negatively?
 - ✔ Are these actions abusive?
 - → How would my son/daughter communicate these kinds of experiences to me?

(e.g. get sad, retreat, withdraw, scream, not sleep, or just act differently)



Quotes

Adversity is the first path to truth.
—Lord Byron

(D) THE EVERYTHING ELSE PAGE also known as THE FEELINGS PAGE

Families provide the greatest degree of continuity in the lives of their sons and daughters with intellectual disabilities. That connection should be honoured and supported. The individual's right to self-determination must be encouraged and supported also.

Parents have come together now for many years to share their stories, expectations, successes, failures, miracles, hopes, dreams, and journeys. It is through these experiences that change has taken place. Families have learned from each other how to help their sons and daughters become all they can be. Each generation of parents has stepped further into the world and created opportunities for their families. This must and will continue.

So now the real reason you're on this page—it's about feelings! Depending on your perception, here are some commonly experienced emotions.

Overwhelmed - This is a lot of information to take in all at once. We need to stop and reflect and discern how we will take the next step—one step at a time. Developing short-term and long-term plans are necessary in creating the best possible outcome for our families.

Frustrated - It may be frustrating for families to plan for the future when appropriate services aren't available, resources limited, and energy running low! The best way of looking out for ourselves may be connecting with others who can assist with developing innovative services, surrounding ourselves with people who support and encourage us, and finding our patience.

Fearful - We all face this emotion every day in some measure. It is a human condition. It's how we deal with the fear that moves us forward or immobilizes us. When we name it, face it, feel it, and do what we fear anyway, we move through it. Besides, worrying about something that may never happen is like paying interest on money you may never borrow.

Grateful - Our son/daughters are fortunate to live in a time when they can experience lives as contributing members of the community. We can use this opportunity to help them create a life that offers them full citizenship. And finally . . .

Inspired/Challenged - We have a chance to dream our dreams and make them happen. Feeling inspired to stretch ourselves out of our present situations and into something better is part of the journey of the human spirit.



- What experiences and emotions are you living through right now? (positive and negative)
- ♥ If you are feeling fearful, angry, or alone (or some similar negative emotion) consider:
 - Finding the opportunity within the fear and moving forward from that position
 - Talking with other families you trust and who know and understand your situation

(E) A NEW UNDERSTANDING

If you've come this far and read through this booklet, you will begin to have a new understanding of the Vulnerable Persons Act. Through study and discussion, we learn that the Act, its concepts and principles, is a foundation that can bring opportunities into the lives of our adult sons and daughters.

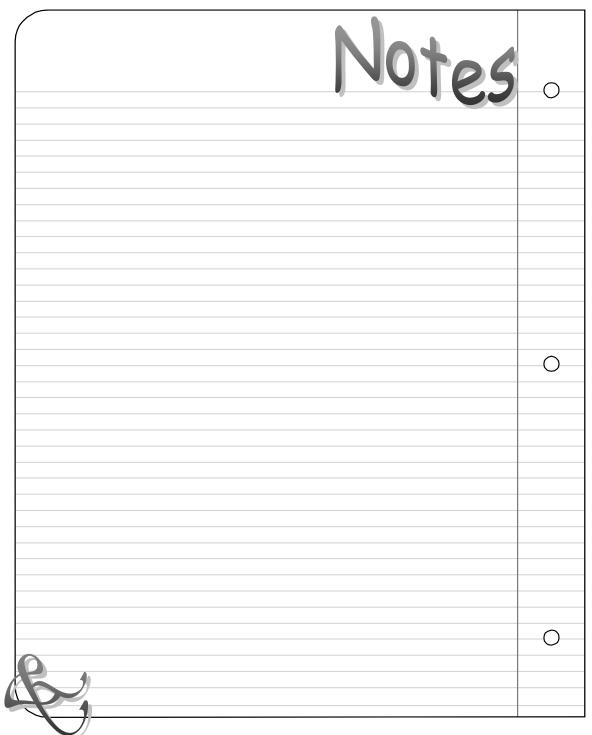
For years our sons and daughters have been seen as disabled first. This legislation instructs Manitobans to see skills and gifts instead. It talks about competencies and abilities . . . and choice. We can now point to the Act in all of our dealings and remind professionals, government, services and citizens in general, that in Manitoba, we are now to respond in a new way.

Our process in preparing this guide to families included lots of discussion. We spent hours together meticulously working through each section, challenging each other every step of the way. As a group we approached each component of the Act as a new challenge and tried to find examples and stories and discussion questions that would invite other families into our process of learning.

As we bring this book to a close, we are more convinced than ever that the learning is just beginning. In order to truly ensure that this Act has meaning in our sons' and daughters' lives, **WE** need to keep the process alive. We urge you to talk within your own family about what the VPA means to you. We encourage you to reach out and talk with other families and share your experiences, confusions, and successes.

Through this experience we have gained a new strength and understanding of what can be. We wish each of you the same.

Marsha Dozar Allison Graham Myers Rose Flaig Judy Walker



You block your dream when you allow your fear to grow bigger than your faith. —Mary Manin Morrissey There are two lasting bequests we can give our children.

One is roots. The other is wings.

— Hodding Carter, Jr.



C
0
n
†
a
C
†
5

The following organizations and departments may be able to provide further information or refer you to appropriate organizations or people.

Community Living—Manitoba		(204)	786-1607
Continuity Care (helping families plan for the future)		(204)	779-1679
Manitoba Family Services & Housing			
Winnipeg Regions	3-139 Tuxedo Avenue	(204)	945-8137
	2-189 Evanson Street		945-6333
	1021 Court Avenue		945-8333
	2015 Portage Avenue		945-8911
	233 Provencher Boulevard		945-8966
Westman Region-Brandon	340-9th Street		726-6173
Eastman Region-Beausejour	20-1st Street South		268-6025
Central Region-Morden	63B Stephen Street		822-2861
-Portage la Prairie 25 Tupper Street North			239-3092
Interlake Region-Selkirk	825 Manitoba Avenue		785-5100
Parkland Region-Dauphin	27-2nd Avenue SW		622-2035
Northern Region-Flin Flon	143 Main Street		687-1700
-The Pas	Box 2550		627-8240
-Thompson	59 Elizabeth Drive		677-6570
The Vulnerable Persons Commissioner's Office		(204)	945-5039
Outside Winnipeg:		1-800-	-757-9857
Manitoba Education, Citizenship & Youth (Special Education) (204) 945-7933			

acknowledgments

This book has been produced and published by The Association of Community Living—Manitoba Spring/Summer 2003

The Association of Community Living—Manitoba wishes to thank

- Judy, Allison, Rose, and Marsha for their hard work in the writing, editing and production of this book, and,
- The many family members who read it along the way and provided valuable feedback and recommendations.

(Graphics and layout by Rose Flaig)