



# Support & Trustee Advisory Services

Parent Planning Guide...  
To help parents begin the  
planning process



THE ONTARIO  
TRILLIUM  
FOUNDATION



LA FONDATION  
TRILLIUM  
DE L'ONTARIO

Support & Trustee Advisory Services

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“The best way to predict the future is to invent it”

(Alan Kay)

### Future planning is a positive process

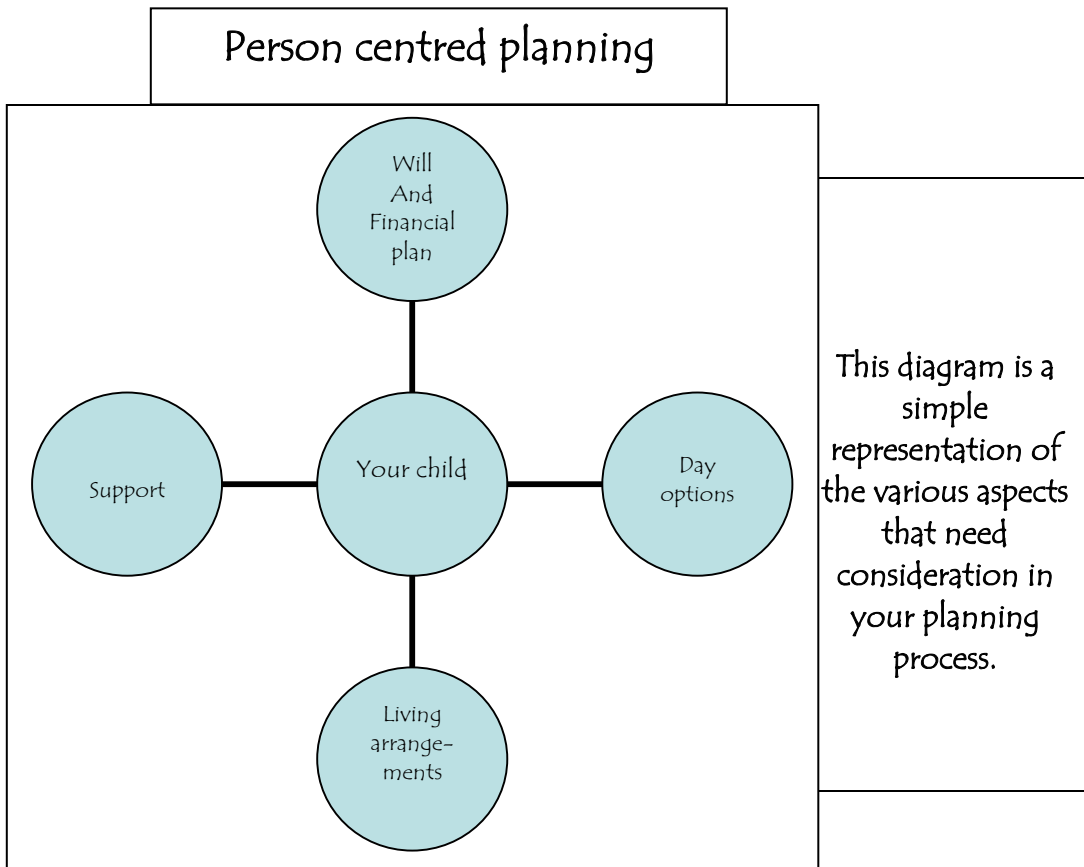
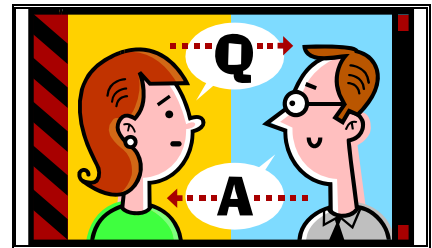
It is the unknown that scares people. For parents with children who have a disability, the big unknown for them is the future. Often parents are frightened by what they think the future holds for their child who has a disability. To them it presents a vague, scary, all encompassing chasm, dark and gloomy, with no hope – only worry. Instead parents need to look at the future, and planning for it, as an opportunity rather than a misfortune. It is an opportunity to shape their child’s future, to be proactive and to take the lead in formulating a vision rather than passively accepting a result.

Future planning is a positive, proactive, goal directed process that allows parents the opportunity to take stock of where their child currently is, where they envision their child ( and where their child sees themselves) to be in the future, be it 6 months, 6 years or 20 years. With that picture in mind, parents can determine what they need to do to help their child reach those goals. By setting goals, parents have a methodical process to follow to help their child attain those goals, and to work towards the vision of the future. By setting goals, parents take the lead when it comes to future planning. By taking the lead when it comes to future planning, parents change the connotation of the future.

Future planning encompasses several different components – day opportunities, housing, networks of support and estate planning. For each component there are a variety of resources available to parents, one being Support & Trustee Advisory Services. This workbook is divided into sections which represent the various aspects of the child’s life. Together they make a complete picture. Parents are welcome to copy the Fact sheets provided and use them from time to time, to make sure they are on track and to revise the goals when necessary. *The goal of this workbook is to give parents a place to start. This workbook is intended as a resource only. The authors are not lawyers or financial planners. Parents need to make informed choices when it comes to planning for their child’s future. Each child, each family is different. This is a guide ... a place to start the future planning adventure.*

Outline:

- A. Support & Trustee Advisory Services.....Page 4
- B. First things first....overview..... Page 5
- C. Wills and Financial plans..... Page 7
- D. Absolute Discretionary Trust..... Page 8
- E. Choosing a Lawyer..... Page 9
- F. Choosing a Financial Planner..... Page 10
- G. Fact Sheet #1 Review of Assets..... Page 11
- H. Fact Sheet #2 Some Decisions about Executor/Guardian... ..Page 14
- I. Fact Sheet # 3 Some Decisions about Division of Estate..... Page 15
- J. Fact Sheet #4 Financial Decisions.....Page 16
- J. Fact sheet #5 Medical Decisions.....Page 17
- K. Day Options.....Page 19
- L. Fact Sheet #6 Some Quality of Life Decisions.....Page 21-25
- M. Living Arrangements.....Page 26
- N. Agency Provided Residential Setting.....Page 26
- O. Private Residential Setting.....Page 27
- P. Fact Sheet #7 Living Arrangements.....Page 28-31
- Q. Circles of Support .....Page 32
- R. Fact sheet #8 Circles of Support.....Page 34-35
- S. Fact Sheet #9 Are There Shortfalls?.....Page 36
- T. Fact Sheet #10 To do List.....Page 37
- U. Conclusions.....Page 38
- V. Resources.....Page 39-40



## Support & Trustee Advisory Services

Support & Trustee Advisory Services (or STAS) was started initially in 1995 by a group of concerned parents and has evolved into a valuable resource in Peel for parents with children who have a disability and who are looking for information about the unique challenges involved in arranging their inheritance. With the uncertainty of government allowances and pensions, parents of individuals who have a disability must carefully plan for their child's future to ensure that it is secure and remains secure throughout that individual's lifetime. In the future, Government funding alone may not be enough to provide a satisfactory quality-of-life for individuals who have a disability. Add to that the concerns about housing and healthcare and one begins to appreciate the importance of thorough planning.

Support & Trustee Advisory Services is affiliated with both Community Living Mississauga and Brampton Caledon Community Living and is governed by a volunteer Board of Directors. The mandate of STAS is to assist families in Peel Region with setting up workable trust funds for their sons and/or daughters who have a disability by:

- ❖ Providing information, public education and assistance to families who are planning for the future of a family member who has a disability;
- ❖ Maintaining and providing up-to-date information on wills, trusts, government benefits, and financial and estate planning; as well as providing names of appropriate professionals who can provide legal and financial advice;
- ❖ Educating and providing information to legal, financial and estate planning professionals about the unique challenges facing individuals who have a disability and their families;
- ❖ Encouraging individuals and families to develop networks of support.



### First things First...overview

In days gone by, individuals who had a disability were looked after by the nuclear family. They were cared for by various members of their family and sheltered from the community at large. That is no longer the case – families now come in many shapes and sizes and are often spread across the country rather than being in one community. Some parents believe that their other children will assume the responsibility for their child who has a disability. In some cases that may be a viable alternative. Parents need to be very clear with their other children as to what tasks will be necessary to look after their sibling. Another question raised would be whether or not this is something that the individual who has a disability wants. And how will this affect their relationship – being a caregiver vs. a sibling?

Many parents believe that the Government will look after their child who has a disability when they become an adult and leave the education system. In reality there are limited resources available and in many instances, long waiting lists. Parents may also assume that once they are supported by a social service agency their child who has a disability will be cared for when they become an adult, or need a place to live. That is simply not the case, and in times when government funding is so uncertain, parents must take the lead in future planning for their child who has a disability.

Now parents can look forward to having their child who has a disability live as independently as possible in their own home (be it an apartment, townhouse etc.), have meaningful day time activities (be it work, volunteer, education or

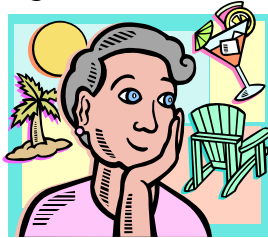
recreational activities) and a supportive group of people around them. How? ... by careful and thorough planning.

#### Things to think about:

- ✓ Register your son or daughter with a community service agency for - residential, programs, support, recreational activities
- ✓ What activities/work experiences have you and/or your child considered?
- ✓ How can you prepare your child for the future?
- ✓ What can you do now to help prepare your child for the future?
- ✓ Where will your child live - at home, supported outside of the home?
- ✓ Inform involved parties of what you have put in place - i.e. support agency, other family, lawyer, etc. Contact your case manager so that he/she is aware of what you have in place and can communicate that for you
- ✓ Support network around your child - a formal support network or will family members represent your child?
- ✓ Wills in place - thorough estate planning so as not to jeopardize your child's ODSP



Often we as parents forget the importance of dreaming for our child, simply because we know the day to day challenges they face. But each child also has unique gifts to share. As with any other child, our children who have a disability have dreams, aspirations; and goals that they strive to reach.



By all means dream!

## Wills and Financial Plans

In Ontario when teenagers who have a disability turn 18, they become eligible for the Ontario Disability Support Program – otherwise called ODSP. ODSP provides the individual who has a disability with a monthly pension of approximately \$730 if the individual is living at home or \$957 if the individual is living outside of the home. ODSP also provides extended health coverage which includes a basic dental plan and a drug card. This extended coverage can be very beneficial to individuals who have a disability, particularly if the person has additional medical needs. The amounts are increased if the individual receiving ODSP is married and has children. The individual will receive ODSP until they turn 65 at which time they will receive old age security benefits rather than ODSP.

The Government will look at the individual's assets before determining whether or not they are eligible for ODSP benefits. An individual receiving ODSP cannot have more than (at time of writing) \$5,000 in "liquid assets" or receive more than \$5,000 during any twelve month period (vs. a calendar year). That figure is subject to change. If your child has RRSPs then they are considered liquid assets as they are easily cashed. The same applies to Canada Savings Bonds.

There are asset rules that do not affect ODSP entitlement such as a principal residence, and a motor vehicle. Certain funds such as a Henson Trust, funds used

to purchase approved disability related items and services, and a trust fund created or derived from an inheritance and/or 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 in this category are also exempt. Please note that this list is not complete.

When parents are planning their estate, the main point to take in consideration is whether or not their child will be receiving ODSP benefits. If yes, then they will want to take precautions to protect their child's ODSP if they receive an inheritance. If no, then their estate may not require an Absolute Discretionary Trust. However, parents may wish to set up some sort of trust fund just to protect the money and the individual it is intended for.

Parents are legally obligated to provide adequately for dependant children in their estate. Many parents think they can leave money to their other children on behalf of the child who has a disability. What happens if after the inheritance has been distributed, the sibling dies? Or divorces? Or goes bankrupt? How will the interests of the child who has a disability be preserved?

Another important aspect to consider when planning an estate for a child who has a disability, is the amount to leave. More than likely, they will need more money to live than their siblings. They may not be able to provide for themselves as well and they may have more expenses - it may take more money to have them live in their own home, etc.

### Absolute Discretionary Trust (Henson Trust)

Parents should also consider how the money will be left to the child who has a disability. A large part of this decision can be made in discussions with the parents' lawyer and other family members. An Absolute Discretionary Trust allows for parents to leave an inheritance for their child who has a disability without affecting the ODSP payments the child also receives. The trust has to be set up very carefully and with specific wording. There is no limit to the amount of money that can be placed in an Absolute Discretionary Trust. Another name for this Trust is the Henson Trust, named after Leonard Henson. He left his assets to his daughter, who had a disability, by establishing a discretionary trust and naming her the preferred beneficiary of the trust. After being disqualified from ODSP because

of the inheritance, the family lawyer took the case to court. It was dismissed in favour of Audrey Henson, ruling that the money would not vest in Audrey as she would only received money at the “unfettered discretion” of the Trustee. This ruling has never been overturned.

If parents choose an Absolute Discretionary Trust fund, then who will be the Trustee? The Trustee wields tremendous power in the case of an Absolute Discretionary Trust. The Trustee determines what funds the individual who has a disability will be allowed. Parents may want to have two or three people act as Trustee. That way there will be checks and balances. Or, parents may decide a family member and professional Trust manager may be the best option for them. Do keep in mind, however, that Trust companies will manage large estates. Their company policies may not allow for them to manage smaller estates. Again, parents need to research what trust options are available to them.

### Choosing a Lawyer

Then there is the question of choosing a lawyer who is knowledgeable in the area of Trust funds, and in particular Absolute Discretionary Trust Funds. Parents must make an informed choice when it comes to selecting a lawyer to set this up. Parents will have to research, talk to other parents and ask questions before choosing the lawyer who best suits their needs. Take some time to speak with other parents to see if they have begun the future planning process. Have they contacted a lawyer? Would they recommend the lawyer they contacted? Do they know of a lawyer who has specialized in preparing these specialized wills?

**Hint: Support & Trustee Advisory Services hosts professional luncheons and maintains a resource list of lawyers and financial planners who have attended one of these luncheons. As well, Support & Trustee Advisory Services can provide you with a list of resources and questions to consider when hiring a lawyer or financial planner.**

There will be expenses in setting up a will. Parents with children who have a disability have more complicated bequests/requirements of an estate than others. A will kit may not be the solution. And because the estate is more complicated – it is likely to cost more than others.

## Choosing a Financial Planner

A financial planner may be another resource that is useful to parents who are planning for their child who has a disability. Again, parents have to ask questions and check to ensure that they have selected the best type of planner for their needs. A financial planner may be able to assist in estimating what the cost of supporting a child who has a disability may be.

**Hint: There are a growing number of businesses who will help you with the planning and be responsible for the maintenance of the plan for a fee. That may work for some people, but do remember that it is not the best for everyone.**

Parents will need to know what questions to ask the professional they have decided to work with, and have given some thought to what their goals are, what will happen to their estate, and other such general questions. The lawyer will ask detailed questions, and probably raise a few issues parents hadn't yet considered. The financial planner will also need to know the family's financial status so that he can best advise parents.

### Check List:

1. Have I talked with my children about looking after their brother/sister when we (parents) are gone?
2. Is my child receiving ODSP?
3. Have I researched about a "Henson Trust"?
4. Have I chosen a trustee?
5. Have I researched for a lawyer?
6. Is the lawyer knowledgeable about ODSP and the Henson Trust?
7. Have I registered with a social service agency?



If I have answered yes to all then I am ready for  
the next step!

PARENT #1 \_\_\_\_\_

WHAT I OWN:

- house value \_\_\_\_\_
- condo value \_\_\_\_\_
- recreational property value \_\_\_\_\_
- car value \_\_\_\_\_
- boat value \_\_\_\_\_
- artwork/jewellery/valuables value \_\_\_\_\_
- cash value \_\_\_\_\_
- RRSP/RRIF value \_\_\_\_\_
- Investments value \_\_\_\_\_
- Insurance Policy face value \_\_\_\_\_ cash value \_\_\_\_\_
- pension benefits value \_\_\_\_\_
- Other \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_

TOTAL OF WHAT I OWN: value \_\_\_\_\_

IS THERE ANYTHING I OWN I WANT TO KEEP IN THAT FORM FOR MY SPOUSE/BENEFICIARIES? \_\_\_\_\_

WHAT I OWE:

- mortgage value \_\_\_\_\_
- loans (bank and personal) value \_\_\_\_\_
- credit cards value \_\_\_\_\_
- line of credit value \_\_\_\_\_
- car value \_\_\_\_\_
- Other \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_

TOTAL OF WHAT I OWE: value \_\_\_\_\_

VALUE OF WHAT I OWN: \_\_\_\_\_

VALUE OF WHAT I OWE: - \_\_\_\_\_

Difference #1 = \_\_\_\_\_

Fact Sheet#1 B: REVIEW OF ASSETS

PARENT #2 \_\_\_\_\_

WHAT I OWN:

- house value \_\_\_\_\_
- condo value \_\_\_\_\_
- recreational property value \_\_\_\_\_
- car value \_\_\_\_\_
- boat value \_\_\_\_\_
- artwork/jewellery/valuables value \_\_\_\_\_
- cash value \_\_\_\_\_
- RRSP/RRIF value \_\_\_\_\_
- Investments value \_\_\_\_\_
- Insurance Policy face value \_\_\_\_\_ cash value \_\_\_\_\_
- pension benefits value \_\_\_\_\_
- Other \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_

TOTAL OF WHAT I OWN: value \_\_\_\_\_

IS THERE ANYTHING I OWN I WANT TO KEEP IN THAT FORM FOR MY SPOUSE/BENEFICIARIES? \_\_\_\_\_

WHAT I OWE:

- mortgage value \_\_\_\_\_
- loans (bank and personal) value \_\_\_\_\_
- credit cards value \_\_\_\_\_
- line of credit value \_\_\_\_\_
- car value \_\_\_\_\_
- Other \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_
- \_\_\_\_\_ value \_\_\_\_\_

TOTAL OF WHAT I OWE: value \_\_\_\_\_

VALUE OF WHAT I OWN: \_\_\_\_\_

VALUE OF WHAT I OWE: - \_\_\_\_\_

Difference #2 = \_\_\_\_\_

Recap:           Difference parent #1 \_\_\_\_\_  
                  Difference parent #2 \_\_\_\_\_  
                  Sum of differences \_\_\_\_\_

Any objects, items to be left in current form rather than converted to  
cash: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Fact Sheet #2 SOME DECISIONS RE: EXECUTOR/GUARDIAN

My spouse will be the executor  Yes  No

Proposed executor(s) if not spouse or if co-executor with spouse:

1. Full Name: \_\_\_\_\_  
Address: \_\_\_\_\_

2. Full Name: \_\_\_\_\_  
Address: \_\_\_\_\_

Proposed back up executor(s):

1. Full Name: \_\_\_\_\_  
Address: \_\_\_\_\_

2. Full Name: \_\_\_\_\_  
Address: \_\_\_\_\_

Proposed Guardian of children under 18 years old:

1. Full Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Relationship to you: \_\_\_\_\_

2. Full Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Relationship to you: \_\_\_\_\_

Fact sheet#3 SOME DECISIONS ABOUT DIVISION OF ESTATE:

- 1. What I will do with the house: \_\_\_\_\_  
If my spouse survives: \_\_\_\_\_  
If my spouse does not survive: \_\_\_\_\_
- 2. What I will do with the recreational property: \_\_\_\_\_  
If my spouse survives: \_\_\_\_\_  
If my spouse does not survive: \_\_\_\_\_
- 3. What I will do with the car/boat: \_\_\_\_\_  
If my spouse survives: \_\_\_\_\_  
If my spouse does not survive: \_\_\_\_\_
- 4. What I will do with investments : \_\_\_\_\_  
If my spouse survives: \_\_\_\_\_  
If my spouse does not survive: \_\_\_\_\_
- 5. What I will do with RRSPs/RRIFs: \_\_\_\_\_  
If my spouse survives: \_\_\_\_\_  
If my spouse does not survive: \_\_\_\_\_

GENERAL

- 1. Who does my son or daughter trust? \_\_\_\_\_  
\_\_\_\_\_
- He/she can be reached at: \_\_\_\_\_  
\_\_\_\_\_
- 2. Who would I trust to assist my child with decision making? \_\_\_\_\_  
\_\_\_\_\_
- He/she can be reached at: \_\_\_\_\_  
\_\_\_\_\_
- 3. Who understands my child's communication style? \_\_\_\_\_  
\_\_\_\_\_
- He/she can be reached at: \_\_\_\_\_  
\_\_\_\_\_

Fact sheet # 4: FINANCIAL DECISIONS

1. My son/daughter's trustees are: \_\_\_\_\_  
He/she may be contacted at: \_\_\_\_\_

2. His/her financial advisors are: \_\_\_\_\_  
He/she may be contacted at: \_\_\_\_\_

3. My son/daughter has a bank account at: \_\_\_\_\_

Account number: \_\_\_\_\_

4. Signing authority includes: \_\_\_\_\_

5. Withdrawals from that bank account are protected by:

◊ joint signature for withdrawals	YES <input type="checkbox"/>	NO <input type="checkbox"/>
◊ my son/daughter is well known to bank employees	YES <input type="checkbox"/>	NO <input type="checkbox"/>
◊ funds in the account are kept to a minimum	YES <input type="checkbox"/>	NO <input type="checkbox"/>

6. I have asked \_\_\_\_\_ to monitor the trust services and investment advice available to my relative.  
He/she can be reached at: \_\_\_\_\_

7. YES  NO  I have set up a living (inter vivos) trust.

8. YES  NO  I have set up a discretionary trust in my will.

9. YES  NO  My son/daughter has a bank account.



Fact sheet # 5: MEDICAL DECISIONS

1. My son/daughter has the following medical condition/diagnosis:

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2. My son/daughter takes the following medication/s:

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3. Who is my son/daughter's doctor?

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He/she can be reached at: \_\_\_\_\_

4. What assistance would my son/daughter need to make medical decisions?

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5. Who would my son/daughter and I want to assist with their medical decision making?

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He/she can be reached at: \_\_\_\_\_

6. What aspect of their medical care do I think my son/daughter might understand? \_\_\_\_\_

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7. What formal arrangements do I need to make to ensure medical care is easily available to my son/daughter? \_\_\_\_\_

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8. My son/daughter's medical plan number is: \_\_\_\_\_

Company: \_\_\_\_\_

Contact information: \_\_\_\_\_

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9. Who is my son/daughter's dentist? \_\_\_\_\_

He/she can be reached at: \_\_\_\_\_

10. Are there other medical people/ or specialists involved in my son/daughter's life?

Name, contact information and specialty:

1. \_\_\_\_\_

\_\_\_\_\_

2. \_\_\_\_\_

\_\_\_\_\_

3. \_\_\_\_\_

\_\_\_\_\_

4. \_\_\_\_\_

\_\_\_\_\_

5. \_\_\_\_\_

\_\_\_\_\_

#### PERSONAL CARE DECISIONS

1. My son/daughter's advocate is: \_\_\_\_\_

His/her name is: \_\_\_\_\_

He/she can be reached: \_\_\_\_\_

\_\_\_\_\_

2. The independent agency that monitors services is: \_\_\_\_\_

Contact information: \_\_\_\_\_

\_\_\_\_\_

## Day Options:



Parents must expect the best for their children and by the same token, plan for the worst. Working within the existing system is the key, and communicating parents' needs and plans is the way to ensure that their careful planning comes to fruition.

*Remember these key words:*

**dream for your child,  
work with the system,  
plan thoroughly, and  
communicate your needs.**

Parents can look at what they picture their child doing once they graduate from high school. Parents can ask what their child pictures for him/herself. Likely this has not been a major source of conversation between most families with children who have a disability because they are busy enough each day with daily life. However, parents must think about this at some point – and once they have given it some thought, set about planning how to realize that goal.



Parents can ask how much support they currently have/provide for their child through SSAH (Special Services at Home) funding or other sources. Does he/she need someone to check up on them, help them with banking or make sure that they are looking after themselves or do they require more complete support with activities of daily living or physical support etc.

Will the child want to work or pursue volunteer or recreational activities? Has the child volunteered already? What support would be required to make this a smooth transition? Is the child interested in taking courses? Does he/she have any hobbies they could develop into a business? After thinking this through and discussing with the child, parents can look at what skills they can help their child develop in order to pursue his/her dreams.

There are day programs available; however they again have lengthy waiting lists; and they may not suit every individual. Individuals who have a disability are entitled to remain in the school system until the age of 21. After 18, there may be a school to work transition program, which also may help with placement for day options. At the age of 21 however, the student is finished at school. Again, the onus is on the parents to make arrangements to fill their child's day meaningfully.

Fact sheet #6: **SOME QUALITY OF LIFE DECISIONS:**

1. What does your son/daughter like to do? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

2. What strengths does your son/daughter have? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

3. How independent is your son/daughter? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

4. What skills does your son/daughter have? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

5. Has your son/daughter expressed any interest in:

Working? \_\_\_\_\_

Further education? \_\_\_\_\_

Recreational pursuits? \_\_\_\_\_

Hobbies? \_\_\_\_\_

6. What would your son/daughter say their goals or passions are? (work, interests, etc.)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. What skills does your son/daughter need to develop to be able to meet his/her goals?

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8. What can you begin to do now to help your son/daughter reach these goals?

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9. What agency/service can you link up with to help meet these goals?

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10. Short term goals: (6 months)

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11. Mid term goals: (5 years)

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12. Long terms goals: (15- 20 years)

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13. Will your son/daughter want to travel?

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OTHER THOUGHTS:

1. What do you worry the most about for your son/daughter who has a disability?

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2. After your death, what do you want your surviving family members to do on your behalf?

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3. What are the two main priorities that you want future caregivers to keep in mind about your son/daughter?

1. 

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2. 

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4. Your son/daughter's week:

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

5.

<b>Things to Figure Out</b>	<b>What are the things that you are still trying to "figure out?" What don't you understand or where do you need more information? What are the things that are getting in the way?</b>
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6. These dates are important to your son/daughter and why:

January \_\_\_\_\_

February \_\_\_\_\_

March \_\_\_\_\_

April \_\_\_\_\_

May \_\_\_\_\_

June \_\_\_\_\_

July \_\_\_\_\_

August \_\_\_\_\_

September \_\_\_\_\_

October \_\_\_\_\_

November \_\_\_\_\_

December \_\_\_\_\_

Your son/daughter's birthday is: \_\_\_\_\_

Your son/daughter's favourite holidays are: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

## Living Arrangements:

One transition parents will need to look at is where their child will live. Currently, a child who has a disability can receive Special Services at Home (SSAH) funding. Parents will find this a very useful program to participate in as SSAH allows families to hire a worker to help support their child who has a disability. It is not charity; rather it provides the opportunity to enrich the child's life. SSAH legislation has recently been changed to allow individuals to continue receiving funding after they move out of their family homes, as long as they are not residing in a ministry-funded residential accommodation. Parents may be able to use the SSAH funding to help offset support costs for their child.

Recently the government has instituted a new program called "Passport" which provides funding for young adults who have graduated from school and who are seeking community participation supports. "Through Passport, participants" ... have the opportunity to be..." exposed to a wide range of experiences that focus on post school activities and the personal development each individual needs to achieve his/her goals for living as an adult in the community." (Passport Initiative memo, Ministry of Community and Social Services)

## Agency provided Residential Settings:

Residential funding is the way that individuals can receive support in the community (staff and support). Hence, planning becomes very important as does communicating the family's needs. Residential funding is what is available to support adults, or those not living at home. Residential funding is awarded from the Ministry of Community and Social Services, based on the provincial budget, to the 9 Regional Offices in Ontario. It is the Ministry which ultimately decides where the funding will go. Keep in mind that there are demands and waiting lists for services across the province - not just in Peel.

Peel is one of 5 regions served by the Central West Region. From the Central West Office, Peel residential funds are allocated to the Residential Service Management Committee (RSMC). This committee is made up of a number of service agencies, such as Community Living Mississauga and Brampton Caledon Community Living. Each of these agencies serves individuals who may be in need of residential support. This committee reviews and considers those people on the

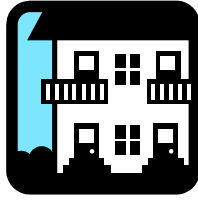
'Wait list'. Funds are then awarded to one of the 7 residential service providers in Peel. These providers offer residential services for people who have a disability and live in Peel. Each of these providers continues to be a contact point between the RSMC and the families they support. The service provider, and more specifically the case manager/service coordinator, is the contact person within the service system.

Families need to consider where they see the child who has a disability living out their adult life. Currently in Peel the "Wait List" for residential funding is very long and no one individual is guaranteed they will have ministry funding to support them. Individuals who have a disability are not guaranteed support or accommodation simply because they are now supported by a social service agency. Period.

### Private Residential Settings:

*Will the child remain in the family home? Will the child move out?* An individual on ODSP can own their own home. If this is an option for parents, then they also need to consider the home maintenance costs and the cost of supporting the child in the home. Residential dollars, if available, and if the child receives support, would allow for that. Otherwise the costs are up to parents. Could the child have roommates to help offset costs and maybe share support? Parents can be creative when designing their child's living arrangements. There is no one answer for all families and individuals. This gives parents greater freedom when determining their child's living arrangements.

How will moving out affect the child? The transition of no longer having parents involved in their lives to the same extent, on top of a move, may be stressful for the child. Will it be a smoother transition for the child to leave home before parents are no longer able to care for them? That way parents can see what their child's life will be like when they are no longer able to be involved. Some of the glitches will be worked through, and they can enjoy a typical parent-child relationship. As well, the child can be involved in the decision making – i.e. choosing the community, type of housing, decorating styles; which will serve to give the individual ownership of their 'home'.



Fact sheet #7: LIVING ARRANGEMENTS:

1. I expect that my son/daughter will live in: (house, apartment, group home etc.) \_\_\_\_\_

2. My son/daughter wants to live in (house, apartment) \_\_\_\_\_

3. Our family (including the family member who has a disability) have decided to: \_\_\_\_\_

4. I must do the following to acquire appropriate accommodations for my son/daughter: \_\_\_\_\_

5. My son/daughter has the following self help skills that will facilitate him/her living independently: \_\_\_\_\_

6. We need to work on the following skills to help our son/daughter become more independent: \_\_\_\_\_

7. These are friends (and phone numbers/contact information) we may contact to see if we can establish a shared living arrangement: \_\_\_\_\_

8. For example, this is what the cost would look like if I were to purchase a house for my son/daughter.

Financial Model					
	Pur Price	Down Paym't	Down Paym't	Mortgage	Mort Rate
<b>Assumptions:</b>	\$ 120,000	50%	\$ 60,000	\$ 60,000	6%
Purchase Price of Home is	\$ 120,000				
Total Purchase price is	\$ 120,000	including purchase price plus:			
\$1,200	Land Transfer Tax				
\$1,000	Legal Fees				
\$300	Miscellaneous disbursements				
50%	of purchase price	\$ 60,000	is contributed as a down payment		
Remainder	\$ 62,500	is carried as a first mortgage			
Mortgage rate is	6%	p.a., amortized over 25 years			
Mortgage payment is	\$400	per month			
Other housing expenses (monthly):					
	Property Taxes		\$0		
	Home Insurance		\$50		
	Condominium Fees		\$450		
<b>Total Monthly Costs:</b>			<b>\$900</b>		
<i>Sensitivities</i>					
Interest rate @ 6.5%: Monthly Mortgage payment is				\$402	
Interest rate @ 7.0%: Monthly Mortgage payment is				\$420	
<b>Additional Costs (per person):</b>					
	Food	\$185			
	Personal Needs	\$100			
	Repairs/Mtce	\$50			
	Miscellaneous	\$50			
	Telephone	\$15			
	<b>Total</b>	<b>\$400</b>			

Summary of Costs per Person		
	Tenant #1	Tenant #2
Housing Cost	450	450
Additional Costs	400	400
<b>Monthly Total</b>	<b>\$ 850</b>	<b>\$ 850</b>
Annual Total	\$ 10,200	\$ 10,200
Weekly Cost	\$ 196	\$ 196

Summary of Income & Expenses		
	Per Month	
ODSP from Tenant #1	\$ 930	
ODSP from Tenant #2	\$ 930	
Less Expenses:	\$ (1,700)	
Less Support Costs	(156)	13 Hours/month
		@\$12/hr
Equals Remainder	\$ 4	per month

Please note that there may be municipal taxes involved in many cases. This has not been factored into this example

9. What will the cost be to support my son/daughter per month?

Rent	_____
Mortgage:	_____
Taxes:	_____
Trustee:	_____
Food/supplies:	_____
Sundries:	_____
Support:	_____
Utilities:	_____
Other:	_____
_____	_____
_____	_____
_____	_____
_____	_____

Estimate monthly living costs: \_\_\_\_\_

10. **Current Monthly Income/revenue:**

ODSP (including work supplement):	
Funds from a Trust:	
Rental Income:	
Other:	
<b>Estimate monthly income:</b>	

Difference income vs. living costs: \_\_\_\_\_

Shortfall/surplus: \_\_\_\_\_

X \_\_\_\_\_ years (in months) expected to live: \_\_\_\_\_

enough through liquidity of assets

not enough – what should I do? \_\_\_\_\_

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11. Our Special Services at Home Funding application renewal comes in:

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12. Our Respite funding application comes in: \_\_\_\_\_

13. Any other funding? \_\_\_\_\_

When is the funding due: \_\_\_\_\_

14. Are there special instructions when applying for funding that will need to be included? \_\_\_\_\_

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15. Currently that funding goes to support in this manner:

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16. My son/daughter's current support workers are: (name and contact info)

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17. To hire a new worker, these are the places/people I have contacted in the past: \_\_\_\_\_

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## Circles of Support:

Planning for an individual is multi-faceted. In this workbook, we have looked at a few key areas; however it is not a complete picture of the individual by any means. There are many resources available to assist parents with this process offering different points of view and presenting different questions for consideration. Tools like MAPS, PATH or Essential Lifestyle Planning are all ways of looking at person centered planning.

While it may seem overwhelming, parents don't have to plan alone. A circle or network of support is a viable option for many parents. Parents may be familiar with other terms such as networks or circle of friends. The network/circle is made up of a group of people who volunteer to have an ongoing role in the child's life. The set up and functioning of such a group can be designed to suit each family's individual situation. They can be very effective, and provide the individual at the centre with a "family" per se. They may be able to assist with any or all aspects of planning, depending on what the individual and his/her family is comfortable sharing. Families may embark on the planning process themselves and then involve the circle; there are no set rules in how families decide to proceed. It is based entirely on the comfort level of the family and individual.

A "microboard" is a circle of support that is established as a non profit agency, so there is a more formal arrangement required to start up something like this. In this arrangement, a small Board of Directors is established and the individual works with the Board in making decisions.

Networks of support require some planning and organization as well. While they will support the individual, it may not be to the extent that "staff" provided by residential funding would. However, circles don't happen by magic. They also require facilitation and commitment from members of the circle. In many cases, the circle of support becomes or develops into a circle of friends who support the individual at the centre. Circles will be more successful if driven by the family or family member at the centre of the circle.

The governance of a circle depends on the circle. Some circles are informal, pot-luck get-togethers. Some circles may opt for a more formal board, with a

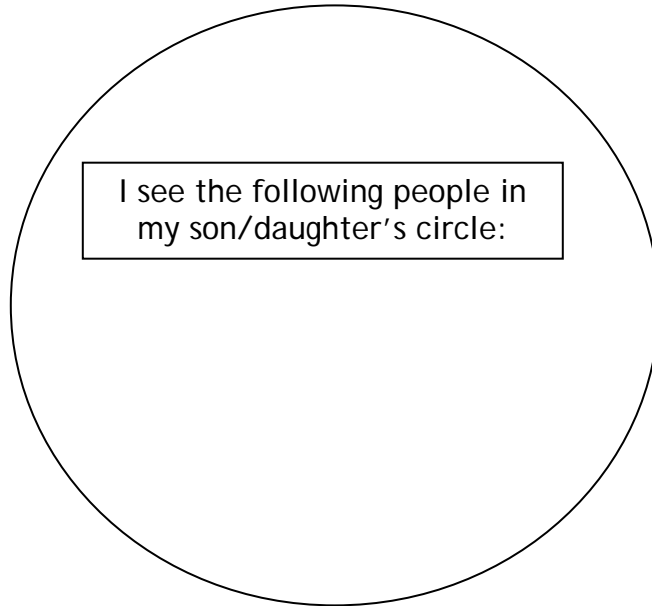
newsletter to keep members informed. Having a skilled facilitator to work with the individual and circle members will be very beneficial. The Facilitator will take time to get to know the individual at the centre of the circle and then strive to ensure that his/her needs, wishes and dreams are realized in the planning process.

The size of a circle can vary as well, however parents should keep in mind that if the circle is too large it may become unwieldy. Parents may decide to start by participating in the circle and then gradually withdrawing their active participation. That way they can assess the effectiveness of the circle, and the individual at the centre of the circle can become accustomed to participating on their own.

Person centered, or person directed planning is a philosophy that encompasses the whole life of the individual. It looks at where the individual is now, wishes, dreams hopes, and aspirations and incorporates this into a plan. The plan should be directed by the individual at the centre of the circle. The goals may be small ones to start with or large ones divided into many steps. Each step of the process should be monitored and evaluated.

## Fact sheet #8 THE CIRCLE OF SUPPORT

1. Who belongs in your son/daughter's circle? Who would your son/daughter like to have involved in their circle?



I see the following people in my son/daughter's circle:

Siblings? Extended family members? Cousins? And parents of your son/daughter's friends that you can work with (they sit in your circle, you sit in theirs)? Any friends? Church members? Club members? Any contacts from your son/daughter's activities? Are you involved with any clubs or associations where you know of people who may want to be involved? Any current support staff that you have a close relationship with?

2. I have contacted the following people to see if they will join in my son/daughter's circle:

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## Conclusions:

The individual plan you have made for your son/daughter will be the guide in determining what your son/daughter's needs will be. This plan will vary from family to family and involves a number of factors such as cultural beliefs, financial situation and familial involvement. The plan expresses the vision that parents have for their children and that the children have for themselves. It explains the support network around the individual as well as any other pertinent information about the individual themselves. It is a work in progress- it will be refined and redeveloped as the parent's and child's life unfolds.

Parents should notify the service agency they are involved with and communicate their plan, contact information and any other pertinent information so that the service agency can hold that information. Remember, although the child may not receive direct staff support, it is to the child's benefit to have an agency know what the plan and what the wishes of the family and individual are if needed.

Future planning is really an uplifting process. Future planning allows parents with children who have a disability to plan with their family for the best future possible for the child who has a disability. Parents want the best for all of their children. Future planning allows parents with children who have a disability to bring their dreams to reality. Future planning gives parents with children who have a disability a glimpse of the future life of their child. Future planning will give parents peace of mind.



*"The purpose of life is a life of purpose." (Robert Byrne)*

**RESOURCES:** These resources are for information purposes only. This is not a recommendation or endorsement for any of the resources found here.

ELP Learning Community – Families Working Together – Starting work on an essential life plan; Smull Bourne Allen, 2004; [www.elp.net](http://www.elp.net)

Worksheet for costing out expenses of the person with the disability;  
[www.nichcy.org/pubs/outprint/nd18txt.htm](http://www.nichcy.org/pubs/outprint/nd18txt.htm)

[www.individualizedfunding.ca](http://www.individualizedfunding.ca) – provides a person centred planning workbook

[www.pdd.org/central](http://www.pdd.org/central) – provides a person centred planning workbook and guidebook

Minnesota Governor's planning council on developmental disabilities

[www.mnddc.org](http://www.mnddc.org)

1. Making Futures Happen
2. It's My Choice
3. It's Never too Early...It's Never too Late

A Future Planning Workbook – Lifetime Networks Ottawa, 2003

Connections – A Planning Guide for Parents of Sons and Daughters with a Mental Handicap:  
Kenneth Pike, Pauline F. Steinmann; Ontario edition

Enablelink - [www.enablelink.org](http://www.enablelink.org) provides links to many types of resources for individuals who have a disability or their families.

From Dreams to Action – Making it Happen, Community Living Mississauga, 1997

Inclusion Press - [www.inclusion.com](http://www.inclusion.com) has many books, videos etc. available for sale that talk about person centred planning, inclusion; as well as numerous other resources, or links, for people to find resources.

Life Trust – an organization that assists parents with planning for their child's future; also offers parents the opportunity to purchase life insurance as a way of leaving their child who has a disability an inheritance; fee for service and publications for sale; contact via [www.life-trust.com](http://www.life-trust.com); or by Life Trust, 60 Harrison Drive, Newmarket, Ontario Canada L3Y 4P4 (Canada & USA); call Toll Free 1-800-638-7256

Ontario Federation of Cerebral Palsy - [www.ofcp.on.ca](http://www.ofcp.on.ca) under **publications** makes a disc available for sale entitled "Removing the Mystery" which deals with future planning. A "Removing the Mystery" workbook can also be purchased.

Plan - A B.C. organization that focuses on developing networks of support around individuals who have a disability; contact them at [www.plan.ca](http://www.plan.ca); or by writing to: PLAN, Suite 260-3665 Kingsway, Vancouver, BC V5R 5W2; Telephone: (604) 439-9566

Special Needs Planning Group - offers future planning assistance for parents as well as the opportunity to purchase a specialized life insurance policy in order to leave an inheritance for the child who has a disability; contact via [www.specialneedsplanning.ca](http://www.specialneedsplanning.ca) ;The "Special Needs" Planning Group, 70 Ivy Crescent, Stouffville, Ontario L4A 5A9 Phone (905) 640-8285

Support & Trustee Advisory Services - an organization whose mandate is to inform parents about the options available to them in terms of future planning; non partisan; does have a trust arrangement with Royal Trust; contact Support & Trustee Advisory Services, 6695 Millcreek Drive, Unit # 1, Mississauga, Ontario L5N 5R8; in Mississauga: 905-542-2694 ext. 2312; in Brampton: 905-453-8841 ext. 548; [www.supportandtrusteeadvisoryservices.ca](http://www.supportandtrusteeadvisoryservices.ca)



There are many more resources available than those listed here. Feel free to share any interesting resources you find with other families who may be planning for their child's future as well.

Additional resources I have found:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_

The information in this workbook has been compiled from researching many of the valuable resources available in print and from the internet. It is not STAS's intention to copy material from any source without permission; however some wording may inadvertently be similar.

Name	Organization/address	Phone number/email
	<b>Community Living Mississauga</b>	<b>905-542-2694</b>
<b>Can help us with:</b>		

Name	Organization/address	Phone number/email
	<b>Brampton Caledon Community Living</b>	<b>905-453-8841</b>
<b>Can help us with:</b>		

Name	Organization/address	Phone number/email
	<b>Support &amp; Trustee Advisory Services</b>	<b>905-542-2694 905-453-8841</b>
<b>Can help us with:</b>		

Name	Organization/address	Phone number/email
<b>ODSP info</b>	<b>Ministry of Community &amp; Social Services</b>	
<b>Can help us with:</b>		

Name	Organization/address	Phone number/email
<b>Can help us with:</b>		

Name	Organization/address	Phone number/email
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