

A Time of Change

**An Information Guide for Senior Parents
Supporting an Adult Son or Daughter with a Disability**

December 2008



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Diversity Includes.

**New Brunswick
Association for
Community Living**

**Association du
Nouveau-Brunswick
pour l'intégration
communautaire**

On se ressemble.

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NBACL is a non-profit organization which works on behalf of children and adults with an intellectual disability and their families. NBACL was formed in 1957 and has 16 local branches throughout the province of New Brunswick.

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Introduction

People with disabilities are living longer lives today than at any other time in history. It has been noted that for the first time in history, people with disabilities are generally expected to outlive their parents. In the next decade, close to six million families in North America will be caring for and supporting their aging relatives with a disability.

These trends indicate that people with disabilities tend to live with their families well into adulthood and even into their fifties. Many families are now asking: “How can I continue to support my son or daughter as I get older?” and “What will happen with my family member with a disability when I die or can no longer support them?” As these families grow older (often with their adult children living in the family home), they realize that there is an urgent need to take action to ensure that their adult children have positive and secure futures.

This guide addresses the need for information and guidance required by senior parents who are supporting an adult son or daughter with a disability at home. It is divided into six main parts:

- Getting the help you need while your son or daughter is still at home
- Planning for emergencies
- Planning for the future: financial and estate planning
- Planning for a future home and support for your son or daughter
- Involving your community
- Dealing with life transitions

This guide also provides information on where senior parents can get additional information and assistance in dealing with the issues that they are facing.

These issues have been identified by senior parents who are part of a group called the Seniors United Network (SUN) based in Fredericton. These parents, along with the New Brunswick Association for Community Living, would like all senior parents to find the help and guidance they need to ensure that they and their adult children can live happy and productive lives in this time of change and transition.

Part 1 – Getting the Help You Need While Your Son or Daughter is Living at Home

As senior parents, you may need some help in meeting your responsibilities toward your son or daughter with a disability. This may relate to many things including:

- Looking after the personal or physical needs of your son or daughter (such as bathing, dressing, etc.)
- Having a break from your financial responsibilities as a parent
- Modifying or adapting your home make sure that it is physically accessible
- Looking after your own personal or physical needs or those of your spouse
- Meeting your financial responsibilities.

Every family situation will be different and will present different challenges. Sometimes the health or age of parents may be an issue as people may be dealing with their own declining abilities. Some families are single parent families. Some may have other people (such as other children) who are readily available to help out, while others may have limited opportunities to call on extended family or friends. Your son or daughter with a disability may be quite independent or may require significant support in his or her day to day life. Remember, you can *ask for help before you have reached a crisis*. In fact, getting help sooner will help to avoid a crisis.

Before we review government and community programs, it is worth remembering that family and friends – our ‘natural’ support networks – are often important sources of help in many ways. They can provide parents with a break from their responsibilities, provide support to your son or daughter in other ways, and offer to help plan for the future. In part 5 of this guide, we review ways of involving family, friends, and other people in your community.

Accessing Help through Government Support Programs

The Government of New Brunswick provides financial assistance to people with disabilities and to seniors who may require additional support and paid services to live in their home or community. For adults with disabilities under age 65, the government is introducing a new *Disability Support Program* that will be effective throughout the province by 2010. In the meantime, areas that are not yet under the Disability Support Program will still have access to services through the *Long Term Care Program*. This is the same program that provides funding for services in the home to seniors who need assistance with some of their activities of daily living.

How is a Person Considered Eligible to Receive Government Funding Under These Programs?

There are two aspects to determining a person's eligibility to receive government funding for services:

- A person must demonstrate sufficient need for supports and services. This need is related to a person's ability to do regular activities of daily living, make decisions, and to look after him or herself.
- A person must also demonstrate that he or she has a financial need for government assistance. A person who applies for government funded supports and services must go through a financial assessment process that looks at his or her *net income*. For adults with disabilities who live with their parents, government will only look at the adult child's own income to determine if he or she is eligible for government funding for services (the family's income is not considered).

What Types of Support or Services Are Available?

There are a variety of types of services that may be available through these government programs. Personal care supports may include help with dressing, bathing, grooming and toileting. Home supports may include help with activities such as cleaning, laundry, meal preparation and other household tasks. Disability supports also include assistance with transportation and for involvement in the community. Respite or relief may also be available.

What are Respite or Relief Services?

These are services that provide parents with a break from their responsibilities as 'caregivers' for a family member with a disability. Generally, government provides funding so that families are able to pay another person or organization to look after and support their son or daughter for a day, week-end or longer period.

If My Son or Daughter Is Eligible to Receive Government Funding for Services in the Home or Community, How Can I find People to Provide These Services?

There are a couple of ways to find people to provide services for your son or daughter with a disability.

- **Using a Community Service Agency.** In many communities, there are a number of service agencies that hire 'support workers' to provide services that may be required. These agencies look after the scheduling and paying of support workers. Government will pay the agency directly to provide services to your son or daughter.
- **Hiring People Privately.** You can also hire support workers privately. This usually requires paying the worker and then submitting receipts to get reimbursed by government. This allows you to hire the people you want to support you son or daughter, but it means that you have to pay the worker, keep records, and sometimes make regular payments to the federal government for tax and other contributions as an employer.

Hiring privately allows you to hire people you know to provide support. There are, however, some restrictions on the hiring of relatives (such as parents and brothers and sisters). When it is very difficult to find support workers for your son or daughter (such as in rural areas), the provincial government can provide permission to hire close relatives.

Adapting Your Home to Make it Accessible

The Government of New Brunswick also offers programs that provide funding to make repairs or modifications to your home in order to make it more accessible. Below is a brief description of some of the programs. Eligibility to receive funding under these programs is based on a person's income.

- **Repair Program for Persons with Disabilities.** This program provides funding to do work to make accessibility changes to a home that will be occupied by someone with a disability. Changes or repairs can include ramps, chairlifts, wheel-in showers and wider doors. Government can provide a grant (which does not have to be re-paid) or a repayable loan up to \$10,000.
- **Home Adaptations for Seniors Independence Program.** This program provides funding for people 65 years old and older to do minor adaptations such as providing non-slip surfaces, inserting hand-rails and relocating the laundry room. Government can provide up to \$3500 in the form of a "forgivable" loan (a loan that not have to be repaid).

For more information about these programs, contact the Housing Branch of the Government of New Brunswick in your area (check in the 'blue' pages of your telephone book under 'Province of New Brunswick' and then 'Housing Services' for the number to call).



Income Support Programs for People with Disabilities

Income support (also known as income assistance or social assistance) is a provincial government program that provides monthly income benefits to people who are in financial need. Financial need is determined by the amount of income and assets that a person has (or sometimes the income and assets of people who live together). If your son or daughter is eligible for income support benefits, these benefits may be reduced (up to 25% of the monthly cheque) while he or she is living at home with you. This will depend on your income as parents.

What is the Income Support Program for People with Disabilities?

The income support program for people with disabilities is called the *Extended Benefits Program*. This program is designed for people who are considered to be disabled, blind or deaf. A person's disability must be verified by a medical advisory board. A disability must be likely to continue indefinitely without substantial improvement and cause a person to be severely limited in his or her activities of daily living. Some people with disabilities do not qualify for this program, but can still qualify for income assistance under another program.

What Kind of Benefits are Available?

Based on a person's other sources and amounts of income and assets, he or she can receive a monthly income support cheque, a health card (to help pay for the cost of prescription drugs, basic dental and eye care, and other health needs), emergency benefits, and assistance with funeral expenses. People with disabilities who are eligible for the Extended Benefits Program are also entitled to a yearly "disability supplement" of \$1000 per year.

For more information about incomes support benefits, contact NBACL for a copy of the *Fact Sheet for Families: Income Support Benefits in New Brunswick*, or contact the income support branch of the government of New Brunswick (check in the 'blue' pages of your telephone book under 'Province of New Brunswick' and then 'Income Assistance' for the number to call).



Part 2: Planning for Emergencies

While your son or daughter is still living at home, it is important to have an emergency plan prepared in case you get sick, are hospitalized, or pass away unexpectedly. Developing an emergency plan can be done with the help of your family or close friends or a 'network of support' (see Part 5). An agency that is involved with your son or daughter may also help prepare this plan. Below is a checklist of questions you can consider for an emergency plan:

- Who is to be contacted in an emergency? Where are the contact numbers? Who will be responsible for contacting others?
- Where will your son or daughter stay if you cannot support them in an emergency (at home with other support, with family or friends, etc)? Are people aware of these plans? Is there a 'plan B' if your first choice not available?
- Does your son or daughter know what to do in an emergency (call 911, get help from a neighbour, etc.)?
- Do you have someone who checks in on you or who calls you on a regular basis?
- What important information needs to be shared about your son or daughter or about you (medications, health, allergies, name of doctors, name of lawyer, location of bank accounts, etc.)? Where will you keep this information and who will know about it?
- Is someone aware of the location of your important documents (Will, Power of Attorney, Medicare cards, birth certificate, pre-paid funeral agreement)?
- Who has a key to your home to enter in an emergency or to get necessities?
- Who will start your plan in the event of an emergency? Where will the plan be kept?
- Who will advocate for your son or daughter to protect his or her well being during an emergency and perhaps afterwards?



Part 3 - Planning for the Future: Financial and Estate Planning

Estate planning is an important aspect of family financial and future planning. Overall, financial planning is about reviewing your family's financial situation, determining your financial needs and goals, and deciding how you are going to achieve your goals. When you have a family member with a disability, financial planning tends to address the goal of providing for your family member today and in the future.

Estate planning is about deciding how you distribute your assets and provide for the people who you care about. There are a number of important things to consider when preparing an estate plan, especially if you are intending to support a loved one with a disability.

Estate Planning Considerations and Options

You have several options for deciding how and when to distribute your assets:

- The most commonly known option is through a Will. A Will distributes your assets only upon your death and has no impact on your estate until you die. Spouses should each have their own Will.
- You can also distribute assets at the time of your death but outside of your Will. This happens when you own assets jointly with another person who has a "right of survivorship". This can include assets such as a home, other real property, or a bank account. Upon your death, the other person who has the "right of survivorship" will automatically own the jointly owned asset. Your Will has no effect on the distribution of the asset.

Another way of distributing assets upon your death (but outside your Will) is through a beneficiary designation. This usually happens with assets such as RRSPs, RRIFs, insurance policies or pension plans. A person who is named as a beneficiary will be entitled to receive the asset upon your death.

You may need to think about the consequences (e.g., the effect on government benefits and the person's ability to manage money) of leaving assets directly to a family member with a disability using these estate planning options.

- A third estate planning option is the distribution of assets while you are still alive. This can be done by giving "gifts" of money or other property to others before your death. It can also involve establishing a trust for a loved one while you are still alive.
- Keep in mind that estate planning is a process rather than a one time event. You may use a combination of the options discussed above. You should also be prepared to review your estate plans regularly (for example, every 2 years) to determine if changes need to be made.

Additional Considerations when Planning for a Family Member with a Disability

When preparing an estate plan to provide for a family member with a disability, there may be some important issues to consider, including:

- How can an estate plan help to provide a good standard of living for a family member with a disability?
- Will your family member with a disability have opportunities to earn an income and to support him or herself?
- Will your family member be able to manage money or other property that he or she may inherit?
- Will your family member need to maintain his or her eligibility for government income benefits or other services? If so, how can your estate plan most effectively maintain and supplement these benefits and services?
- Will your family member need help with housing or maintaining a home?

Creating a Will

A Will is an important component of an estate plan. It is a legal document that only takes effect at the time of your death. You can make or change your Will up until the time you die so long as you are able to understand what assets you own and what you are doing with a Will (that is, signing a legal document to distribute your assets).

Remember, a Will deals only with estate assets that have not been distributed through other means. A Will allows you to appoint an executor who will look after your assets upon your death and to give directions to your executor on how those assets should be distributed.

Before you use the services of estate planners/lawyers there are a number of things you can do to be better prepared:

- **Prepare a list of your assets and liabilities.** For any family assets, you should record who owns them and how they are owned. Also, make a list of assets or insurance policies for which you have already selected beneficiaries. Your lawyer will need to know if you have named your family member with a disability as a beneficiary of assets (such as a RRSP or an insurance policy).
- **If possible, identify your executors and trustees.** You may wish to get some more advice on how best to select people for these roles and whether it makes sense to use financial institutions, family members or friends, or a combination of these possibilities.
- **Identify how you would like to distribute your estate assets.** There may be a lot involved with these decisions and you may need professional help to work out the details. You may want to give people (or charities) specific amounts of money or other property you own or decide who should get a share of your estate.

Creating a Financial Trust

A trust is a legal arrangement whereby a person gives assets (that he or she owns) to a trustee to manage and use for the benefit of another person or a group of people (known as “beneficiaries”). The trustees of a trust have strict legal responsibilities to hold and administer trust assets, to follow the terms of the trust and to act in the best interest of the beneficiary or beneficiaries. Trustees cannot use trust assets for their own purposes and must keep trust assets separate from their own assets.

There are a number of important decisions that must be made when establishing a trust as part of your estate plan.

- **When to establish the trust?** There are two basic types of trusts that differ on when they are established. A living trust is established while you are alive. To become effective, this type of trust requires creating a legal document and the transfer of assets to trustees. The benefit of this type of trust is that it sets aside assets for a beneficiary at an earlier time. It also will allow families to oversee the administration of the trust or even be a trustee of the trust. There are tax issues to be considered when setting up a living trust. Income earned within these types of trusts is taxed at the highest federal tax rate. There may be ways to limit the amount of tax that will have to be paid. When setting up this kind of trust, make sure you obtain good advice from an expert in tax issues (for example, an accountant or lawyer who specializes in tax law).

The second main type of trust is called a *testamentary trust*. This is a trust that is established through your Will and only takes effect upon your death. This means that you can change the terms of the trust while you are still alive. This type of trust also allows you to continue to use your assets while you are alive. Testamentary trusts are taxed in the same way as individuals. This means that tax rates will depend on the amount of income that the trust earns each year from investments. For most modest sized trusts, the lowest tax rate will be used.

- **Who will be the trustees?** Choosing a trustee or trustees is a very important estate planning decision. Your trustee will decide when and how to use the money or other property you have put in trust for the benefit of your family member. There are a variety of options for choosing trustees. You can rely on other family members or friends or you can appoint a financial institution to fulfill this role. You might have one trustee or two or more trustees. When you have two or more trustees (called co-trustees) they must usually decide jointly about how to manage and administer the trust properly. You can also appoint alternate trustees who will take the place of a trustee who may be unwilling or unable to continue to act as a trustee.

There are a number of important considerations when choosing trustees:

- Your trustee’s willingness and desire to take on this responsibility.
- The trustee’s relationship with your family member with a disability. Generally, the trustee should be someone who knows and cares about your family member.
- The trustee’s ability to manage and invest assets.
- The trustee’s knowledge and understanding of rules regarding government benefits and services (particularly if your trust is intended to supplement these sources of support).
- Your trustee’s age in relation to the age of your family member with a disability.

- **What assets will be put in trust?** Again, there are a variety of options that you can consider for establishing a trust. A trust can receive a specific sum of money, a share of your estate, proceeds from a life insurance policy, or real property such as a home. A living trust will usually be established with a specific sum of money or an identified asset. Testamentary trusts can be set up to receive a share of your estate or the proceeds of a life insurance policy.
- **What kind of trust will be created?** This issue requires careful consideration if you are planning for a family member with a disability. Make sure you get good legal advice before you decide on how to establish a financial trust. There are provincial rules that you may need to consider (for example, the provincial government now allows people with disabilities who receive income support benefits under the Extended Benefits Program to have up to \$200,000 in a financial trust, as well as some monthly income from the trust, without affecting their monthly cheque).

Generally, there are three kinds of trust options to consider:

- **An income trust.** This type of trust is designed to pay the beneficiary a regular income from a trust. This kind of trust can be a useful way to supplement the income of a family member with a disability. Depending on how much income is paid each month (or otherwise), an income trust may affect the amount of money the person can receive from government programs that provide income support benefits and disability related services.
- **A support trust.** In this type of trust, trustees are given some specific direction to use the trust to support and maintain the beneficiary. Trustees can be given some discretion about how the support should be provided and how much money is paid from a trust either monthly or more or less frequently.
- **An absolute discretionary trust.** An absolute discretionary trust (sometimes referred to as a “Henson” trust) is a trust that gives trustees full and complete discretion to decide if, when and how to use the trust for the beneficiary. Under this kind of trust, trustees have no specific obligations and cannot be forced to pay the income or capital to the beneficiary. A potential drawback of this type of trust is that the trustees may, in their discretion, decide not to use the trust for the beneficiary with a disability.
- **Who will receive trust assets following the death of the beneficiary?** In the event that the trust has assets remaining at the time of the beneficiary’s death, your estate plan must indicate who will receive trust assets. Normally, the trust will be terminated at this time and the assets will be distributed according to your wishes.



Registered Disability Savings Plans

The government of Canada has recently established a new savings plan for people with disabilities who are eligible for the federal Disability Tax Credit. Registered Disability Savings Plans (RDSPs) will provide opportunities for parents and others to make contributions and for people with disabilities to receive government grants and bonds.

For more information about estate planning, RDSPs, and government program rules contact NBACL for a copy of the information kit on *Estate Planning for Families who Have a Family Member with a Disability*.

Part 4 – Planning for a Future Home and Support for Your Son or Daughter

Planning for a future home for your son or daughter is one of the most important aspects of planning for the time that you, as parents, will not be the main support providers in your adult child's life. Over the years, your son or daughter has known the comfort and security that comes from living in your family home. The family home has provided a sense of belonging and security that your son or daughter will want in any future home that they may have.

Before reviewing some possible future home options, it is important to think more carefully about what home provides to all of us. For most of us, home is a place:

- Where people exercise control over their daily routines, including who enters to visit and stay;
- That is private and which matches each person's chosen lifestyle;
- Where people who share a home live in some kind of chosen and mutual relationship with each other;
- Where people have a connection to their communities;
- That provides some type of legal right to belong (for example, as a home owner or a tenant in a leased apartment).

When thinking about a future home for your son or daughter, try to keep these important points in mind. The other key point for your adult child is support and assistance that he or she may need to be able to live in his or her home. The type and amount of support will vary from person to person.

What are Some Possible Options for a Future Home?

There are a number of possible options to consider. Below is a brief description of these options. Later in this part, we explore in more detail the option of planning for your son or daughter to have a home of his or her own.

- **Living with Another Family Member.**

Some families will consider having your son or daughter with a disability move into the home of another family member (such as a brother or sister). This option can provide a home in a place that is usually familiar to your son or daughter. There are, however, a number of questions to consider before choosing this option:



- Is this where your son or daughter wants to live?
 - Is the other family member committed for the long term? Is there a backup plan if the living arrangement does not work out?
 - Is the location of the family member's home suitable? Is there space available for another person to live comfortably?
 - Will there be extra cost of family member? How will these costs be covered?
 - Will your son or daughter with a disability have opportunities to be involved in his or her community?
 - Will services be required (for example, relief support, support during the day, etc.)?
 - Is the family member, his or her spouse and children, fully aware of the wishes and needs of your son or daughter with a disability?
- **Living with an 'Alternate Family'**. Under this option, your son or daughter would go in live with another family. This option is part of a government program called an Alternate Family Living Arrangement (AFLA). The provincial government provides funding for alternate families provide a home and support to people with a disability. In these arrangements, an alternate family is not permitted to have more than two individuals with disabilities living in their home. This option can provide your son or daughter with a home environment as he or she would live in a typical home in a neighbourhood or community. The questions listed above for living with another family member are also relevant to this option.
 - **Living in a Residential Facility**. Residential facilities are government licensed buildings that provide housing and support to groups of people with disabilities who are usually unrelated. In New Brunswick, there are three main types of facilities for adults: group homes (or community residences) that are operated by non-profit organizations; special care homes that are for-profit operations, and nursing homes. These facilities are subject to rules that are established by the government of New Brunswick. The most widely used facilities are the for-profit special care homes. If you are considering a residential facility as an option, it is important that you (and your son or daughter with a disability) find out as much about the facility as possible. There are also a number of potential drawbacks of residential facilities that you need to consider, including:
 - The facility may not have the look and feel of a home or at least the kind of home that your son or daughter is used to.
 - Facilities can have six or more people living together with different personalities, wishes and needs. Also, people may be different ages (for example, some may be seniors while others are younger adults).

- The "rules" of the facility are usually set by the people that operate the facility. This may place some restrictions on your son or daughter's ability to make choices about his or her daily activities, and whom she or he wishes to spend time with.
- The facility may be in a neighbourhood or community that is not familiar to your son or daughter. Sometimes, people are "placed" in a facility in another community.

How Can My Son or Daughter Have His or Her Own Home?

The first three options noted above all involve your family member with a disability living in someone else's home or facility. Increasingly, adults with disabilities (and their families) are interested in exploring the possibility of establishing their own homes in the community. This could involve your son or daughter living in his or her own house, apartment, condominium, town-house or "granny suite."

This option provides more flexibility and opportunity to design a living arrangement that suits the wishes and needs of your adult child. Also, it allows for the strong possibility of creating a home that provides the kinds of things that we value in a home.

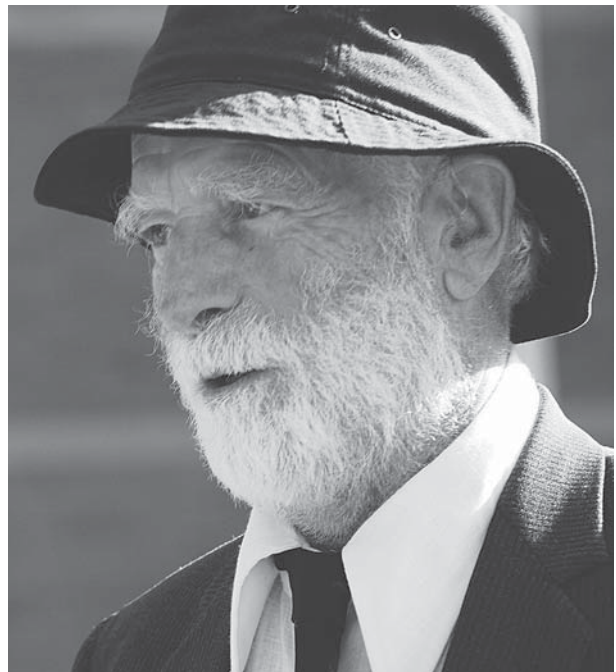
How Can We Make This Option Happen?

The own home option will likely require some detailed planning in order to develop the best possible living arrangement for your son or daughter. You will benefit greatly from some help in developing a good plan and then putting that plan into effect.

A "network of support" can provide this help. This is a small group of people who agree to support your son or daughter to achieve his or her goals. Members of a network can help in many ways. They can help find affordable housing, plan for and arrange the support your son or daughter will need in the home, manage money for housing and support services, and help monitor the living arrangement. For more information about networks of support, see Part 5 of this guide.

You may also get help from an agency in your area that helps people with disabilities live in their own homes. Unfortunately, not every area has an agency that provides this kind of service. NBACL is working to make this kind of help available in areas throughout New Brunswick.

You may also want to check out some living arrangements that have been developed for people to live in their own home with support. NBACL can put you in touch with other families or people who have already made this happen.



Planning for Affordable and Adequate Housing

One key part of your son or daughter having a home of his or her own is affordable and suitable housing. Many people with disabilities live on fixed (and often low) incomes and may need assistance with housing costs. Here are some ways to plan for affordable housing:

- **Apply for Government Housing Programs.** The government of New Brunswick has programs that assist people who are in need of affordable rental housing. One program involves accessing housing units that are owned directly by the province or by non-profit housing organizations in local communities. Another program involves “rent supplements” that are paid to landlords for people who cannot afford regular ‘market’ rents. In all of these programs, people pay 30% of their total income towards rent. People must apply to be considered for these programs. Eligibility is based on the person’s income and their level of priority as determined by government. These programs usually have waiting lists. For more information about these programs, contact the Housing Branch of the Government of New Brunswick in your area (check in the ‘blue’ pages of your telephone book under ‘Province of New Brunswick’ and then ‘Housing Services’ for the number to call).
- **Use Family Assets.** Some families may want to use their own assets to provide a home for their adult child. This can involve leaving the family home to be used by the family member with a disability or using some family assets to purchase or finance a home. There are many types of housing options to consider including a single family dwelling, townhouse, condominium, duplex, and so on. This approach will be much more affordable if the home is mortgage free or has only a small mortgage to re-pay. Planning options include:
 - Transferring the ownership of a home to a family member with a disability.
 - Making your family member a joint owner of a home with another person.
 - Providing for a “life estate” (the right to own and use of property for a person’s lifetime).
 - Creating a housing trust. A housing trust provides a legal right for the beneficiary of the trust to occupy the home while leaving the management responsibilities in the hands of trustees. Trustees can also be given the authority to collect “rent” from the beneficiary or possibly other occupants of the home. Trustees can also be given some discretion to change the housing arrangement if the beneficiary’s needs or circumstances change.
- **Supplement Your Adult Child’s Income.** You may also use your own assets to supplement your son or daughter’s income. If he or she is **not** receiving provincial income support benefits you can supplement income at any time and in any way you wish. If he or she is receiving income support benefits as a person who has been certified “disabled”, deaf or blind, you can supplement income by using a financial trust or a Registered Disability Savings Plan (RDSP). Provincial rules allow money from a trust (up to \$200,000 in value) or an RDSP to be used to supplement the income of a person with a disability. A trust or RDSP can be used to pay for housing expenses beyond what the person is able to

afford from his or her own income. This can be done without affecting the person's monthly cheque.

- **Share the Home to Share Living Expenses.** Some people may want to share their home with another person and share the cost of housing. People with disabilities can share a home with another person with a disability or with someone who is providing support without having provincial income support benefits affected. It is important to make sure that people are compatible and able to live with one another before considering this option.

Planning for Support in the Home

Ensuring that you son or daughter will have adequate and appropriate support in his or her home is crucial. Some people will require very little support while others may require much more. Good planning about how support in the home will be provided will be necessary. It will also likely require an application for funding from the government to pay for the supports.

There are a variety of support options which include:

- **On-demand support.** This involves establishing some system to allow the person to obtain support only when needed. For example, this could be accomplished through a beeper, an intercom, or a call button. It may also be accomplished by a person telephoning or visiting another person who is available to help.
- **Scheduled assistance or support.** In this option, people simply obtain the support they need on an agreed upon schedule. For example, an attendant may arrive at 6:00 a.m. to assist someone to get out of bed.
- **Immediately accessible support.** Much like "on-demand" support, the person obtains his or her assistance when needed; however, immediately accessible support is always available within minutes. For example, in case of an emergency, someone living across the hall in an apartment complex could be available to help.
- **Roommate support.** A number of own home living situations use roommates as a method of providing supports. Roommates may be paid or unpaid, or may receive free room or board (or both) in exchange for supporting an individual. Roommates are frequently offered the opportunity to have time away from the home. In some situations, where support needs are greater, individuals may have two roommates who perform different support functions. Having roommates also helps to avoid isolation and loneliness for the person with the disability. Roommate situations may be short-term, but



may also last for years, during which the individuals who share the home often develop a strong relationship. There is no one “model” for arranging roommate supports. It is individualized and may change as the individual decides upon different things or as different needs for support arise.

Planning for On-Going Monitoring

Setting your son or daughter up in his or her own home offers many potential benefits for a good life in the community. It will, however, be important to monitor the living situation carefully. When planning to establish a home, give consideration to who will be responsible for checking in on your son or daughter on a regular basis and for resolving issues that may arise from time to time. Here are some options to consider:

- **Family.** Family members may be willing to take on this responsibility. This may include other members of your immediate family or people from ‘extended’ family. They will need to be committed to taking on this role.
- **A network of support.** Networks are discussed in greater detail in Part 5. Network members can include family members, friends and others (such as your child’s social worker) who are committed to ensuring that your son or daughter has the support he or she needs to live in the community. One or more of the network members can assume responsibility for monitoring your adult child’s living arrangement. Issues can be addressed with the help of the entire network.
- **A community agency.** Some agencies will assume responsibility for helping to establish and monitor supported living arrangements for people with disabilities. These agencies will likely receive some funding for their services (this can be built into your son or daughter’s support plan that is submitted to government). When using an agency, make sure to clearly spell out their responsibility for monitoring the living arrangement and for addressing issues that arise. Even with agency involvement, it will be important to have other family or network of support members involved in making sure your son or daughter is safe and happy in his or her home.

Part 5: Involving Your Community: Networks of Support

For many years, people with disabilities enjoy the dedicated support and encouragement of their parents. For some people, their parents are their main source of support well into adulthood. As parents age, however, they may realize the need to involve other people in the life of their son or daughter. They realize that having caring and committed people involved will provide many benefits for their adult child. These benefits include companionship, community participation, advocacy to deal with issues, and safeguarding the well-being of the person.

Networks of support are an important aspect of planning for a safe and secure future for people with disabilities. A network is a group of people who care about a person to the extent that they will commit to being involved in the person's life on a regular basis. Networks of support usually involve the individual with a disability, family members, friends and other community members. They can also involve service providers and support workers.

Networks of support can play many different roles depending on the circumstances and needs of the person who is at the center of the process. This can include the following:

- Help the person and the family to make decisions
- Help the person and the family make plans for the future
- Make sure that the person's voice is heard
- Make a commitment to the person's future and security
- Provide companionship, enter into a relationship and have fun
- Provide practical support
- Help manage supports and money
- Advocate with service systems and address issues that may arise (Bruce Kappel, *Stronger Together: Ideas, Reflections and Suggestions About Networks of Support*, 1998).

A full list of possible roles is available from NBACL. For each individual, the actual activities of the network may change from time to time. This may depend on the needs of the individual and any issues that may need to be addressed. Likewise, the membership in the network may also change. People may move away or take on other commitments. If people leave the network, it is important to find others who will take their place. Parents may also decide to fade out of being the most active members of the network to allow other people to assume more responsibility.

Getting a network started and then maintaining it can involve some time and effort. Parents can get things started by thinking about who should be initially invited. A first gathering of the network can talk about why the network is necessary and then what needs to be done to support the individual and the family.

Parents may want to find an outside facilitator who can help establish a network of support. A facilitator can help:

- with invitations to prospective network members;
- run network meetings;
- identify roles for people in the network; and
- keep the network going well into the future.

For more information about networks of support, contact the New Brunswick Association for Community Living or visit the website of the Planned Lifetime Advocacy Network at www.plan.ca. For people who live in the greater Fredericton area, Opal Family Services may also be able to assist with facilitating a network of support.

Part 6: Dealing with Life Transitions

The issues discussed in this guide have dealt with different aspects of life transitions that are based on the reality of parents aging while trying to meet their ongoing responsibilities to care for and support a loved one with a disability. Dealing with these changes can be difficult. Parents who have been through these transitions have learned some lessons and offer their wisdom to others.

Plan for Change as Early as Possible

Planning for the time that you will not be the primary supporter of your son or daughter should happen as early as possible. It is important to not wait until the last minute. If you have other children who are willing to help, involve them in the planning. Having a “draft” plan can be useful even if you are not ready to put it into action. This gives you time to modify the plan if necessary. Putting plans into effect while you are still here allows you to oversee how things are going and to keep other people accountable.

“Think outside the box. Just because something isn’t available doesn’t mean you can’t create it. Everything there is today is because a parent or parents got together and created it.”

“Parents want perfection and guarantees. In real life we can’t re-create that outside the family relationship.”

Being Able to Let Go

Letting go can be hard, but it is necessary. The alternative may be a crisis situation that will not offer or provide a good life for your son or daughter.

“It’s okay to let go. You’re still involved. You’re still giving them quality time of yours, rather than quantities of time. And quality is better.”

“I’ve been there and I know how you feel. But it does change. We’ve all been there, just do it gradually and you will be fine.”

“The secret is finding the right place to let go to. Find a comfortable fit and it will be easy. Well, easier”

Don’t Rely Only on Government

Government programs will be helpful in looking after basic needs and addressing some of your son or daughter’s needs for support. Life in the community involves much more.

Your son or daughter will need supportive relationships and opportunities to contribute their gifts and talents. Help your son or daughter be connected to other people and activities in the community.

“Government looks after survival, not thriving.”

Having a Life of Your Own/Dealing with Loneliness

If you have been supporting your son or daughter for many years you may want to have time to yourself and enjoy other aspects of life. Feeling this way is perfectly natural.

"There will never be a perfect time. You reach the point of putting your needs, and time for yourself before your days are past, first."

"I will always be the girls' mother, but still, I want to be Leena. Not their mother all of the time"

At the same time, you may be concerned about being lonely if your son or daughter moves out. It seems that the longer your adult child lives with you, the harder it is to change the living arrangement for both you and adult child. As part of your planning consider how you can have opportunities to spend time with other people.

Dealing with Financial Realities

Sometimes parents and their son or daughter with a disability are dependent on each other financially. If your son or daughter were to leave the family home you may not be able to afford to live there yourself. Part of the planning process may involve thinking about how you can manage financially if you had to live by yourself. If you and your adult child need to live together for financial reasons, make sure that you have an emergency plan (see Part 2) and if possible, a plan for where your son or daughter will live in the future.

Seek Out Help and Support

Parents should not have to face these issues alone. You may need help with planning or with dealing with service systems in order to get the right support for your son or daughter. It may be important to not accept 'no' for an answer when you are looking for help. Organizations like NBACL may be able to help you deal with these issues. Seek out other families who are dealing with the same issues to support one another.



50
YEARS
ANNÉES

**New Brunswick
Association for
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Nouveau-Brunswick
pour l'intégration
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