WILLS, TRUSTS, AND ESTATE PLANNING: A GUIDE FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES

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Families are very familiar with positive planning processes that are focused on helping their child with disabilities to have a good life. You may have had help by many people in your unique situation to develop a good plan: extended family and friends, members of your child's support circle, other families in similar circumstances, or facilitators.

In order for your plan to continue after you are gone, it is also necessary to develop a will and estate plan. Your lawyer's responsibility is to help you understand how certain legal tools can help you to attain the goals of your child's plan. However, it is you - the family of the child with disabilities - that knows and understands what you need and want for your child. Remember that your lawyer can only help you to be protected by the law by assisting you to have the right documents in place, and it is your responsibility to give your lawyer all the information needed so that your wishes are carried out. Being well prepared when you meet with your lawyer will save your lawyer's time and your money.

WHAT DO YOU NEED TO KNOW BEFORE YOU MEET WITH YOUR LAWYER?

How can you be prepared?

Lawyers have such tools as Wills, Trusts, Powers of Attorney for Personal Care and Property, which can be used to assist parents in providing for their child with disabilities. Before meeting a lawyer to discuss your will and estate plan, you need to prepare yourself with:an understanding of the abilities and the challenges of your child a recognition of what parents are required to do on a daily basis in order to implement the plan an understanding that the plan must be designed so it can be continued when parents are no longer here to perform all of the duties and tasks that enable the plan to thrive an understanding that there will be a financial cost to pay for the continuation of some of the things that the parents did to support their child during the parent's lifetime a recognition that other people may wish to help your family by providing gifts of services or money to support this plan an understanding that in order to prevent these well intentioned gifts from hurting the plan, the parents must be aware of the gifts and ensure that the gifts are co-ordinated into the plan.

Do you have your own Will?

A will is the legal document that will guide people to carry out your decisions about your estate. If your children are under the age of 18, you will have named people (guardians) who will be legally responsible for your children if you and your spouse pass away before your children are adults. You will have also named one or more executors responsible for carrying out the instructions in your will.

Can your child make their own Will?

A person 18 years of age or older is considered capable of making a will if that person: (i) understands the nature and effect of a will; (ii) is aware of the nature and value of his or her property; (iii) understands the extent of what he or she is giving under the will; (v) is aware of the individuals that he or she would be expected to benefit under his or her will; and (vi) understands the nature of the claims that may be made by certain classes of individuals if they are not included in the will. If your child is not capable of making a valid will their assets do not automatically revert to the government. The assets are distributed to spouses, children, parents or other relatives of your child, according to the terms of provincial legislation.

Put simply, a lawyer might ask your child if there are certain belongings that are important to them, and is there anyone that he/ she might want to have them in the future. For example, if they can understand that their brother would really love their hockey card collection, then this simple understanding is strong evidence that your child may be capable of making their own will.

What is a Power of Attorney for personal care?

A power of attorney for personal care (sometimes called a Living Will) is a legal document that allows you to appoint another person (the "attorney") to make personal care decisions for you if you become incapable of making those decisions on your own, such as medical decisions or issues relating to accommodation, hygiene, food and clothing.

A person may be capable of preparing a power of attorney for personal care even if they cannot make their own personal care decisions. A person is considered capable of preparing a power of attorney for personal care if they are able to understand whether the person named as "attorney" has a genuine concern for his or her welfare and

appreciates that this “attorney” may need to make personal care decisions on his or her behalf.

A power of attorney for personal care may contain instructions or directions to the attorney with respect to how personal care decisions are to be made. However, sometimes such directions have caused disputes in the interpretation of the meaning of them, which can result in a delay of treatment. Therefore, it may be prudent not to include such instructions or directions in the document.

A person must be at least 16 years of age in order to prepare a power of attorney for personal care. If your child child does not have the capacity to make a power of attorney for personal care, legislation sets out a hierarchical list of people who are authorized to consent to medical treatment on behalf of another person and to provide instructions with respect to most other personal care issues. This list is limited in scope to include a persons’ spouse, partner, child, parent, brother, or sister or any other relative of the person unable to make the decision. If no one in the list is available to act on behalf of the person, or if the plan is designed with someone not in the approved list as the personal care decisions maker, then an application to Court for the appointment of a Guardian of Personal Care may be the only option available.

What is a Power of Attorney for property?

A power of attorney for property is a legal document which allows you to appoint another person (the “attorney”) to make decisions with respect to your property which may include such things as making bank deposits, paying bills, managing investments, buying, selling or refinancing a home and filing income taxes. A person does not need to able to manage his or her own property to be capable of preparing a power of attorney for property.

A person must be at least 18 years of age in order to prepare a power of attorney for property. If your child is capable of making a power of attorney for property, his/her assets can be managed by parents or others through the creation of a continuing power of attorney for property. If your child is not capable of preparing a power of attorney for property, it is often possible for parents to assist their child through informal arrangements such as holding a joint bank account, and submitting tax returns and other documents on behalf of the child. Such informal solutions will often be sufficient if the child's asset value is small and there is a parent living to act on behalf of the child. These types of informal arrangements often cease to be possible on the death of the

surviving parent and some of the leniencies afforded to parents do not seem to pass easily to siblings or other individuals, in which case it may be necessary for a family member or other person to be given the authority to manage the property of the child with disabilities through a formal appointment as Guardian of the Property by the Court.

Does your child receive Ontario Disability Support Program (ODSP) benefits now or will they receive ODSP Benefits in the future?

The Ontario Disability Support Program provides financial assistance to individuals who are 18 years of age or over and who met the eligibility requirements under the relevant legislation. The main benefits available from ODSP include income support, an allowance for shelter and a health plan. The amount of financial support received by a qualifying individual is directly related to each person's unique situation and is calculated based on a certain amount being allocated for basic income support and a certain amount being allocated for shelter. The amount allocated will vary depending on where the person lives (with parents or in the community), and the amount, if any, of other income received by the person.

What is the ODSP Allowable Asset Limit?

In order to apply for and remain eligible to receive ODSP benefits, a person cannot have more than $5,000.00 in assets. Assets include cash, bank accounts, stocks, bonds, RRSPs, investments and other securities or assets that can be readily converted to cash. Assets that flow directly to a person who is receiving ODSP benefits can result in a reduction or suspension of the benefits. Therefore, simply giving money or other assets or leaving money or other assets in a will to an individual with disabilities can negatively impact their benefits and can disrupt the plan that has been set up for their care.

How can we protect our child from loss of ODSP benefits?

When the parents of a child with disabilities are alive, they dedicate time and money to their child in a way that supplements the ODSP benefits while at the same time ensuring the assistance provided does not result in a reduction or suspension of such benefits. If the plan is to continue effectively after the death of the parents it must be set up in a way that will allow the same services to be provided to the child in the same manner as when they were alive. A tool called a **discretionary Henson Trust** has been developed and approved by the courts which, if used properly, allows parents and

others to leave an inheritance to a person with disabilities without reducing or suspending their ODSP benefits.

What is a trust?

A trust is a legal arrangement whereby asset(s) are transferred from one person to another person (the “trustee”) for the benefit of a third person ("the beneficiary"). The assets are held by the trustee and must be used by the trustee in accordance with the rules set out in the trust document. The types of assets that can be placed in a trust are unlimited, although some may not be appropriate. A trust is often used because it permits you to give assets to someone else, namely the beneficiary, while at the same time it allows you to retain some measure of control over the asset after it is given, and the types of controls are set out in the rules of the trust document. A trust can also be used to separate the burden of property management from the benefits of its enjoyment, making it an ideal vehicle for providing for those who, for whatever reason, can’t manage assets on their own. A trust can be created and become operational during your lifetime (inter vivos) or it can be created and become operational upon your death through the terms of your will (testamentary).

What is a Henson Trust?

- A Henson trust is a specific kind of trust that is named after the trust that Mr. Leonard Henson set up to provide for his daughter with disabilities after his death. A Henson trust is most commonly set up by a will, to help your child after you pass away (a Henson Testamentary Trust). However, depending on your specific situation, an additional and separate Henson Trust may also be set up outside of your will and become operational while you are alive to help your child during your lifetime (an inter vivos Henson Trust), and which will continue to benefit your child after you pass away. Usually an inter vivos trust is created if parents have substantial assets and it is determined by their advisors that it is beneficial to set up trusts for their children in order to reduce income tax of the parents.

- A Henson trust is also an absolute discretionary trust, which means that the assets in the trust are in the complete control of the trustee and the trustee has total and absolute discretion to decide when and if the beneficiary of the trust (the child with disabilities) will receive any payments or distributions from the trust. The trustee is under no obligation to distribute the trust property to the beneficiary and the beneficiary, therefore, is only entitled to that part of the trust property that the trustee has chosen to distribute to the beneficiary.

In this way, the beneficiary cannot be said to have any interest in the assets of the trust because he or she does not have access to the assets and cannot compel the trustee to make any sort of payment and or distribution from the trust. If the assets are held in an absolute discretionary trust, only the amounts actually paid out of the trust to the person with disabilities will be included in that person's assets and income in determining whether he or she is entitled to ODSP benefits. The assets in the Henson Trust may be used by the trustee to enhance the life of the beneficiary with disabilities and to support and ensure the continuation of the plan devised by their parents, while at the same time ensuring that such actions do not interfere with the individual's receipt of ODSP benefits. It is not necessary for parents who, during their lifetime, are using their own assets to provide extra support and services for a child with disabilities, to create an inter vivos Henson trust to protect ODSP benefits. As long as the child does not have assets in his or own name, the parents can use their own assets, within the limits set out in ODSP legislation, to help their child without disrupting ODSP benefits. An intervivos trust will not allow parents to spend more money on their child than they would without the creation of that trust. The most commom use of an inter vivos Henson trust is to provide parents with income tax advantages.

How do I create a Henson Trust ?

The parents or other person planning for an individual with disabilities must have a will in order to ensure the plan that has been implemented in their lifetime is continued for the benefit of the person with disabilities. If the person is receiving ODSP benefits or may receive such benefits in the future, the will must, in most circumstances, include a Henson Trust.

What should I consider when setting up a Henson Trust?

1. Choice of Trustee (s)

The selection of the appropriate trustee to manage a trust for an individual with disabilities is of paramount importance. If an inter vivos Henson trust is set up by parents, then while the parents are living, they can be the trustees, but they also need to think about who will run the trust after they passa away. If a testamentary Henson trust is set up by parents in their wills, then the trust will not begin to provide support to the child with disabilities until after the parents pass away. Therefore, the parents cannot be the trustees of a Henson trust created by their own wills. The Henson Trust, as an absolute discretionary trust is not permitted to give directions to the trustee with respect

to the operation of the trust. The trustee must understand and believe in the plan that has been developed and must be trusted to make decisions in a way that will allow the plan to continue. It may be necessary to have more than one trustee in order to provide all of the skills that are required to operate the trust. For example, one person might be good at managing the money, and the other might be best at knowing how and what to spend the money on so your child is supported to live in the way that you planned.

Some of the jobs of the trustees include: investment and management of the assets of the trust; making sure your child receives benefits according to what you have planned; using their discretion to give funds when needed; coordinating any needed maintenance or repair of real estate; preparing tax returns of the trust; keeping records of the trust.

2. Conflict of Interest and Family considerations

Family members may not always be the appropriate choice of trustee in each situation. The Henson Trust must name the beneficiaries of any funds remaining in the trust when the person with disabilities passes away. A conflict of interest may occur because often the logical first choice for a trustee is a brother or sister of the individual with disabilities, and in most cases that sibling, or their children, are also the logical choices to receive the funds remaining at the end of the trust. We are all subject to outside influences in our lives that can create pressures and cause us to make decisions that may be contrary to the interests of those that we are entrusted to protect. It is the responsibility of a parent to do their best not to put children in a position of conflict that could result in harm to both their child with disabilities and another child who is named as a trustee. If a trustee is also a beneficiary at the end of the trust, at the very least, additional or co-trustees should be named to address the conflict of interest situation. Parents must also consider whether they want to entrust another child or children with the responsibility of acting as a trustee of the trust. You may consider naming a trusted friend to help your children make decisions that will support your child with disabilities as you have planned for.

3. Understanding the Government Legislation

The trustee of the Henson Trust must be aware of the rules that govern ODSP benefits, have the skills to follow these rules, and understand how to spend the trust funds in a way that does not result in a loss of the ODSP benefits. Generally, an individual receiving ODSP is entitled to receive a total of $5,000.00 each year by way of gift or voluntary payments, which would include payments from the Henson Trust. In addition to this $5,000.00, unlimited payments can be made from the trust for disability

related expenses. The trustee can work within the scope of the legislation and use the Henson Trust assets to purchase personal use and household items, provide various forms of recreation, vacations and entertainment, pay for special equipment or a personal care attendant and to provide for a multitude of other special services.

4. Consent and Age

It is important that you talk to those who you want to name as trustees before you name them in your will. A person cannot be forced to act simply because he or she has been named as trustee in the trust document, so it is best that they have agreed to act as trustees beforehand. The age of the trustee is also something to think about, because the trust is designed to continue during the lifetime of the individual with disabilities. More than one trustee can be named to act together, and one or more alternate trustees can be named to act in the event the first named trustee is not able to act. Regardless of the situation, at least one of the named trustees should be young enough to carry on for the lifetime of the individual with disabilities.

5. Investment and Income Tax

The trustee must be aware that there are many important income tax and investment management issues relating to the proper management of a Henson Trust. A trust is a taxpayer, so it pays taxes on its earnings, and must file an annual tax return. The trustee must understand the plan and the impact that the specific tax and investment management issues will have on the plan. The required tax and investment planning is determined by the specific characteristics of each trust. One of the major factors that influence tax issues and the type of investment strategy required for a trust is the timing issue of when the money in the trust is going to be needed to support a individual with disabilities. The money may be needed now, or perhaps the money is left in a Henson Trust by a grandparent and will not be required to be used until the death of the parents of the person with disabilities.

6. Probate Planning versus Funding the Trust

If a Henson Trust is included in a will, it is mandatory that some funds flow **into** the estate at death so that there is money available to be paid into the Trust.

Many people are told by financial institutions and other advisors to name beneficiaries in the policies in order to avoid paying estate administration tax (formerly known as probate fees) to the Court at death (about 1.5% tax rate). If an asset (such as an RRSP,

RRIF, life insurance policy, pension plan, or any other type of asset) has a named beneficiary, the asset does not form part of the deceased's estate, and the value of the asset is not subject to estate administration or probate tax. The proceeds of that policy will be paid by the controlling institution directly to the named beneficiaries upon the death of the owner. But more importantly, the asset will pass outside of the estate and therefore it is not available to form part of the Henson Trust money. Also, if the policy names the person with disabilities as a beneficiary of the policy, the proceeds will be received directly by that individual, which may result in the reduction or suspension of their ODSP benefits. If you include a Henson trust in your will, the most important factor is always making sure that there will be money in your estate to be paid into the Henson trust. The desire to save probate/ administration tax cannot be allowed to interfere with this goal. In most situations, the safest and easiest way to ensure that funds are available to be paid into the Henson trust is to name the spouse, if there is one, as the beneficiary of any life insurance policy, RRSP, RRIF or any other asset which allows a beneficiary to be named, and to name your estate as the alternate beneficiary to receive the proceeds if your spouse has predeceased you. If you do not name an alternate beneficiary, the estate will automatically be the alternate. By doing this, even though probate/ estate administration tax must be paid on the value of the proceeds, you are guaranteed that the asset proceeds will be paid to your estate at the death of the surviving parent, and will be available to be paid into the Henson trust. If your estate is named as the beneficiary, the proceeds will form part of all of the other assets in your estate. Those assets will then be divided according to the specific terms in your will among your beneficiaries, one being the Henson trust set up for your child with disabilities, and may also include other children or trusts set up in your will to hold money for your other children who are not yet old enough to manage their own money. The importance of ensuring that there are funds in your estate to be paid into the Henson trust and to allow for the other specific terms of your will to be carried out, far outweigh the importance of saving probate/ administration tax.

The same principle applies to assets owned jointly with other individuals. If you own such things as a house, bank account, or investments jointly with another individual that joint asset will pass outside of the estate to the surviving joint owners upon the death of an owner. Again, probate/administration taxes are avoided but the funds cannot form part of the Henson Trust. If a person with disabilities is a joint owner, he or she will receive the asset directly and his or her ODSP benefits may be reduced or suspended. Naming benefiaries in any asset policy, or owning property jointly with others, may destroy the plan that has been devised for the person with disabilities.

7. Home Ownership

(The scope of this article does not allow great detail to be discussed around the complicated issues of home ownership, and because every individual situation is different, it is adviseable that you talk to your lawyer about the possibilities and financial implications for you and your family member.)

As you go through the planning process, you may think about whether your child with disabilities does now or plans to own their own home in the future. A home owned by a person who receives ODSP is not considered an asset when dealing with the asset eligibility requirements for ODSP. This does not end the question, however, because in the claim for ODSP, expenses for room (or rent) and board are normally identified and included in the calculation of the amount of ODSP entitlement. It is more difficult to explain that a person is paying room or rent when the person owns his/her own home. An option that could be considered if owning a property is to be part of your child's plan would be to have the home owned by the Henson trust. The Henson trust would then be able to charge the person receiving ODSP rent, which would then come from their ODSP room and board entitlement. Using a Henson trust for this purpose could involve the creation of a testamentary Henson trust, or may justify the creation of an inter vivos Henson trust. There are income tax issues that would have to be considered if creating an inter vivos Henson trust, and a full review of these issues would have to be conducted on an individual basis, before this should be considered as part of the plan.

What if I can't manage my own assets while I am living? Who can help?

Parents of a child with disabilities must have a Power of Attorney for Property in place that names someone (the "attorney") to manage their own assets and carry out the plan for their child in case one or both parents are living but are mentally incapable of managing property. The "attorney" must be someone who understands and is able to carry on with the plan. It often makes sense that the "attorney" is the same person or persons who will act as trustee of the Henson trust following the death of the parents.

Can I decide who will be my child's Guardian?

The will of the parents should state who should make an application to the Court to be appointed Guardian of the Person and Property of their child with disabilities once the child reaches 18 years of age. It may not be necessary for someone to obtain this

appointment, but if it is necessary, because of an institution (eg hospital or bank) refuses to accept instructions on behalf of a child with disabilities without such appointment, the court may appoint the person who meets the wishes of the parents, if there are competing applications to become Guardian.

What if relatives want to contribute to my child's care?

Parents must also take steps to protect their child with disabilities by ensuring that their own parents and siblings include a Henson Trust in their wills if they are leaving an inheritance to that child. Many good plans are destroyed by other well-intentioned individuals who leave money to a child with disabilities in their will without the protection of a Henson Trust. Such gifts can result in the suspension of the child's ODSP benefits and disrupt the plan set in place by the parents. The parents must take the time and make the effort to educate other family members and friends about the plan. If more than one trust is set up for an individual with disabilities (for example, a Henson trust set up in the parents' wills, as well as Henson trusts set up in any other family member's will), it is important that the trusts are coordinated to ensure that they each fit in with the plan, and to ensure that the total amount spent from trusts is within the legislation's allowable limits, and is used for allowable items.

What if someone leaves my child money that is not in a Henson Trust? What is a Disability Expense Trust (Rescue Trust)?

If a child with special needs receives an inheritance by way of a Will that does not protect the money in a Henson Trust, or if the inheritance is received because the child with disabilities was a named beneficiary of a Life insurance policy, pension fund or RRIF, or if funds are received for pain and suffering by way of a personal injury award, then it may be possible to place the funds, to a maximum amount of $100,000.00, in a Disability Expense or Rescue Trust which will prevent such funds from disqualifying the child with disabilities from receiving ODSP Benefits.

The Disability Expense Trust can be used within the limits of the relevant legislation to supplement the ODSP Benefits. One extremely limiting factor in the use of this trust is that the individual with disabilities receiving the funds must have the legal capacity to create a trust or a Guardian of Property must be appointment by the court to create the trust on behalf of the person with disabilities. As mentioned previously, if a Disability Expense trust is set up, it must be coordinated with any other trusts which have been set up to help the child with disabilities.

Children with disabilities have unique care requirements that will continue throughout their lifetime. For those people who have the responsibility of caring for a child with disabilities, ensuring that those unique care requirements are properly fulfilled and funded after caregivers have passed away is both critical to the child's well-being and fundamental to the caregiver's peace of mind. The Henson Trust is a tool that is often used to provide for children with disabilities and is generally set up by parents through their wills. It must be remembered that a Henson Trust is only one tool which may or may not allow parents to reach the desired outcome. To reach the desired outcome, a strategic plan must be put in place that may or may not include a Henson Trust. Trusts and other solutions may be used to address current problems and improve the life of an individual with disabilities while the parents are still alive without affecting the individual's government benefits, so such tools are not just important after parents pass away. An assessment of both present and future strengths, capabilities and needs of the person you are planning for must be addressed in formulating a successful plan that will co-ordinate all the requisite tools to ensure that the plan is tailored made to best fit the individual's circumstances.

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