

What you can do to enhance
the quality of life for a family
member with a disability?



CONSIDER A HENSON TRUST

In this booklet

Introduction: Caring for your relative with a disability	3
Part 1:	
How Henson Trusts can support people who receive ODSP benefits	4
What is a trust?	4
When is it a good idea to provide fully for your loved one using a trust?	5
What kind of trust could help your relative?	5
Part 2:	
Everything you need to know about ODSP	7
What is ODSP?	7
Who can get ODSP?	8
How does ODSP define disability?	8
How does ODSP decide how much money a person with disabilities will get?	8
Answers to common questions about ODSP	10
Part 3:	
Setting up a Henson Trust	13
What to consider when you choose a trustee	13
What to include in the Henson Trust provisions	14
Answers to common questions about Henson Trusts	15
Part 4:	
How to prepare for the future	20
Developing a financial plan	20
Building up your estate	22
Other things you can do to meet your relative's needs	23
Answers to common questions about wills and estates	26
Part 5:	
Is a Henson Trust a good choice for you?	29
Profiles of families considering a Henson Trust	31
Part 6:	
Resources	32
Part 7:	
Glossary	33



Introduction: Caring for your relative with a disability

Caring for a family member with a disability, and planning for their support for a whole lifetime, is a big responsibility. It poses special problems and challenges. If your relative with a disability lives in Ontario, you must consider two things when you plan your will:


- What are the conditions for getting social assistance benefits? In Ontario this means benefits under the Ontario Disability Support Program (ODSP).
- Can your relative take care of their own financial affairs? If they cannot, what resources does the family have to help support him?

Your family has **three main options**:

- **You can fully support your relative with a disability.** A family needs a very large estate to support someone who may not be able to work for their whole life and who may have very high expenses related to their health and disability. With this option, your relative would not claim ODSP benefits. If your family has the money and your relative would have a better quality of life if the family fully supported her, you should carefully consider this option.

- **You can plan for ODSP to take care of all of your relative's needs.** Some families cannot provide much for their relative with a disability. They may not be able to provide anything. ODSP, together with other government programs and support from community agencies, should cover their relative's basic needs. If this is your situation, consider opening a Registered Disability Savings Program (RDSP). An RDSP is a good idea, even if you and your relative cannot contribute to it, because the Government will make payments to an RDSP for low-income people. For more information, go to page 19.
- **You can leave money in a trust.** If you have some assets, you can set up a trust to help support your loved one for the rest of his life. A trust can usually provide the same support as parents do during their lifetime. You must be careful when you set up the trust, so that you do not affect your relative's ODSP benefits.

This booklet is for families who want to help support a relative who receives ODSP benefits. It explains how you can help your family member without affecting their ODSP benefits.



Part 1: How Henson Trusts can support people who receive ODSP benefits

ODSP benefits are available to adults in financial need in Ontario who have mental or physical disabilities. Details about the program are outlined in Part 2.

Under the current rules, a single person who is receiving ODSP benefits can only have assets of \$5,000 at one time, unless the assets are exempt. If you want to do something to enhance the life of a relative who receives ODSP, you must remember two very important rules. Make sure that your relative:

- does not have money and non-exempt assets worth more than \$5,000 at any time **and**
- is not given gifts of more than \$5,000 in money and assets in any twelve month period, unless the gifts are for a disability-related item or service.

Before you give your relative any money, find out how much money and assets they already have, and how much they have been given as gifts. If their assets are more than \$5,000, they may no longer be eligible for ODSP benefits until they spend the money. If they are given more than \$5,000 in a 12-month period, it will be considered income and their ODSP benefits will be cut by the amount of the extra payment over \$5,000, unless the gifts are for a disability-related item or service.

Your relative is allowed to get more than \$5,000 if they spend the money on **items or services**

related to their disability. ODSP is generous about what kinds of expenses are related to people's disabilities. To find out what items and services are allowed, go to: http://www.mcass.gov.on.ca/mcass/english/pillars/social/odsp-is-directive/ODSP_incomesupport.htm

ODSP may examine their spending to see whether it is 'legitimate'. This means that ODSP can ask whether the money was spent just to help the person qualify for ODSP.

A trust can be an ideal solution if you want to provide some money for a relative. With a trust, your loved one can continue to receive ODSP benefits. The trust money can help with extra expenses such as items and services they need, and holidays. The trust can also be an emergency fund in case ODSP benefits are ever cut off for any reason.

What is a trust?

A trust is a legal arrangement where someone sets up an account to help someone else, called the **beneficiary**. The account is in the name of another person or persons. These persons, the **trustees**, must use the money or assets in the trust for the benefit of the beneficiary.

The person who sets up the trust is called the **settlor**. Usually the settlor is a parent, some other relative, or a friend of the beneficiary. A

settlor can also be the beneficiary of a trust. A trust may be set up while the settlor is living (an 'inter vivos' trust) or in the settlor's will (a 'testamentary' trust).

The person or persons who manage the money and assets are called the **trustees**. The bank account or assets are in the trustees' names, but the trustees must use them for the **beneficiary**. If you use a trust for your relative with a disability, you must make sure that the trustees are reliable and honest.

When is it a good idea to provide fully for your loved one using a trust?

Ask yourself four questions when you consider whether to set up a trust to provide fully for your relative with a disability:

- Would my relative enjoy a better quality of life if the family fully supported her rather than if she received ODSP?
- Do I, or other relatives, have enough assets to fully support my relative?
- Are my other beneficiaries self-sufficient? If not, do I and other relatives have enough assets to support the other beneficiaries as well as my relative with a disability?
- Is it possible that my relative with a disability will not qualify for ODSP in the future, or not need ODSP in the future? For example, is it possible that he will be employed and earn enough to provide for his own needs?

If you think that your relative's quality of life would **not** be significantly better if the family provided for them fully, then you should consider leaving the bulk of your estate to your other beneficiaries and setting up a modest trust for the person with a disability. If you are considering this option, keep in mind that the trustees must understand and comply with the ODSP rules.

On the other hand, if your relative with a disability could enjoy a lifestyle which they could not have if they were dependent on ODSP benefits and you or other family members have enough money, you could leave most of your estate in trust for the relative with a disability.

What kind of trust could help your relative?

Two kinds of trusts can help your relative with a disability:

- Henson Trusts **and**
- Inheritance or Shelter Trusts.

Here is general information about these two types of trusts. More detail about Henson Trusts is in Part 3 of this booklet (starting on page 13).

Henson Trust

Henson Trusts have been allowed ever since the mid 1980s, when Ontario's Court of Appeal decided that a person with a disability receiving Family Benefits should not be cut off from benefits if they were getting money from a trust set up to help them, so long as the trust gave a complete control (or 'absolute discretion') to the trustees about when to make payments from the trust. The Court said that the assets in a trust set up to support that person should not be considered as that person's assets, since someone else made decisions about how to spend the money in the trust. The court decided that the person should qualify for Family Benefits as long as the support they got from the trust was permitted under the Family Benefits rules.

The same rules apply to people receiving ODSP benefits. In July of 2005 the Social Benefits Tribunal confirmed that a person receiving ODSP could be supported by money in a Henson Trust. In that case, the trust had assets of more than \$100,000. The Tribunal found that the person receiving ODSP, Ms. Fisher, could not force the trustees to give her money from the trust. Because of this, the Tribunal decided that the money in the trust was not an 'asset' and that Ms. Fisher was still eligible for ODSP benefits.

You can set up a Henson Trust while you are still alive with an *inter vivos* trust agreement, or you can put a Henson Trust in your will, to be set up after you die.

The current law says ODSP cannot count the money in a Henson Trust when they do the asset test to decide if your relative is eligible for ODSP. The only money that will affect your relative's eligibility is money that they own and control, or money spent to benefit them.

When you set up a Henson Trust, the trustee can spend up to \$5,000 on your relative during any consecutive 12-month period without affecting their ODSP benefits. The \$5,000 limit is for money given to your relative and money spent for their benefit. The trustees can spend money on 'comforts' such as a radio or television, clothing, extra food, recreation or entertainment. The trustees could pay part of their rent so they could afford a nicer apartment than the ODSP shelter subsidy would cover. The trustees could also give your relative spending money. Your relative does not have to tell ODSP how they spent this money, but they must report that they received it.

The trustees could also spend additional amounts for disability-related items and services, in accordance with MCSS policies.

If the trust provides for it, the trustee can spend both the capital and the income in a Henson Trust.

Inheritance Trust or Shelter Trust

You can set up this kind of trust if:

- you want your relative to inherit some money but less than \$100,000, or
- if you have named your relative as beneficiary for life insurance benefits, again less than \$100,000.

Your relative can even set up this kind of trust after your death if they inherit under \$100,000

from an estate or from insurance benefits, but it is usually simpler and more effective for you to set up the trust in your will for them.

Your relative will still qualify for ODSP benefits as long as there is less than \$100,000 in the Inheritance or Shelter Trust. (If there is more than one Inheritance or Shelter Trust established for them, the total placed in all such trusts must total less than \$100,000 under current ODSP rules.) Each year, your relative can be paid all of the income from the Trust, or some can be reserved by the trustees to meet extra expenses.

While the ODSP rules do not say that a recipient with a disability must sign a formal trust agreement, in general it is a good idea for them to do so, where the trust has not been established in their parent's will. The ODSP rules do say that money in the trust must be kept separate from an account controlled solely by the person with a disability. To make sure that the money in the trust is kept separate, you should get legal help to prepare a simple trust agreement. It should say who the trustees are and how money in the trust will be handled. For example, the trust agreement should say what the trustee should do with any income earned by the trust -- whether the income the trust earns must be given to the person, or whether it can be added to the capital in the trust to meet extra expenses in the future.





Part 2: Everything you need to know about ODSP

In Ontario, two social assistance programs give allowances and benefits to people with low incomes: Ontario Works and the Ontario Disability Support Program (ODSP). Both of these programs are for people under 65 who need support. Ontario Works is sometimes called welfare. It is for people who do not have a disability which has qualified them for ODSP. ODSP is for people with disabilities. People receiving ODSP benefits do not have to get a job. They can get more benefits than people on Ontario Works.

Old Age Security and the Guaranteed Income Supplement (OAS/GIS) are the income assistance programs for people over the age of 65. They are for people across Canada. When people who receive ODSP turn 65, they will get benefits from the OAS/GIS program. They will continue to have a modest income. If they have not been in Canada long enough to qualify for OAS/GIS, they may continue to receive ODSP benefits.

What is ODSP?

The Ontario Disability Support Program (ODSP) supports adults who need an income and who the Ontario government has certified as having a disability. It includes basic income, and some health benefits and disability-related supports including a drug card and dental card. ODSP also provides employment supports. People who receive ODSP benefits are not required to work to receive ODSP benefits.

It is important to understand the rules for ODSP. ODSP has complicated rules about who qualifies. It uses a detailed test of need. Many people with disabilities and their families find the rules very confusing. Some rules are about money. Some rules have nothing to do with money.

ODSP was set up in 1998. Before then, social assistance in Ontario for persons with disabilities was called Family Benefits. Under the previous Family Benefits program, people who were disabled or blind got slightly higher benefits than people who were not disabled. Now, people receiving ODSP typically get about 75% more each month than people receiving OW.

Who can get ODSP?

To qualify for ODSP, a person must

- live in Ontario
- be 18 or older, and
- be a 'person with a disability' as defined by ODSP.

ODSP looks at the person's place within a family. In this handbook, we will mostly discuss ODSP recipients who are single persons with no dependants. However, about one-quarter of ODSP recipients have spouses or are the heads of families with dependent children. When a person applies for ODSP benefits, the income and assets of their spouse are considered. In some cases ODSP pays additional amounts for the spouse as well as the children.

Finally, ODSP tests for financial need. People receiving ODSP are allowed to have some assets and income. What they are allowed to have depends on the kinds and sources of assets and income that they have. You need to know these rules about asset and income exemptions in order to develop a financial plan for your relative.

How does ODSP define disability?

Here is how the *ODSP Act* defines 'disability':

A person is a person with a disability for the purposes of this Part if,

- (a) the person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
- (b) the direct and cumulative effect of the impairment on the person's ability to attend to his personal care, function in the community and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and
- (c) the impairment and its likely duration and the restriction in the person's activities of daily living have been verified by a person with the prescribed qualifications."

When a person applies for ODSP, a health professional must complete a Health Status Report and an Activities of Daily Living Index. The Health Status Report must be completed by a physician, psychologist, optometrist, or nurse practitioner who is licensed to practise in Ontario. The Activities of Daily Living Index must be completed by a physician, psychologist, optometrist, occupational therapist, physiotherapist, nurse practitioner, chiropractor, audiologist, registered nurse, speech language pathologist or social worker who is licensed to practise in Ontario. These forms must be completed carefully by the health professional, as they are the main basis ODSP uses to decide whether the applicant is 'a person with a disability'. There is also a Self-

Report Form, which is optional to submit – it can be helpful to the applicant, but **only** if it is completed carefully.

How does ODSP decide how much money a person with disabilities will get?

ODSP uses three steps to test financial need. This process is called the Budget Deficit Needs Test.

Step 1: Assets test

First, ODSP tests a person's assets. They check that a single person does not have more than \$5,000 worth of assets. For this test, ODSP does not include every asset. For example, a home that the person lives in is exempt from this test. ODSP uses the asset test to check that people who apply have no other way of paying for the things they need.

A person with a disability who is 18 or older and has no assets worth more than \$5,000 can qualify for ODSP if they pass the other tests. ODSP does not consider their parents' assets.

If the person with disabilities has non-exempt assets worth more than \$5,000 they will not qualify for any ODSP benefits. The person must be supported by their **assets or by their family**.

Exempt assets. A number of items are not considered as assets and do not affect a person's entitlement to ODSP. Families can give these exempt assets to a relative applying for or receiving ODSP without affecting her or his entitlement. They include:

- the home where a person lives (called their **principal residence**)
- a second property, if it has been approved for their health and wellbeing
- a motor vehicle of any value
- a second motor vehicle valued up to \$15,000 if the person's dependant needs it for work.

Certain funds are also exempt, including:

- a trust fund created or derived from an inheritance and the cash surrender value of a life insurance policy, up to a cumulative total of \$100,000 for all trust funds and life insurance policies
- a trust fund of any amount if it qualifies as a Henson Trust (absolute discretionary trust), where the trustee makes all of the decisions about spending the money
- funds used to purchase approved disability-related items and services (no financial limit)
- interest earned on cashable assets
- a compensation award of up to \$100,000 for pain and suffering, or for actual expenses
- business assets of up to \$20,000 for ODSP recipients who are self-employed (plus any **tools of the trade**, such as a special machine)
- loans made for an approved purpose, such as approved business expenses, education, and training
- a prepaid funeral.

Step 2: Needs test

If a person's assets are less than the limits, ODSP will calculate what the person, or their family, can get. Their family includes their partner or spouse and any dependent children. It does not include their parents, even if they live with their parents.

Here is what ODSP does:

- » ODSP decides what the individual or family needs. This is based on a set budget for each month. It is based on:
 - how many people are in the family
 - who is in the family (number of adults and children)
 - the ages of children in the family.
- » ODSP determines an amount that the family needs for food, clothing and shelter. This number is based on:

- where the person lives (Are they a boarder? Do they rent? Do they own where they live?) and their shelter costs (the costs of board, rent, or home ownership) up to a maximum set by a formula
- the cost of any special things they need (such as a special diet) that are allowed under the ODSP rules.

The total of these amounts is the person's **budgetary entitlement**.

Step 3: Income test

Then ODSP subtracts the person's monthly income from the person's budgetary entitlement. If the person's income is higher than the budgetary entitlement, they are not eligible for ODSP. If the person's income is less than the budgetary entitlement, they can get ODSP.

The government looks at different income in different ways. They do not include some forms of income, like the GST credit, that lower income people get. They include income from work at a 50% rate, because ODSP wants people to try to pay for the things they need, and to be able to meet costs that are related to work. ODSP also exempts voluntary gifts or trust fund payments of up to \$5,000 during a 12-month period (not just a calendar year) for any purpose. (Gifts or voluntary payments from all sources are included in this limit.) Additional payments are permitted if they are for things related to the person's disability. On the other hand, ODSP does not exempt most money from Workers' Compensation and CPP.

Example: Carla

Carla qualifies for a benefit of \$979 a month. This is the maximum for a single person who is a renter or home owner, without taking into account additional benefits such as special diet. Because Carla also gets \$300 from CPP each month, then ODSP will only give her \$679 a month (\$979 minus \$300 equals \$679). Carla also earns \$300 a month in net income from a part-time job. The rule is that 50% of her net income

is ignored and 50% of it is counted. In this case, the reduction from the payment would be \$150, which is 50% of \$300. So Carla's monthly ODSP cheque would be \$529 (in addition to \$300 from CPP and \$300 from employment).

Answers to common questions about ODSP

1. Is ODSP a pension?

Many people call ODSP a pension, but it is not. ODSP is a financially-tested social assistance program.

Programs like Old Age Security and the Canada Child Tax Benefit have fewer rules. The government tries to make sure all people who qualify get the benefits.

The ODSP program has lots of rules. People must meet many requirements to get support. People must apply to get ODSP. The government does not make a specific effort to help find people who might qualify, but officials may refer people to the program. They do not help people with their applications.

2. How is social assistance different from a pension or compensation?

Social assistance is different from a pension or compensation. It is for people who are in need. This means that they do not have enough income and assets to support themselves. Governments only give social assistance to people who can show they need the money. To see if a person is eligible, governments review people's finances.

Generally speaking, people can get pensions and compensation without a financial test. Here is how they work:

- **Pensions** are benefits paid to the people who paid into them, or their beneficiaries. Usually people pay

into a pension plan by having money deducted from their paycheck.

- **Compensation** programs usually pay benefits based on something that happened to a person. For example, a person who is hurt at work may get compensation from the Workplace Safety and Insurance Board (WSIB). People can also get compensation if they were victims of a crime or of discrimination.

3. Why is family status important for ODSP?

Unlike ODSP, many pension programs and compensation programs give benefits to individuals. In other words, the person gets the same benefit whether or not they have dependants. However, for ODSP there are additional benefits for dependants, while the assets and income of spouses and partners are taken into account in determining eligibility.

For ODSP purposes, a single adult over 18 without dependants is considered as an independent applicant, even if she or he is living with parents or other relatives. The 'family' of a person for ODSP application purposes includes only the applicant's spouse or children. So any person with a disability who is 18 or older can apply for ODSP. It does not matter whether they live on their own or with their parents.

If your relative is single, their application for ODSP will be simpler. If your relative has a spouse, their application will be more complex. ODSP will decide if their relationship affects what benefits they could get.

4. What if my relative is married or living common law?

ODSP will pay extra benefits to a person who is married or living common law if their spouse has limited assets or income. The person receiving benefits must tell

ODSP that they have a spouse, or ODSP may decide that two people have a spousal relationship. Once ODSP decides that a person has a **spousal relationship**, it will look at the spouse's income and assets. If the spouse has a low income or few assets, the person receiving ODSP benefits can get the extra benefit amount. But if the spouse has 'too much' in assets or income, ODSP may reduce the person's benefit or decide that the person no longer qualifies for ODSP benefits.

5. What can we do to make sure other relatives and friends don't do things that would disqualify our loved one from ODSP?

Make sure that other relatives and friends do not give your relative money that would take them over the \$5,000 limit. If someone wants to give your relative a gift, they could buy them an asset that is exempt from ODSP limits, like a car, a house to live in or a medically necessary item.

Make sure that other relatives and friends do not name your relative as a beneficiary of life insurance, wills, or trusts without getting advice and advising your relative or you. If someone wants to name your relative as a beneficiary, they should usually set up a discretionary Henson Trust.

6. How do government programs test financial need?

Governments use four different ways to test whether someone is in need:

- Means testing
- Income testing
- Needs testing (usually a budget-deficit needs test)
- Asset testing

Here is what each one is, and how they work.

Means testing

A means test looks at a family's circumstances. It asks whether the family has the 'means' to provide for its needs. For example, if the family had a large vegetable garden, a means test might decide that they need fewer benefits for food than a family without a vegetable garden. A family that could cut wood for their wood stove might get fewer benefits for heating costs.

In the past, many government programs used means testing to decide if a person was needy enough to be eligible for programs. Now few programs use means tests.

Income testing

With an income test, any person with an income below a certain amount qualifies for the program. The income level depends on the size of a person's family. Many broad programs use an income test as the main way to decide who is eligible. Two examples of income tested programs are the Canada Child Tax Benefit (CCTB) and the Guaranteed Income Supplement (GIS) for seniors.

Needs testing

A needs test is a more complicated way of deciding who qualifies. Programs that use needs tests set standards about what different households need. They can give households more or less money depending on their situation. The basic amount of money depends on how large the family is, and who is included in the family. The needs test can also give households different amounts for the basic costs of living. For example, a family that must pay more for rent and utilities could get extra money.

ODSP uses a needs test to decide how much people need. To calculate the person's need, ODSP subtracts a person's income from a presumed amount that a household with the same number of people, and the same "shelter costs" (i.e. housing costs), would need. The person will be eligible for ODSP if their income is less than what ODSP says a household like

theirs needs. This is how ODSP screens out people who could support themselves without ODSP benefits.

Asset testing

Assets are savings or property that can be easily turned into cash. An asset test can show the difference between two applicants with the same income based on what property or savings each person has. Governments use an asset test to try to be fair when they assess what people need.

Programs with an asset test limit what assets people can have. This is called an **asset**

ceiling. Putting a limit on the assets allows people to have some money while they are on benefits. It is one way to make sure that being on benefits will leave a person some money to pay for unexpected costs that come up in daily life. For example, single people who qualify for ODSP are allowed to have up to \$5,000 in assets such as cash at any one time. The asset test for ODSP does not include a home that the owner lives in as an asset. An individual or family’s first motor vehicle is also an exempt asset. A second motor vehicle can also be exempt if the spouse needs it for work and it is worth less than \$15,000.

Examples of government programs that test for financial need

Type of program	Who can qualify	What the government considers	How much it costs the government	Examples in Canada
Universal benefits	Any person who is part of a group named by the government. For example, all people over 65 or parents with children under 18	<ul style="list-style-type: none"> Does the person belong to this group? 	The most expensive kind of program, because many people can get the benefit	Canada does not have a truly universal income security program
Income-tested benefits	People who are part of a group and who <ul style="list-style-type: none"> have income below a certain amount 	<ul style="list-style-type: none"> Does the person belong to this group? How much income does this family have? 	Cost less than universal programs	Guaranteed Income Supplement (GIS), CCTB (Canada Child Tax Benefit), NCBS (National Child Benefit Supplement), GST credits
Assets-tested benefits	People who are part of a group who <ul style="list-style-type: none"> have income below a certain amount and do not have other assets 	<ul style="list-style-type: none"> Does the person belong to this group? How many assets does this family have? 	Costs much less than income-tested programs, because it disqualifies many people from benefits	Ontario Works ODSP
Needs-tested benefits	People who are part of a group who <ul style="list-style-type: none"> have income below a certain amount do not have other assets and who have a need 	<ul style="list-style-type: none"> Does the person belong to this group? How much income does this family have? How many assets does this family have? What does the person need? 	The least expensive kind of program because <ul style="list-style-type: none"> not many people qualify and it limits how much it gives people for their basic needs 	Ontario Works ODSP



Most often, parents set up the Henson Trust in their wills. However, a Henson Trust can be set up by people who want to take care of a relative with a disability during their own lifetimes. This often happens where parents divorce and make a trust as part of the divorce settlement.

A Henson Trust is different from an Inheritance or Shelter Trust. It gives the trustee **absolute discretion** to pay or not pay income and capital to the beneficiary. This means that the trustees are the only ones who can make decisions about giving money to the person with a disability or paying for things that will benefit him or her. In contrast, a Shelter Trust directs the trustees to pay all of the income from the trust to the beneficiary if the capital is \$100,000.

A Henson Trust can allow the trustees to pay money only to the person with a disability or to other beneficiaries as well. The other beneficiaries could include the other daughters and sons and grandchildren of the person who set up the trust. The trustees could invest the assets and allow income from the trust to build up. They could give more or less income and capital to each beneficiary. Of course, if there are other beneficiaries besides your relative with a disability, even more care must be taken to ensure that the trustees will act responsibly. A disabled beneficiary is often not able to monitor the trustees and keep them honest. They depend on the trustees' integrity to use the trust funds fairly on their behalf.

In this section, we will tell you more about how to choose trustees, and what terms should be included in a Henson Trust.

What to consider when you choose a trustee

Since a Henson Trust is an absolute discretionary trust, it gives the trustees a huge amount of responsibility. You need trustees who are honest and whom you can trust completely. Be very careful when you choose the people who are going to be the trustees. Look for someone who:

- is highly involved in the relative's life and has an ongoing concern in their health and welfare
- will be sensitive to what the beneficiary needs and wants
- will understand the terms of the will and why you set up the trust
- understands ODSP rules and how payments from the trust could affect the beneficiary's ODSP benefits
- can invest the money wisely so that there will be enough assets in the trust for what the beneficiary needs, over the long-term as well as meeting immediate needs
- will be careful with money in the trust and make payments that will help the beneficiary
- has good judgment and business sense

- knows how to keep careful records and accounts
- knows how to prepare tax returns or arrange to have them done.

Possible problems with trustees

When family members or friends act alone as trustees, they do not always act in the best interest of the person with a disability. When a trustee is also a beneficiary of the trust, they can be in a conflict of interest and not make wise or fair decisions.

It is not easy to remove a trustee, particularly a trustee of an absolute discretionary trust like a Henson Trust. The only way a trustee can be removed, other than by a court, is if the trust document names a person who can remove the trustee. You cannot rely on the courts to get rid of a poor trustee. A court will only remove a trustee if there is proof that the trustee did not act in good faith. It is both difficult and expensive to prove this.

Here is what you can do to make sure that the trust is managed properly and that the trustees make fair and reasonable decisions:

- Choose a group of trustees who each bring different skills.
- Choose at least one trustee who is not a beneficiary of the trust.
- Hire an affordable lawyer, financial professional or trust company to be the trustee or to be one of several trustees.

You could also ask the Office of the Public Guardian and Trustee to act as a trustee, although this Office is reluctant to act if family members or friends are available. If the Public Guardian and Trustee is the guardian of property of the person with a disability but not a trustee of the trust, the Public Guardian and Trustee tries to work with the trustees of the trust in the best interest of the person with a disability.

What to include in the Henson Trust provisions

When you set up a Henson Trust, either in your will, which will be effective on your death, or in an agreement made during your life, make sure you include the following provisions:

Give your trustees the authority to transfer money to your relative

If you think that your relative might be capable of handling her or his own funds, set up the trust so that the trustees could transfer some or all of the money from the trust to them. The wording must clearly state, however, that the beneficiary cannot force the trustees to transfer moneys to her or him, or else the absolute discretionary nature of the Henson Trust will be lost. The clause should allow the trustees to be flexible in dealing with improvements in your relative's ability to manage money, and with future changes to ODSP rules.

If the estate, or part of it, is held by trustees in an absolute discretionary trust, the capital of the trust could be distributed among your other daughters and sons, or grandchildren, or among other relatives and friends, or to a charity, when the beneficiary dies. Under the law, this kind of provision in a Henson Trust would not make it an asset for ODSP purposes. Also, it would not be subject to claims by the beneficiary's creditors, and the beneficiary could not spend it.

Name a beneficiary for income after 21 years

With most absolute discretionary trusts, the income earned from the estate investments may be kept by the trustee on a discretionary basis as well. In Ontario, under the *Accumulations Act*, R.S.O. 1990, c. A.5, the trustee can only keep this income until the beneficiary turns 18, or 21 years after the death of the person who made the will, whichever is later. This is called the accumulation period. After that time the trust must pay out all of the income each year either to the person with a disability or another substitute beneficiary.

Relieve the trustee of the ‘Even Hand’ rule

Trustees of most trust funds must invest and spend so that the trust is shared fairly between the person who receives benefits during their lifetime (the ‘life beneficiary’) and the people who will inherit the funds after the life beneficiary dies. This is called the ‘Even Hand’ rule.

Inflation and taxes can eat into fixed funds. Since most parents set up Henson Trusts to benefit their relative with a disability, they do not want the Even Hand rule to limit the support for the disabled person. Make sure that your will includes a clause that specifically says that the trustees do not have to apply the Even Hand rule.

Avoid conflict of interest

You need to think about what to do with money or other property left in the trust when your relative with a disability dies. The people who inherit this money are called the residual beneficiaries. In many cases, a family’s other daughters and sons are the trustees or co-trustees of the Henson Trust and also its **residual beneficiaries**. This creates a conflict of interest and can sometimes mean that the trustees choose not to spend money on the relative with a disability so that more money will be left in the trust for them. To minimize this problem you could name at least three trustees of the fund, and require that any two trustees can override the third one.

Give the trustee flexibility

Henson Trusts give the trustees total flexibility. This allows the trustees to respond to changes in social assistance legislation, regulations and services. Think about what policies and trends lie behind the statutes and regulations. Choose trustees that can cope with change. Give the trustees enough flexibility to deal with changes in policies that affect your loved one with a disability. For example, for many years the trend has been to support people who would have been institutionalized in the past to live

relatively independent lives in the community. Choose trustees who will be prepared to deal with social changes such as this.

Cover funeral costs

Many families worry about how to pay for their loved one’s funeral. You can clearly give the trustees the power to spend trust funds on funeral expenses or pre-pay for the funeral. A prepaid funeral will not affect your relative’s ODSP benefits.

Ongoing support, care, planning and consultation

To make sure that the trustees are always involved in your relative’s care, tell the trustees to review your relative’s support services and care plan. The trustees should do this regularly, at least twice a year. Directing the trustees to do this will put a duty on them to stay involved in your relative’s planning. You can also state in your will that your trustees should consult with the agencies and professionals providing support and care to your relative, so long as the provision also states that the trustees retain an absolute discretion to make final decisions about spending.

Answers to common questions about Henson Trusts

1. After I die, can my trustees use a Henson Trust or Inheritance Trust to give my relative the same kinds of supports that I am providing now?

Yes. They can do so as long as there are enough assets in the trust to provide payments, or to buy items and services. Under the ODSP rules, trustees can provide the same supports as a parent, or other relative, could provide while they were alive.

2. Can I leave my home to my relative? Can I buy a home for my relative? Can my trustees buy a home after I die?

A person receiving ODSP is allowed to own the home where they live (the principal residence). So, if they will live there, you can leave your home to a family member who is receiving ODSP. You can also buy a home for them to live in. And you can let your trustees buy them a home after you die.

If you want to do this, you need to plan carefully. Get advice.

Make sure that any money you put in a trust for your relative will be able to pay all of the expenses for the home. Most of these are legally the responsibility of whoever owns the home. If your relative owns the home, the expenses would come first out of the ODSP shelter allowance and then out of the \$5000 they are allowed to receive within 12 months. Remember to calculate how much it will cost for the mortgage, and for taxes, insurance, utilities, upkeep, furnishings and repairs. If the home is a condominium, calculate how much the monthly condominium fees will be. The ODSP shelter allowance will cover some of these expenses, but they do not provide much money. Even if you or your trustees can provide extra money for these costs, ODSP limits how much you can give.

Another important thing to consider is how well your relative will get along in their own home. For example, can they live on their own and are the supports in place to ensure that this situation will work out well? Will your family member need support to live in the home in the future? You may be able to find an agency that will give these supports. If your relative does not need more than a limited amount of support or supervision, buying a home can be a good idea. Talk to the disability organizations which provide the services, and talk with your trustees.

If you decide to buy a home, make sure that it is an affordable home. Check to see that it is close to the supports your relative needs and to their educational, employment, social and recreational programs, as well as any other activities they are part of.

3. Can the trust own a home?

The trust can buy a home for the person with a disability. The trust can also pay capital expenses required to maintain the home, such as fixing the roof. Spending trust funds in this way will not affect the beneficiary's ODSP benefits. If you want trust funds spent in this way, give the trustees power to do so. You could also give the trustees the power to rent part of the home to another person who could share the costs with your relative. This has to be considered carefully, however – it will be an awkward situation for the trustees to deal with if your relative turns out to be incompatible with the other person, especially if the other person also has a disability.

However, it may not be practical **for the trust** to buy property for your relative with a disability because it will be responsible for the property taxes, all utilities and ordinary decorating and repairs. Make sure that the trust will be able to afford these expenses. These expenses will be covered partly by the ODSP shelter subsidy if your relative is responsible for them as a tenant, but what it provides is quite modest.

Finally, remember that what may seem like a suitable home for your relative now may not be suitable at all, or may not be what he wants, in 30 or 40 years. If your trustees are to buy a home or maintain a home for your relative, they should also have discretion to sell it and buy another, or if necessary to use the funds to meet other needs of your relative.

4. Who should own the home?

You have many choices. This is a big decision and can be very complex. Before you arrange for a house for your relative, get **legal and financial advice** Here are your options:

Who could own the home?	Will this affect ODSP benefits?	When is this option a good idea?	What should I think about before I make this choice?
Your relative could own the home where they live. This is called a 'principal residence'.	AODSP does not count a principal residence as an asset.	This is a good idea when your relative is most comfortable living in their own home and has the capacity, with ongoing and secure supports, to remain there for a long time.	As the owner, your relative would have to pay for all of the costs for the home. They would also be allowed to sell it. If they sell the home, your relative would receive the proceeds from the sale. If this exceeded their asset limit of \$5000 they would no longer qualify for benefits unless they purchased another home.
You could own the home where your relative lives. In this case, they are your tenant and you can charge them rent.	The ODSP shelter allowance can pay the rent, as long as the rent is not too high.	This option is a good idea where secure arrangements are in place for the future and the home is judged the best place for the relative to stay.	Many parents charge their sons and daughters little rent. Canada Revenue Agency (CRA) has decided that parents who charge low rent are not landlords. These parents do not have to report the rent as income, and they cannot claim a loss if the home costs more to maintain than the rent they get.
A Henson Trust or another kind of trust	In this case, the person receiving ODSP is called the 'beneficial owner'. They should be able to get money from ODSP for insurance, taxes, utilities and other costs, if they are responsible for these payments as a tenant of the trust.	This is a good idea in situations where <ul style="list-style-type: none"> • a Henson Trust is the best option, • there are no alternative secure arrangements available, and • it is still in the relative's best interests to remain in the home. 	All the decision-making that goes into deciding to arrange a Henson Trust also applies here.
A disability organization that will provide services to your relative.	In this case, your relative would be a tenant of the agency.	This is a good idea when there are no secure family arrangements available and it is in the best interests of the person with disabilities to remain in the home.	If you want to do this, meet with the agency. Find out what policies it has about owning homes. Make sure you are confident that the organization is making a long-term commitment to your relative.
Your relative could be joint owners with another family member, such as a sibling.	It is possible to do this under the ODSP rules, as the home would be the principal residence of the ODSP recipient. The siblings could share the expenses of the home, so long as the expenses borne by the ODSP recipient were within the limits of the ODSP shelter allowance.	This is a good option where there are secure family arrangements in place, family members are comfortable with the arrangements, and it is best for the person with a disability to stay in the home.	If you make this kind of arrangement, be sure to say in your will what you want to happen in these different situations.

5. What happens if another person lives with my relative in her or his principal residence?

If the other person is living with your relative to share expenses, ODSP may think of them as a tenant, a boarder or a lodger. ODSP would count any money your relative receives as income. This would reduce their monthly benefit.

If the other person lives with your relative as a caregiver and does not pay rent or board, your relative's ODSP benefit would not be affected.

Either way, if someone lives with your relative, ODSP officials might want to check whether the other person is their spouse. To learn more about how a spouse can affect their benefits, go to page 10.

6. Can I leave my relative a cottage as well as a home?

A person receiving ODSP can own a cottage or other property, if it helps their health or well-being. For example if the person receiving ODSP would be healthier being able to breathe clean air and swim in a lake, this may be an option.

If you are considering this, remember that your relative's circumstances may change in the future. Make sure your will clearly says what you want to happen to the property in case your relative can no longer use it.

7. Can I leave my relative or their spouse a motor vehicle?

ODSP allows people receiving benefits to own vehicles. There is no limit to the value of their vehicle. For example, if your daughter has a mobility impairment, she could own a van adapted for wheelchair access.

ODSP limits the value of vehicles owned by the spouses of people receiving ODSP. If your

relative's spouse needs a car to work outside the home, he or she can have one as long as the car is not worth more than \$15,000.

8. Can I buy life insurance for my relative?

Yes, as long as the cash value of the policy, added to the amount received through an inheritance trust or a trust set up with life insurance money, is not more than \$100,000. This limit does not apply to a Henson Trust. The capital of a Henson Trust is not counted in the limit of \$100,000. To learn more about life insurance, read Part 4.

9. Can I buy a pre-paid funeral for my relative?

Yes, a person receiving ODSP can have a pre-paid funeral. There is no limit on what you can spend and a pre-paid funeral does not count as an asset. As long as the person receiving ODSP does not use the funds in the pre-paid funeral account, they are exempt. If your relative takes the money out of the pre-paid funeral account, ODSP would count the money as an asset.

10. Can I invest in a Registered Retirement Savings Plan (RRSP) or a Guaranteed Income Certificate (GIC) for my relative?

RRSPs and GICs are **not** exempt assets under the ODSP rules. Any money in an RRSP or GIC for your relative would count as an asset.

The only time RRSPs are exempt is if the funds are **locked in**. But RRSPs are only locked in when the primary beneficiary earns them at work.

If you want to leave funds from an RRSP, GIC or other financial plan to your relative, you should direct the funds to a Henson Trust or inheritance trust set up for them.

11. What is the Registered Disability Savings Plan? Will it help my relative with a disability? Is there anything I should do to help my relative prepare for it?

The Registered Disability Savings Plan (RDSP) was announced by the Government of Canada in its 2007 Budget. When we wrote this booklet, complete information about the RDSP was not yet available. In the Budget, the Minister of Finance, the Honourable James Flaherty, promised that the RDSP would begin in 2008.

The RDSP is based on the report of an expert panel. RDSPs will be a new kind of registered savings plan. They will allow you to save for the future of your relative with a disability. As with other registered plans, the investments within the RDSP will grow tax-free until payments are made to your relative. When you contribute to your relative's RDSP, you will not get a tax deduction, but the Government of Canada will give Grants to match some or all of your contributions. There will also be Bonds for low-income families with children under 18, and for low-income adults with disabilities.

The full details of the RDSP are not final. However, the Government has said that only people who qualify for the Disability Tax Credit will be eligible for an RDSP. Low-income adults who qualify for the Disability Tax Credit, or their families, should open an RDSP account. The Government will contribute money into the RDSP account. The government contribution is called a Disability Savings Bond. The government will contribute Bonds of up to \$1,000 a year, to a maximum of \$20,000

in the person's lifetime. To get the Disability Savings Bond, the person with a disability or their family does not have to contribute to the RDSP account. A child who qualifies for the Disability Tax Credit and who lives in a low-income family will also get Disability Savings Bonds.

Remember that your relative must have a Social Insurance Number and **must** file an income tax return to get the Disability Tax Credit, the Disability Savings Bond and to set up the RDSP account. To prepare for the RDSP you should help your relative qualify for the Disability Tax Credit and get a Social Insurance Number. If your relative is an adult, you should also help them file an income tax return. Filing an income tax return is also a good idea because it will help your relative get money from the GST credit and Ontario tax credit. These credits are not taken out of their ODSP benefits.

12. Can I give my relative money to start a business?

ODSP rules say the things a person needs to run a business are exempt assets. For example, a computer, a sewing machine, or electrician's tools could be the tools needed for different kinds of businesses. Businesses can also have up to \$20,000 of exempt assets if the business needs supplies, including raw materials, or has an inventory.

It is very difficult for people receiving ODSP to develop a business because the rules about bookkeeping and reporting to ODSP are very complex. This option should only be considered in very specific circumstances where the development and conduct of a small business is in the clear best interests of the person with a disability.



Part 4: How to prepare for the future

If you have dependants, you are responsible for them and should arrange your affairs to provide for them. If your estate is not large enough to provide for them, you should do some financial planning, with the assistance of qualified financial professionals if necessary.

Developing a financial plan Write a Will

The first thing you must do is to write your Last Will and Testament! Each year in Ontario, it is estimated that between one-third and one-half of all people who die do not have a will. For parents who have a relative receiving ODSP, this is unfortunate. If you do not have a will, you will not have a trust and it will be more difficult to help take care of your relative.

Set up a Continuing Power of Attorney

You should also draft and sign a Continuing Power of Attorney for Property. A Continuing Power of Attorney for Property will allow someone to manage your affairs while you are still alive if you cannot take care of your own affairs. You can appoint a family member or a friend, or perhaps more than one person, as your attorney. The Continuing Power of Attorney for Property is important. In the last years of their lives, many people are unable to make decisions about their assets. A Continuing Power of Attorney for Property is a good way to plan for

what might happen in case you can no longer make decisions, including providing support for your loved one with a disability.

Set up a Power of Attorney for Personal Care

A Continuing Power of Attorney for Property is not the same as the Power of Attorney for Personal Care, which is also important. With a Power of Attorney for Personal Care you appoint someone to make personal decisions for you in case you cannot.

When you plan your Will and your Continuing Power of Attorney for Property, consider three things:

1. What money, investments, insurance and other property do you have that can be used to look after yourself and your family?
2. Who do you have to take care of, legally or morally?
3. Who do you trust to carry out your wishes?

Calculate how much you need in your estate

First, look at all of your assets. Make a list of all your bank accounts, your investments such as RRSPs, RRIFs, and mutual funds, your property such as your home and cottage, and any other assets such as motor vehicles, valuable

collections such as art or other valuable collectibles such as coins or stamps.

Then list the life insurance and pension benefits that your family will get after your death, and any disability benefits that you would get if you became disabled. If you have these kinds of benefits through work, carefully find out what they are. If you have any questions, talk to your employer's human resources department, your union, or an advisor with proven expertise in the areas that you have questions about.

Next, list all of your debts. Include your mortgage, loans, and any amounts that you owe to family members and friends.

Now calculate how much you will need to take care of your dependants. For more information about how to do this, read the next section.

If you think your estate may not be large enough to meet your family's needs, consider buying more life insurance. If you think you will not have enough income if you become disabled, consider buying disability insurance.

Keep all of these lists up-to-date and make sure your trustees and attorneys know where the lists are. Trustees and attorneys cannot follow your wishes if they do not know what you have. If your trustees or attorneys do not know about investments or insurance policies, your family cannot use them!

Make sure that your plan will meet your relative's long-term needs

Consider developing a personal plan for the future with, or for, your family member with a disability. When you know what they want, build your financial plan to help them meet their personal plan.

To begin to develop a personal plan, start with basic information. Here are some factors you may want to consider:

- What **age** is your family member? This will affect what benefits and services they may be eligible for and how long they may need support.
- What type of **disability** does your family member have? How does it affect their ability to perform activities of daily living? This will help you identify their future needs.
- Which **social service** and **health** organizations, professionals, and staff are most knowledgeable about your family member's goals and needs?
- Can you get any information about the future **prognosis** for your family member's disability? This will help you identify what needs they may have in future.
- What **education** and **training** has your family member had?
- What is your family member's **employment** history?
- What past and current sources of **income**, especially **disability-related** income such as the Ontario Disability Support Program, has your family member had? This will help you think about the estate planning discussed in this booklet.
- Where has your family member **lived** in the past and where are they **living** now? Do they live in a group setting, care facility, supportive living situation, or rent-geared-to-income housing? Where they live is a large part of figuring out what support they may need in the future.
- What are their **goals** for things such as education, employment, or independent living?
- What are their most significant **needs**, for things such as transportation, personal care and supervision, assistive devices and supplies, and medications?

- What **skills** do they have and what are their **limitations**? For example, can they manage money and property? Can they make important personal decisions?
- What **personal relationships**, including family, friends and service providers, are most important in the life of your family member?
- Does your family member have a **spouse, partner or child**, and might they have **dependants** in the future?
- Are **other family members or friends** planning to provide for the person with a disability in their estates?

It is very difficult to know how your family member's life and hopes could change in the future. This is why the personal future plan should be **flexible**. It must allow for changes you cannot expect.

A good resource to help you develop a personal plan for this future is a guide called *Safe and Secure*. It was written by the Planned Lifetime Advocacy Network (PLAN). The guide can help you and your family member with a disability in developing a personal plan for the future. See Part 5 of this booklet for how to contact PLAN and other community resources.

Building up your estate

Here are some of the things you can do:

- Buy life insurance to increase the amount of money in your estate.
- Set up a tax shelter or invest money in ways that could support your dependants.
- Buy annuities.

This section includes general information about each of these choices. Before you make any investments or other financial decisions, be careful and get good advice. Ask about things like fees, long term commitments, and if there is any risk of losing the money you invest.

Buy life insurance

Before you buy life insurance, carefully consider what is available. Decide what kind of insurance meets your family's needs and what kind you can afford.

Some families that do not have a large estate use life insurance to build up a fund for their relative with a disability. They do this by naming the relative as the beneficiary of their life insurance.

This is not a good idea, especially if the relative is receiving, or may need to receive, ODSP benefits. Even if your relative does not need ODSP, making them a beneficiary is only a good idea if you are confident that they can manage their own money effectively.

To get around these problems, you could name your estate as the beneficiary of the insurance. If you do, your will can say what to do with the money. Or you can put the money into an **inter vivos** trust (see below). The trust agreement will tell the trustee how to spend the insurance money.

Set up an *inter vivos* discretionary trust

Most relatives of persons with a disability use their own assets to help their relative who is receiving ODSP. In some cases, parents may want to set aside property to care for their relative while they are alive. This kind of trust is called an *inter vivos* discretionary trust. Here are some reasons why parents or other relatives set up *inter vivos* trusts:

- One parent has a large amount of money from a divorce settlement.
- A parent has a large estate and wants to save taxes.
- A parent wants to judge how a person acts as a trustee.

If you decide to set up an *inter vivos* trust, make sure you set up the trust in a way that will not affect your relative's ODSP benefits. The trust should give the trustees absolute discretion to deal with the assets. This means that only the

trustees can make decisions about the money and your relative does not have direct access to the money. The trust agreement should also say that the trustees can keep in the trust any income that is not paid to your relative.

If you decide that your relative will not need ODSP benefits and that the family will take care of their needs fully, the trust could be for the benefit of the person with a disability alone. In this case, the trustees can pay both income and capital to, or for the benefit of, the person with a disability. The trust could last until your relative reaches a certain age, or for their whole life. The trust could say that the capital in the trust could be transferred to the person with a disability if the trustee believes they can handle it.

If you establish an *inter vivos* trust primarily to save income tax, get good advice. You must be very careful to take into account the income attribution rules set out in sections 74, 75 and 76 of the *Income Tax Act*.

Buy annuities

If you use some or all of your assets to buy an annuity, you could give your relative a monthly income for the rest of her life. Be careful. Her ODSP benefits will be affected if she gets money from the annuity. ODSP counts money from annuities dollar-for-dollar as income.

Annuities are not flexible. Once you buy an annuity, nobody needs to make any other decisions. This means that nobody can change the terms of the annuity. If your relative's circumstances change, nobody can change how much income they get from the annuity.

Other things you can do to meet your relative's needs

Set up a legal guardian for your relative

Many parents assume that they are the **legal guardians** of their sons or daughters with

disabilities, particularly intellectual or mental health disabilities, even when they are adults. Parents think they can manage their child's property and make decisions about their health care. This is often a mistake.

In Ontario, the law presumes that every person over the age of 18 can manage their own affairs and make their own decisions about their health care. Adults have legal guardians for financial and personal decision-making only if one is appointed for them by the Courts, or if the Office of the Public Guardian and Trustee becomes their financial guardian under the *Substitute Decisions Act*.

For many adults with an intellectual or mental health disability, this does not create a problem. With careful explanations and supports, the person may be able to make her or his own decisions. If necessary, ODSP can appoint a person, such as a parent, sibling, or case worker, to assist the person in the management of their ODSP without requiring the person to seek legal guardianship. Similarly, if a person is incapable of understanding a particular health care decision, the next of kin can usually give the required consent under Ontario's *Health Care Consent Act*.

Serious problems can arise, however, for adults with intellectual or mental health disabilities where:

- there is major conflict among their families, friends or support agencies about important decisions in their lives, and
- the adult is not capable of understanding the nature and consequences of decisions that have to be made.

There may be conflict about where the person will live, who the person will associate with, or whether or not the person will have a certain type of health care treatment. If counselling and discussion fail to resolve these issues, legal guardianship through the courts may have to be sought to protect the person's rights.

Other reasons for pursuing legal guardianship are when:

- the person is being abused, or is at risk of being abused
- the person has come into a great deal of money to manage, such as an accident settlement.

Legal guardianship is a process which is somewhat difficult, and costly, for everyone. In cases where it may be necessary, get legal advice. You can also contact the Office of the Public Guardian and Trustee. They can give you information. They can also intervene in a crisis, especially if family and friends are not available or willing to do so.

Information about the Office of the Public Guardian and Trustee is available online at <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/>

Help your relative with a disability develop a plan for the future

Here are some suggestions to help you get started:

- Talk to your family member with a disability about her or his personal goals, priorities, plans, and wishes.
- Talk to other family members and friends.
- Talk to the director or supervisor of the agency providing services to your family member with a disability (if there is one).
- Talk to caseworkers or caregivers who know your family member with a disability well on a day-to-day basis.
- Investigate the services and supports that may be available to the person in the community. This is especially important for parents whose daughter or son has lived at home with them their whole life, to begin to explore residential options.

Many parents find that it helps to talk about these issues with other families who have faced similar challenges. If you are involved with a

disability organization or service provider, ask if they have a 'peer support' or 'parent-to-parent' group or program. If they do not, find out if they can refer you to one.

Some parents have spent many years trying to take care of everything for a family member. If this has happened to you, you may be feeling that you do not know where to start. You can contact:

- your regional office of the Ontario Ministry of Community and Social Services
- the Community Care Access Centre in your community
- the Community Information Centre in your community.

Contact information for these organizations is given in **Part 6** of this booklet.

Help a relative without many assets to manage their property

If the person with a disability owns no property and does not have a large amount of money, the family can assist the person to make informal arrangements or set up a Power of Attorney for Property.

Make informal arrangements

You can make different kinds of arrangements, depending on the situation of your relative. For example, you could arrange for a group home where your relative lives to hold small amounts of cash for them, or you could open a joint bank account with your relative. If an organization is managing your relative's money, make sure that it uses a good bookkeeping system. Check from time to time that your relative is actually benefitting from the money.

Set up a Power of Attorney

In many cases, the best way for a person with a disability to manage their assets is by setting up a Power of Attorney for Property. Only a person with the necessary capacity can do this.

A Power of Attorney for Property is a document that a person signs to appoint some person to make financial decisions for him or her. The person granting the Power of Attorney is called the donor. The person making these decisions is called an attorney. The power of attorney must be signed in front of two witnesses. The witnesses cannot be the attorney or the attorney's spouse.

The person with a disability must have sufficient capacity to understand the nature and consequences of the Power of Attorney when he or she signs it. The attorney could be a relative or a friend. The Office of the Guardian and Public Trustee could also act as attorney, although they will not act on a Power of Attorney without written consent. The Office is very reluctant to act if family or friends are available.

Witnesses are important, especially if the person with a disability expects that they may lose their ability to make decisions after they grant the Power of Attorney, and the Power of Attorney is a Continuing Power of Attorney for Property. By a 'Continuing' Power of Attorney, we mean that the power of attorney is written so that it will be continue to be valid if the person who set it up later loses the ability to make their own decisions.

The power of attorney can also name someone as the substitute attorney. This is a very good idea where an attorney may act under a 'Continuing' provision that extends the power of attorney to after the time when the donor becomes incapable.

An interested person or any person permitted by the court, or the Public Guardian and Trustee, can ask the court to require the attorney to produce accounts. They can also apply for an order appointing another person as attorney. This means that the Court has a way to discipline an attorney who is acting for a person without legal capacity. However, there is a significant cost in any court application, including one for an accounting.

Help a relative with large amounts of assets to manage their money

Some people with disabilities own property or have lots of money. For example, they may have received money from a damage settlement. In these cases, you **must** get good legal and financial advice.

If the person is not able to manage their property, you should consider asking the court to appoint a guardian. In Ontario the court will make an order under the *Substitute Decisions Act*, R.S.O. 1992, c. 30.

If the person is able to make financial decisions but ongoing property management will be difficult for them, they may choose to place their own property in a trust. They may also choose to create a **revocable trust**. This means that they could regain control of the trust property if they needed to, for any reason.

A revocable trust may be better than a Power of Attorney because the trust will continue after the person who sets it up is dead. In this way, a trust could make sure that the person's property is disposed of as she would wish after she dies. Also, a trust makes the trustee responsible for decisions. Finally, once property is transferred to the trust, the person with a disability gives up their right to deal with the money and make decisions about the trust property.

On the other hand, an attorney cannot make decisions about the person's property after the person who appointed them dies. Also, a person with a disability who has appointed an attorney still has the power to use their assets and make decisions about their property, as long as they are capable.

The law does not make it entirely clear what obligations an attorney has while he or she is acting under a power of attorney, but the standard for an attorney acting for a donor who has legal capacity may be less than the standard

for a trustee. An attorney who acts for a person without legal capacity may be subject to the same fiduciary obligations as a trustee. The **fiduciary obligation** is the standard of honesty, prudence, and skill required of a person who is managing the assets of another person.

Answers to common questions about wills and estates

1. Can a person with a mental disability make a will?

When people who have a mental disability can understand the nature and consequences of what they are doing, including what assets they have and who their potential beneficiaries are, they can make a will.

If there is any doubt about the person's ability to make decisions, the will may be disputed. This is more likely, of course, if the person leaves a significant estate or if the person leaves their estate to someone other than close family or friends.

Any lawyer who writes a will for a person with a mental disability should feel confident that the person is able to make decisions. The lawyer must check that the person has the testamentary capacity they need to make a will. They must also verify that the person is capable of understanding the nature of their assets and what responsibilities they have toward their dependants. If the lawyer has any doubt about the person's capacity, they should ask a qualified assessor to assess the person's capacity to make a will. Qualified assessors are health professionals who have taken a special training course in capacity assessment through the Office of the Public Guardian and Trustee. A list of qualified assessors in your area can be obtained through that Office.

2. Do I have to support my relative with a disability in my will?

Courts can override your will if it does not provide for your dependants. Dependants are

family members who are actually supported by you, or who you are legally required to support. The law says the dependants who you **must** support include your spouse or common law spouse, your parents, and your children who are unmarried and under 18.

In general, under Ontario's family law you do not have to support children who are 16 or older who no longer live at home because they have voluntarily withdrawn from your care and control. You do not have to support your children after they turn 18, even if your child has a disability. However, if you are involved in a divorce, support can be ordered for a child who is in post-secondary education or who is dependent because of a disability.

Remember, the courts try to make sure that people with disabilities are treated fairly. A court can override your will and order your estate to support an adult relative if you are **either**:

- legally required to support that relative **or**
- you are actually supporting that relative when you die.

So, your adult relative who is actually receiving money or other support from you can challenge your will, or someone may help them to do so.

It is unlikely that the government will try to avoid paying ODSP benefits to your child by challenging your will. If your child is receiving ODSP benefits, the Ministry of Community and Social Services considers that they are not dependent on you. This is true even if your child is living with you. Under the policy in effect in 2008, the Ministry considers that the person is supported by ODSP.

This means that the Ministry of Community and Social Services (MCSS) will not apply to override your will unless a flagrant abuse exists. The Government seems to recognize that many parents have already made a big commitment to supporting their child during their lifetimes. It is very rare for MCSS to apply to the courts to override a parent's will and ask the court to order

the estate to pay to support a person who receives ODSP. If the Office of the Public Guardian and Trustee acts as your relative's financial guardian, they are also not likely to make a claim against your will. Instead, they will continue to have your relative receive ODSP benefits. The Office of the Public Guardian and Trustee would only make a claim against your will if they determine that your relative's quality of life would be better if she got money from your estate rather than from ODSP.

Although current policy means that it is rare for the Ministry of Community and Social Services, or the Office of the Public Guardian and Trustee, to challenge parents' wills, these challenges are allowed by law and could happen in the future. So it is best to provide for your relative with a disability in your will by doing things such as setting up a trust.

3. What is the role of an estate trustee?

When you write your will, you must appoint an estate trustee or trustees. Estate trustees are traditionally called **executors**. Your estate trustee(s) are the person or group of people who will carry out the wishes in your will. It is good to name more than one estate trustee if possible, so they can work together, and to take account of the possibility that one or more estate trustees may die, become ill, or move far away before you die. However, if you name a group of people to act as the trustees of your will, remember that all of the people must work together. Your will could say how decisions should be decided if the trustees do not agree. For example, it could say that disagreements will be decided by a specific trustee, or by a vote. There is no legal limit to how many people can be your trustees, but a large number of people may make it difficult for the trustees to administer your estate.

The trustees must do work at two stages. First, in their capacity as estate trustees, they must take care of many details soon after you die. Once that work is done they must administer any trusts that continue for a period of time, such as your relative's lifetime.

The person or persons who carry out the initial administration are often the same people who administer ongoing trusts, but they do not have to be. You may want to choose **disability trustees** or **special trustees** for your relative who are different people than your estate trustees. For example, it may be more important to have a younger person as an on-going disability trustee, while an older person with more business experience may be more suitable as an estate trustee.

Here are some of the things estate trustees (executors) must do shortly after a person has died:

- Make funeral and burial arrangements.
- Find the names and addresses of any beneficiaries, and tell them what they were given.
- Make a list of the deceased's assets and what they are worth.
- Contact banks or trust companies to find out what is in the deceased's safety deposit boxes, if they have any.
- Hire a lawyer to help administer the estate.
- Ask the lawyer to assist them in applying to the appropriate Court for a Certificate of Appointment as Estate Trustees.
- Make a list of what debts the deceased owed and arrange to pay them.
- Research any debts that they do not believe are legitimate.
- Calculate how much income tax the deceased and the estate will owe (with the assistance of an accountant if the estate is large or complicated), file returns with the Canada Revenue Agency, pay any tax that the deceased or their estate owes and get an income tax Clearance Certificate.
- Distribute the assets of the estate according to what the deceased said in their will.
- Set up any trusts that are provided for in the will, such as a Henson Trust or other trust for a relative of the deceased with a disability.
- If the trust will be administered by 'disability trustees' or 'special trustees' who are different than the estate trustees,

the monies directed to be held in trust would be paid to them.

The estate trustees are responsible for making decisions about the estate. They can ask for advice from lawyers or other experts but they must make the final decisions.

4. Who can be an estate trustee or disability trustee?

You can name a person or persons or a trust company to be your estate trustees and disability trustees. If you want to leave everything to your spouse, it is often best to name them as the sole trustee. This will make it easier for them to do all of the paperwork. Your children who are at least 18 years of age can also be estate trustees and

disability trustees. Other trusted relatives and friends can be as well.

Finally, you can name a trust company that does business in Ontario as an estate trustee. Your will should say who you want to be your estate trustees and disability trustees, and consider alternatives in case one or more of your original choices is unable or unwilling to act when the time comes.

When your will includes a beneficiary who is a person with a disability, it is a good idea to name a group of people with different skills as the trustees. Skills should include:

- financial management skills and
- skills in responding to the needs and wishes of your loved one.



Part 5: Is a Henson Trust a good choice for you?

1. Will you have some money in your estate that you would like to leave to your relative with a disability?

Where will this money come from?

- Bank accounts?
- GICs, RRSPs or RRIFs?
- Life Insurance?
- Sale of family home or other property?
- Benefit plans from your employment?

Note: Do you have questions about whether you will have any money from any of these sources? Do you want to find out how to increase any of these sources of money? If so, talk to a financial advisor such as an insurance broker or a certified financial planner.

2. If you will have money in your estate, how much money will you be able to leave to your relative with a disability?

- If the total amount is less than \$5,000 dollars for a single person, and your relative does not have any other savings, you do not need a trust. People who receive ODSP are allowed to have up to \$5,000 in assets.
- If the total amount of money is between \$5,000 and \$100,000, you should set up a trust so that your relative can continue to be eligible for ODSP. You do not have to set

up a Henson Trust, but a Henson Trust may be the best option if your relative may receive an inheritance from someone else. This booklet can help explain trusts.

Note: These are general guidelines. If someone else leaves your relative an inheritance or names them as beneficiary of life insurance, you will not be able to leave your relative as much money unless it is in a Henson Trust. The other person should also put their inheritance or life insurance in trust. If your relative has already been given money that is **not** in trust, help your relative put it in trust.

3. If you will have more than \$100,000 to leave to your relative with a disability, we have some more questions

Would you like to buy a house where your relative would live with any supports they need?

- If yes, and you will you have less than \$100,000 left over, please read Part 2: Wills and Estates.
- Would you like to buy some special supports for your relative? For example, do you want to buy them a van?
- If yes, and you will have less than \$100,000 left, please read Part 2: Wills and Estates. If you answered no to these questions, continue to question 4.

4. Do you have a large enough estate that you do not need ODSP to help support your relative?

That is, will the capital and income in your estate, together with other programs like the Trillium Drug program, take care of your relative for the rest of their life? Remember to take into account the health-related and disability-related benefits such as the drug card and the dental card that are included in ODSP benefits. Also, remember that your relative can get up to \$5000 in gifts during any period of 12 months in a row.

- If your estate is so large, you may not need a Henson Trust. Please read Part 4, How to Prepare for the Future.
- If your estate is not that large, go to question 5.

5. You may now be ready to set up a Henson Trust. We just need to ask a few more questions.

Can anything in your relative's life be improved with more money? For example, could money help their medical condition, social life, job prospects or anything else? Can the trust make a real difference in their life? Do you expect them to live for many more years?

- If the answer is **yes**, go on to question 6.
- If you believe the answer is **no**, are you absolutely certain? Remember that there may be significant changes in medical science and in society generally over the next several decades.

If your relative's life would **not** be improved with more money, a Henson Trust may not be a good

idea. The purpose of a Henson Trust is to use the money to improve their lifestyle and support.

However, you may still wish to set up a Henson Trust because you are worried about the future of government programs and think ODSP benefits may be changed at some point. You could give the trustees the power to use the money for your other beneficiaries and your relative with a disability, in case they need it because of an emergency or because their circumstances have changed.

6. If you got to this point, then a Henson Trust is probably right for you. We still need to ask a few more questions.

Do you have relatives and friends who fully understand what it will mean to be trustees? Do they know about all of a trustee's responsibilities?

Do these people take an interest in your relative? Are they beyond reproach in their lifestyle and activities? Do you have complete peace of mind trusting them with financial decisions about your relative's life and well-being?

- If the answer is yes, go on to number 7.
- If the answer is no, you may wish to set up a Henson Trust that is managed (at least in part) by a trust company. Please see pages 14 and 28.

7. You are now ready to consider a Henson Trust that involves trusted relatives or friends as trustees.

Profiles of families considering a Henson Trust

Family situation	<p>Wealthy family with a child whose medical needs are not covered by ODSP and the Ontario Drug Plan.</p> <p>Alana and David have an estate of close to \$2 million. The estate has been invested wisely and will pay out \$120,000 per year.</p> <p>Their 30-year-old only son, Henry, is employed while receiving an additional monthly amount from ODSP. He does not have many expenses apart from medical ones.</p> <p>Henry needs prescriptions that are not covered by ODSP and the Ontario Drug Plan. He also needs orthodontic and mouth reconstruction therapies that are not covered by ODSP.</p> <p>Alana and David do not have any family members who could help administer a trust.</p>
Comments	<p>Alana and David have had good legal and financial advice. Still, they are unsure about setting up a discretionary trust such as a Henson Trust. They do not understand all of the rules about ODSP. They worry that if their son continues to do well at his job, he may not qualify for ODSP in the future.</p>
Advice	<p>Alana and David should consider planning their estate to take care of all of Henry's needs. The estate seems to be large enough to support Henry, and many of his health care expenses are not covered by ODSP and the Ontario Drug Plan. When the estate starts to support Henry, he must withdraw from ODSP.</p> <p>The above advice does not refer to an appropriate structure of the estate. It would make sense to have the estate placed in trust if the parents are concerned that Henry will be unable to manage it himself. Alana and David may want to consider a trust company to ensure that the capital is appropriately invested. Henry could be given a substantial monthly allowance to spend as he sees fit, if he is capable of managing these funds, so his independence could be maintained, while his long-term financial interests were also protected.</p> <p style="text-align: right;"><i>(Continued on following page)</i></p>

Family situation	<p>Modest income family. The daughter needs medical supports that the estate could help provide.</p> <p>Sally and Michael have an estate of close to \$150,000. They have made good investments, and the estate will pay out \$7,500 per year.</p> <p>Their 37-year-old daughter, Nancy, has schizophrenia. She does not have a job, and probably will never have an income from employment. All of her prescriptions are covered by the Ontario Drug Plan. Nancy needs special teeth cleaning that she can get through the ODSP special care dental plan. She cannot live on her own, and cannot live with her brothers and their families.</p> <p>Nancy's brothers are successful and well-established, and likely will not require support from their parents' estates, at least for a long time.</p>
Comments	<p>Sally and Michael have had good legal and financial advice. They understand the rules about ODSP and feel that a discretionary trust is a good possibility. Their sons have been involved in planning the estate, and would be reliable trustees.</p> <p>ODSP benefits are \$12,000 a year plus the drug and dental program. Clearly, ODSP provides more than their estate could provide for Nancy's housing, food and other basic expenses. ODSP also covers all of Nancy's health-related costs.</p> <p>With Sally and Michael's estate, Nancy will have a yearly income that is well within what ODSP will allow. From the estate, Nancy could get</p> <ul style="list-style-type: none"> • \$5,000 a year in gifts and • up to \$2,500 a year for expenses related to her disability (such as payment to a support person).
Advice	<p>Sally and Michael should consider planning their estate so that Nancy can continue to receive ODSP benefits.</p> <p>In their situation, a discretionary trust is a very good option. Sally and Michael's estate is not large enough to cover all of Nancy's needs.</p> <p>A Henson Trust would allow them to add to what ODSP can provide for Nancy.</p> <p>Nancy's brothers and their families could be residual beneficiaries of the Henson Trust.</p>

Part 6: Resources

General information

For information about **ODSP**, including the Policy Directives for the program, go to: <http://www.mcss.gov.on.ca/mcss/english/pillars/social/programs/odsp/htm>

For information about the **Trillium Drug Program**, which provides drug coverage for individuals and families who have high drug costs compared to their income, go to: <http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>

To find the Community Information Centre in your community, go to: <http://www.211ontario.ca/main.htm>

To find the regional office of the Ontario Ministry of Community and Social Services, go to: <http://www.cfcs.gov.on.ca/mcss/english/pillars/developmental>

For information about **home care**, through the Community Care Access Centres: http://www.health.gov.on.ca/english/public/contact/ccac/ccac_mn.html

For information about **mental health services** in Ontario, go to: http://www.health.gov.on.ca/english/public/pub/pub_menus?pub_mental.html

To read about the **Registered Disability Savings Plan** announced in the 2007 Federal Budget, go to: <http://www.cra-arc.gc.ca/agency/budget/2007/rdsp-e.html>

To contact the **Planned Lifetime Advocacy Network (PLAN)**: <http://www.plan.ca/>

Resources for people with developmental and mental health disabilities

A listing of services for people with developmental (intellectual) disabilities: <http://www.mcsc.gov.on.ca/mcsc/english/pillars/developmental>

Reena, a non-profit serving persons with intellectual disabilities in Ontario: <http://www.reena.org>

Community Living Ontario, a non-profit with affiliates throughout Ontario: <http://www.communitylivingontario.ca/>

The Ontario Division of the Canadian Mental Health Association: <http://www.ontario.cmha.ca/>

For detailed information about mental capacity, visit the Ontario Ministry of the Attorney-General website. This site describes the role of **Office of the Public Guardian and Trustee**, explains what laws and policies apply to adults with limited capacity, includes information on the *Substitute Decisions Act* and the *Health Care Consent Act*, and outlines Powers of Attorney and capacity assessment: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/>

Part 7: Glossary

Asset Testing (Asset-Tested Benefits) – a type of eligibility test that looks at a family’s or individual’s savings and other investments

Beneficiary (of a Trust) – a person who is legally entitled to benefit from a trust

Compensation – payments that a person gets because of an injury or illness caused by someone else, such as being hurt at work or being in a car accident

Family Benefits – the name for Ontario’s social assistance program from 1966 to 1998. Family benefits included benefits for adults with disabilities, single parents, and a few other groups.

Henson Trust – a trust which gives the trustee or trustees absolute discretion to make decisions on behalf of the beneficiary, following the precedent established by the Henson case decided by the Ontario Courts in the 1980s.

Income Attribution Rules – income tax rules which treat income paid to one person as if it were paid to another person. For example, sometimes people must pay taxes on income they earn on investments they have given to their spouse, partner, or child.

Income Testing (or Income-Tested Benefits) – a type of eligibility test based on a person’s or a family’s income. Two examples are the Canada Child Tax Benefit and the Guaranteed Income Supplement for Seniors.

Inheritance Trust (or Shelter Trust) – a trust of \$100,000 or less set up by a person receiving ODSP, or on their behalf, that uses funds from an inheritance or life insurance

Means Testing (or Means-Tested Benefits) – a type of eligibility test based on a family’s circumstances, needs and resources. This kind of test is no longer used very much in Canada.

Needs Tests (or Needs-Tested Benefits) – a type of eligibility test which combines asset testing and income testing with needs based on a budget. ODSP is a needs-tested program.

Ontario Disability Support Program (ODSP) – the main income and benefits social assistance program for adults with disabilities in Ontario. It started in June, 1998.

Ontario Works (OW) – the main income and benefits social assistance program for non-disabled adults in Ontario. It began in May, 1998.

Pension – payments that people receive as a right, usually because the person has contributed to a plan.

Registered Disability Savings Plan (RDSP) – a program to be started by the Government of Canada in 2008. An RDSP account is a long-term savings account for people with disabilities. Persons with disabilities and their relatives will be able to open RDSP accounts, which can grow tax-free.

We are grateful for the input and feedback we received from Susan Rudnick and the parent group convened by Reena

Thanks to the sponsors who made this project possible:



Acknowledgements

Written by: Harry Beatty, Mary Louise Dickson, John Stapleton

Edited by: Clear Language and Design

