

New Step: Advocating with Empathy

EXPANDED
WITH ALL
new
stories

safe and secure

**SEVEN STEPS ON THE PATH
TO A GOOD LIFE FOR PEOPLE
WITH DISABILITIES**

Al Etmanski

with Jack Collins and Vickie Cammack

Additional contributions by Jack Styan and Kathy Bromley

NEW
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First edition, 1996

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The strategies offered in this **book** are provided for the general guidance and **benefit** of the reader. This **book** provides information. It does not provide legal **advice**.

The information contained in the **book** is accurate at the date of publishing. However, we recommend that readers contact their own professional **advis**or or consultant when planning to implement any strategies. This will ensure the latest **availab**le information is taken into consideration and matched with individual circumstances.

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This **book** uses the term “dis**abil**ity” to refer to those challenges, conditions, circumstances, handicaps, and impairments that limit the functional **abil**ity of people. As is common in all PLAN **pub**lications, the person is the focus, the dis**abil**ity is secondary.

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Statement from Minister of Social Development and Social Innovation

On behalf of the Province of British Columbia, I want to extend sincere congratulations to the authors and the many other families involved with producing this revised RDSP edition of *Safe and Secure: Seven Steps on the Path to a Good Life for People with Disabilities*. I would also like to thank Vancouver Foundation for funding this important initiative.

The timing of this release is particularly meaningful as Premier Clark has recently released Accessibility 2024, the 10-year action plan to make B.C. the most progressive province in Canada for people living with disabilities by 2024. Accessibility 2024 responds to the voices of thousands of British Columbians who took part in a public consultation on what we, as a society, can do to reduce barriers and increase accessibility for people who have disabilities. The plan is built around 12 building blocks, and includes targets and measures that set the framework for ongoing dialogue with businesses, municipalities, the disability community, and every citizen of this province.

Financial Security is one of the building blocks of Accessibility 2024. In this building block, government sets the goal of B.C. having the highest savings rate for persons with disabilities in Canada by 2024. To support this goal, government proclaimed October 2014 as the first annual RDSP Awareness Month. Other initiatives are underway including creating an RDSP Action group and working with leaders in financial and disability communities to create a centre for financial

expertise for persons with disabilities.

Our government has a vision for B.C.—where disabilities are no longer barriers to living full lives and contributing to communities, and where people with disabilities can achieve their goals and dreams.

Having resources like *Safe and Secure* and organizations like PLAN are helping to make government’s vision a reality. By working together—government, communities and business—we can create a more accessible and inclusive British Columbia.

Sincerely,

Don McRae

Minister of Social Development and Social Innovation



Sincere thanks...

The original content of this book emerged from the collective experiences and inventiveness of PLAN's founders. Without their vision and persistence, there would be no PLAN and thus no *Safe and Secure*. Particular thanks to PLAN's leaders over the past quarter century: Jack Collins, Joan Lawrence, Arthur Mudry, Ted Kuntz, Susan Whittaker, and Rob Bromley.

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Thanks to London Drugs for distributing *Safe and Secure* throughout their BC outlets. You are a valued partner of PLAN.

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And to Linda McDaniel, whose editing and trouble shooting talents

are exceeded only by her commitment to make *Safe and Secure* the preeminent resource for families. Thank you.

Family is who loves you.

WAYSON CHOY

Foreword to the revised RDSP edition

“Who will take care of my son or daughter when I am gone or no longer able to care for them?” This is the question that motivated Al Etmanski, Vickie Cammack, Jack Collins and a handful of families to create **Planned Lifetime Advocacy Network Society** (PLAN) in 1989. What these parents knew is that their responsibility to their son or daughter with a disability didn’t stop when they died. Their parental responsibility only ceased when their son or daughter made their passing. *“Who will care for my child if they outlive me?”* is the challenge of every thoughtful, loving and courageous parent.

Fortunately, there are answers. Since its first printing in 1996, *Safe and Secure* has been an invaluable resource to parents and other family members of a loved one with disabilities who grapple with questions such as: Who will take an interest in our family member after we are gone? Who will love them? Who will protect and keep them safe? Who will appreciate and nurture their gifts? Who will advocate on their behalf? Who will help them make good decisions?

Safe and Secure captures the wisdom and experiences of thousands of families and caring friends that have come through the journey. These families are united in the belief that we *can* create a safe and secure future for our loved ones with disabilities. For more than two decades, PLAN has focused on the gifts and contributions of our family members rather than on their disabilities. We have shared the understanding that safety and security is dependent upon the number of relationships a person has. The more relationships, the safer they are. The fewer relationships, the more vulnerable they are.

PLAN also recognized the power of having a vision and working with clear intention. And PLAN has been realistic enough to know that safety, security and quality of life are dependent upon basic principles such as shared decision-making, and taking care of financial matters through the development of an estate plan and completing a proper Will. In 2009, *Safe and Secure* was extensively revised to include the introduction of the Registered Disability Savings Plan (RDSP), the first financial tool of its kind in the world for people with disabilities. This PLAN-led initiative provides a way for families and friends to help secure the financial future of a loved one, ensuring that people with disabilities do not live in poverty.

This edition of *Safe and Secure* adds to the rich body of knowledge and wisdom accumulated from over a quarter-century of innovation and experimentation, and provides more stories and examples of the impact these seven steps have made to creating a safe and secure future for people with disabilities.

As the father of a vulnerable young man, I am indebted to Al Etmanski, Vickie Cammack, Jack Collins and the many families who pioneered a better way of supporting our children—one that relies on the depth of care and compassion that exists within our communities. And, by providing opportunities for citizens to express their care and compassion, our communities have become richer, more vibrant and more welcoming places for everyone.

Ted Kuntz, Josh's Dad
Chair, PLAN

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My Life

People make assumptions. They don't know that life as me can be rich and full and fun and, dare I say it, happy. I like my life. Can you believe that?

I know lots of people—my workers, family, friends—and they all care about me. I know that they all like me too. They like to be with me because I am fun to be with. I help people see what is really important in life—and that's connection.

I am lucky. No one expects anything of me. It's like being given an ideal life for inner exploration.

We live in such a “doing” society that we automatically pity someone with a disability because they can't “do” in the same way, instead of seeing the inner benefits. Just because you can't do, can't work, don't have a career, doesn't mean to say you're not valuable.

I think this gets back to who we are essentially without all the labels. I mean, who are you or anyone without their professions, their possessions, house, car, money, talent, etc? Stripped of everything, who are you?

KIRSTEEN MAIN

About Kirsteen...

Kirsteen is a Vancouver born and raised poet. As well as being published by the Poetry Institute of Canada, she has been published in both the Scottish and Alberta editions of *Safe and Secure*. A complete collection of her work entitled *Dear Butterfly* has recently been published. For details, visit the Resources Section.

Introduction

Love is not enough

THERE are at least two emotions that inspired you to pick up this book. The first is love. The second is fear. We know this because we experience them too, as do the hundreds of families who have relatives with disabilities we have met over the years. You are definitely not alone.

Like everyone else, you want to die with your affairs in order. You want to leave a clear blueprint of your wishes for your relatives. At a time of great emotional stress—your death—you want to minimize the trauma. You also want to provide a secure future for those who survive you, particularly your relative with a disability.

That's the voice of love speaking.

Nevertheless, over **50** per cent of Canadians die without a Will. Most of the other **50** per cent haven't had their Will reviewed and updated for at least five years. And surprisingly, over **90** per cent of all business owners die without a viable estate plan.

That's the voice of fear speaking.

So let's get right down to it. In matters of future planning, love is not enough. That's one of the main reasons this book has been written.

We want to do three things:

- 1.** We want to inspire and challenge you:
 - to begin and complete the future planning process for your relative
 - to conquer your fears

- to replace *fear* of the future with *faith* in the future.
2. We want to guide you through the process of creating a Personal Future Plan for your relative with a disability. We want to expand your vision of the possibilities and to help you put them into concrete terms.
 3. Finally, we want to shed light on the legal/financial/technical solutions available to assist you to carry out your last wishes, and to share practical tips on how to apply these solutions to your unique circumstances.

Our Experience

- Family and friends are the heart of the matter.
- An imperfect plan is better than no plan at all.
- Safety and happiness for your relative are the main goals.
- There are creative solutions for every challenge.

What we believe

We believe in families. We believe in your initiative, your dedication, your creativity, your tenacity, and your commitment. We believe that your wishes, dreams and desires for your relative can shape the future. We believe in a world of possibilities. We believe that if you are willing to commit to the process of future planning outlined in this book, then that is the future your relative will have.

This book allows you to look over the shoulders of other families who are on the same journey. You will meet people who are breathing life into their dreams right now and giving shape to a brighter future for

themselves and for their relatives with disabilities. While the details of their plans may be different, the issues they are confronting are remarkably similar to yours.

This book will provide you with an overview of the whole future planning process. There are no single answers, no single solutions, and no miracles. In fact, some of the solutions will never look perfect. A Personal Future Plan is just a mixture of old-fashioned common sense, commitment, hard work, and a dash of bravado.

So enjoy, create, laugh, and cry.

Seven steps to a safe and secure future

Many of us never really take the time to sit down and discuss what our future intentions are for our relative with a disability. Nevertheless it does come up. Maybe it pops up when you are driving home from a family gathering. Maybe one of your children mentions something in passing, but the topic quickly changes. Maybe you wake up in the middle of the night and decide it's time to talk about it in the morning. But then you don't.

So many thoughts, ideas, worries and concerns go rolling around in your head. You can hardly remember them all. How could you expect someone else to? There are many confusing messages, countless pieces of advice, and so many complications. The need for resolution lurks just beneath the surface, emerging at the most unexpected times.

Community is where “we” become “us.”

TIM BRODHEAD

Sound familiar? That’s our experience, too. Virtually all of the families we have worked with have encountered the seemingly overwhelming bits and pieces of advice and action required to prepare for the future.

Our work with families has taught us that the process is not as complicated as it first appears. Further, we are convinced there are only a few key elements you need to focus on. We have combined these elements into what we call a Personal Future Plan. That is what this book is about. It is what we advise you to develop for your relative. But really, you will be developing it for yourself.

A Personal Future Plan is a seven-step process that families can follow to create a safe, secure, and pleasant future for their relatives with disabilities. It includes the best of your experiences, your dreams and nightmares, your wishes for the future, and your knowledge and expertise. It combines all of these with the active involvement of your relative with a disability, other members of your family and selected knowledgeable professionals. It is a plan that you create, control and direct. It is focused on the here and now. It is also geared to a time when you will no longer be around.

The seven steps are as follows:

Step one—Clarify your vision

Step two—Nurture friendship

Step three—Create a home

Step four—Make sound decisions

Step five—Achieve financial security

Step six—Advocate with empathy

Step seven—Secure your plan

Advice for parents of younger children

As you will discover, there are a number of sections in the book specifically written for parents who have children under the age of 19.

Parents with younger children are faced with enough daunting challenges: Being first time parents, dealing with the news of a child's disability, and responding to additional health challenges. We know this can be a tumultuous and intense period. You may not wish to focus on the future. We understand. Here are some tips to help you along the way:

- Grandparents can help in a variety of ways including making contributions to your child's RDSP or leaving money in their estate to create a discretionary trust.
- Life insurance can be an affordable way to finance a trust. You control the monthly payments and, should you die, the proceeds finance a discretionary trust for your child.
- Don't hesitate to invite friends into your child's life. Keep track of everyone who is a friend with your child. You will be pleasantly surprised at how many of these people will become Personal

Network members when the time comes.

- During high school is a good time to begin organizing a social network for your teenage child.
- Remember to create a Will and indicate who you want to become guardian of your children. Step Five outlines what happens if you don't.

How to use this book

We suggest you skim through this book until you come to a section you'd like to work on. Once you've decided to focus on one section, answer all the questions and complete all the Worksheets. If you don't want to mark up the book—and most don't—you can download the worksheets from www.PLAN.ca. Click on *Safe and Secure* Worksheets.

You'll be surprised how the questions in one section will lead directly into the concerns of another section. Each one informs and guides the other. Before you know it, your planning will be complete and you'll have a record of your intentions, all contained in one place.

This book allows you to be an informed consumer of the professional services that are available in the future planning industry. By following the steps and advice presented here, you will be better prepared, use less professional time, and save yourself money.

We invite you to customize this book to your needs. Add your own personal data, photos, records, medical information, and so on. Keep this book in a safe place. You should never underestimate how valuable this information will be to your survivors.

Think of *Safe and Secure* as your manuscript for the future.

step one

clarify your vision

I am a sailor in my dreams
I travel from land to land
My heart is a compass
I will never be lost.

LIZ ETMANSKI

The Bromley story

The dance

THURSDAY I received a call from the Intake Coordinator at Home Health Services who rather coldly said to me, “You have a lot to get done before Shannon’s birthday. You’d better get busy!” I found myself fighting back tears as I quietly said, “I know.”

Shannon was about to turn 19—a pivotal time in her life. No more high school, no more Children’s Hospital and the familiarity of the 28 specialists.

School has been such a great place for our daughter. It’s hard to believe that this is the beginning of the end of something very special.

Today, as I have done every year since she was five years old, I spent my day in Shannon’s school. I have offered an in-service to each of Shannon’s classes since kindergarten where I share a little of her story. I have always been made to feel welcome by her teachers and the other students.

No one wants the extra attention of having their Mom come into class and share personal information, but when you arrive in a wheelchair with a feeding pump, talking devices, a computer and all kinds of staff, the other students in the class are bound to be a little curious. And curiosity is a good thing if there is opportunity to talk and have your questions answered.

Throughout the years, my basic message stayed the same: treat Shannon exactly as you would any other classmate. If she’s bothering

you, ask her to stop; if she's not looking at you, ask for her attention and—most importantly—if she's off on her own, go get her and include her in your group.

I let the students know that Shannon began her life very much as they did, as a beautiful daughter to two very excited parents. We've worked hard to make sure she's had all the proper medical care but, almost more importantly, we've worked hard to make sure she is experiencing life and having fun.

I try to impress the students with the sports she's involved in, the concerts she has attended and her travels. I feel that the more I can make her sound like one of them, the more she will be included.

The pay off for my time is immediate. Shannon's support staff has told me that the students are less shy and feel more confident talking to Shannon. The students are eager to learn how to program her speaking devices, choose a costume for her for a drama assignment or help her with a dance move.

Late last term we had a wheeled platform made to attach to Shannon's wheelchair to make dance more fun. The other dancers had sparkles in their eyes when we brought it out today. The students laughed as their teacher struck a dance pose while being towed behind Shannon's chair.

The biggest smile of the day, next to mine of course, belonged to Shannon. With her head up high and her smile shining bright, I'm guessing she doesn't really mind having her Mom come into her class.

FRIDAY As part of Shannon's transition from youth to adult services, I finished up some paperwork. In order to qualify for funding, I had to

write down everything that is done for Shannon, either by others or me, in one 24-hour period. That's every little thing including clipping her fingernails and toenails. After completing the five-page document, I felt rather overwhelmed.

Not 10 minutes after I emailed the document, I received a call from Shannon's teacher regarding staffing for next term. This call came as a disappointment. Shannon has five months of high school left before she moves on to, well, we don't really know yet but it's not high school, and it didn't even enter my mind that her staff might change. The phone call changed all that. I spent the rest of the morning trying to figure out a plan.

Later that day as I was cleaning out Shannon's bag in preparation for her big dance production at the theatre, I came across a play.

I don't know who wrote it but I do know it was written with Shannon in mind, as she often has her head down and rarely makes eye contact.

Actions speak louder than words

Description: two teenage girls are having a sleepover on a Friday night. Will these two remain friends?

Hannah: *Shannon, I heard you told my secret to the whole entire school.*

Shannon *(Silent)*

Hannah: *I thought that I could trust you. You promised that you wouldn't say a thing.*

Shannon *(Silent)*

Hannah: *You don't really have anything to say right now, do you?*

Shannon *(Silent. Doesn't make eye contact. Head is down.)*

Hannah: *Come on Shannon, we were best friends.*

Shannon *(Long silence)*

Hannah: *(Gets up): I mean, we were best friends. (Exits room)*

step one

Clarify your vision

REMEMBER the old saying: If you don't know where you are going, any road will get you there? Well, we think it's true. That's why, as you begin planning for the future, you need to be clear about what you want. What are you trying to achieve for your relative? What do you imagine for their future? What are your goals? What do you want to prevent? What do you want to maintain? What do you want people to know when they gather to discuss your wishes after you are gone? Without specific answers to these questions, the rest of your planning will be cloudy and incomplete. Knowing what you want to achieve is the first step in creating a Personal Future Plan.

For most of us, the obvious place to start is by completing our Will and establishing a trust for our relative.

Most of the planning time should be spent identifying what you are trying to achieve, thinking through your goals and objectives, and clarifying your vision. Once these steps become clear, you will be in a better position to evaluate the various options available. Then the technical solutions such as increasing the value of your estate, choosing your trustees, and finding the precise legal clauses will follow. Then—and only then—should you seek the advice of professionals. Your Will and estate plan will be more relevant and useful because your directions are clear.

Think of your last plane ride. Did you ask the pilot where you should go? Of course not. You made that decision first. Then you examined the scheduling options and made your decision about price and so on.

That's the most effective way to utilize the services of Will and estate planning professionals. It saves them time and you money.

We still need dreams as adults. It amazes me how many people either deny themselves this experience or are so tied to the reality of survival that they fail to grasp the importance of being able to dream.

We're talking conscious dreaming here as opposed to what occurs when we are asleep, although the two may be linked subconsciously.

ROBERTA BONDAR — CANADIAN ASTRONAUT

What is a vision?

Visions are creations of the heart as well as of the mind. A vision is your description of a desired future for your relative. A vision is about passion—your passion for the future economic and social well-being of your relative. That's why it is so important to address dreams as well as nightmares. Fears, worries, hopes, and dreams are all keys to unlocked passion.

A clearly written statement of your vision will help focus your attention. Since a vision reflects your values, your traditions, and your family history, it creates a context for the other components of your Personal Future Plan.

Clarifying and sharing your vision of a desired future for your relative:

- enables you to see the world through your relative's eyes
- invites the involvement of other members of the family

- encourages others to **better** understand what is **involved** and gets them thinking as to how they can help
- **brings** preferred and desirable scenarios into the open
- suggests new opportunities
- **moves** you forward
- changes the present.

The fundamental **job** of the imagination in ordinary life is to produce out of the society we have to live in, a **vision** of the society we want to live in.

NORTHROP FRYE

We have learned that sharing your ideas, particularly when you put them in writing, is important. Since you won't **be** around, it is **better** to **begin** the discussion with your other children, **extended** family, friends, and potential supporters now. Relying on others without telling them could create **problems** for **everyone**.

You don't want to assume, as one Mom we know did, that her other children know and understand the complete medical **background** of her son, only to find that they were too **busy** growing up to notice, let alone to make notes! Or a Dad who told us that he intends to rely on his **next-door neighbours** to carry out his wishes for his daughter, without determining first whether they are interested in discussing any of the details with him.

You wait for fate to bring about changes in your life which you should be bringing about by yourself.

DOUGLAS COUPLAND

So what are we afraid of?

What keeps so many of us from even thinking about the future let alone formalizing our future wishes for our survivors? What causes our paralysis? Why don't we act? Maybe it's fear.

Love and fear are two sides of the same coin. The coin is called passion. The word, passion, stems from the Latin word for suffering. Wouldn't you agree that suffering is a mixture of love and fear?

Fear is an intriguing emotion. It distorts our perception and confuses us about what is going on and about what is possible. When we use words like can't, ought to, if only, doubt, and impossible, we are under the influence of fear. Fear draws a dark and cold curtain between our intentions and our actions. Like a schoolyard bully, its appearance is deceiving. It's actually more imposing in our minds than in reality.

In our own personal struggles with the issues of future planning and in our work with families, we can identify three "schoolyard bullies" that everyone must find the courage to confront. We offer them here because we believe that where there is clarity, there is comfort. Where there is understanding, there is the ability to change.

FEAR OF OPENING UP Sharing your hopes and worries means discussing intensely personal matters with others—our spouse, family members, friends or acquaintances, and professionals. This may be

awkward. We may need to contact people who have never demonstrated any interest in our relative. Or we may not know whom to turn to or whom to trust. And we risk rejection.

We've grown up being self-sufficient. We've taken our responsibilities seriously. We've tried all our lives to make sure others wouldn't have to shoulder our responsibilities. We've done the best we can.

With future planning we have to share our hopes, our dreams, our fears, and our anxieties with others. We need to ask others to:

- help us with our planning
- carry out our wishes after we are gone
- believe in our relative and the possibilities for their future.

To do this, we need to reach out. We need to know whom we can rely on. After all, what good are your plans if no one else knows about them? Sure, they could read about your wishes in your Will. But will the readers get the complete picture? Will they know what you really want? What if they have questions? Maybe they aren't interested? How can you be sure you will be understood?

Life is full of dying; life is full of death.

When the reality of death strikes, it reminds us of our physical limitations, and of the depth of our spirit.

We may have regrets and yet be thankful that we have a new beginning, an awareness that while we are in the shadow of death, a new life has begun.

DAVID KUHL, M.D.

FEAR OF DEATH Death is not a popular topic in our society. Even a cursory look at the popular media suggests that our culture is obsessed with youth, living forever, and avoiding sickness and infirmity. An illusion is offered: We can cheat death. While it may not be stated, the implicit message is that diet, exercise, and medical intervention will keep us forever young or forever alive. As Margaret Mead said of our culture, “When people are born we rejoice, and when they’re married we celebrate, but when they die we try to pretend nothing has happened.”

The fear of death is there for all of us. It lurks just beneath the surface, never quite deep enough, though, to be ignored. Perhaps it presents itself as anxiety, perhaps as an awful sense of impermanence, perhaps as loneliness. We may harbour the belief that parents who have sons and daughters without disabilities have fewer anxieties about death than we do. Not true. Perhaps what separates us from those parents is our need to address the future of our relatives not just for our lifetime, but for their lifetime.

Reflections on having a personal future plan

- It's fair to other family members. They now know what's going on.
- My worries about outside interference are gone.
- I'm better prepared to face the unknown.
- I've done the best I can.
- I've left a legacy of love.
- I'm at peace.

For younger people, death can feel very remote. Even thinking about it seems perverse. But death is inevitable and is a natural part of life that we all have to face sooner or later. The Dalai Lama says there are two ways we can choose to deal with the prospect of our death: we can ignore it or we can confront it. Confronting and accepting our own mortality spurs us into action. We gain the wisdom to accept the inevitable and the knowledge to realize that it's better for everyone if we think about, and as importantly, begin to organize our affairs.

Statistically, 100% of the shots you don't take don't go in.

WAYNE GRETZKY

FEAR OF MAKING A MISTAKE, OR FEAR OF NOT BEING PERFECT Now here's an irony for you. In thinking about the future,

many of us feel we need to create the “perfect” plan. We are afraid that we haven’t covered all the bases. Somehow we think we can make the future perfect even though the day-to-day doesn’t always turn out the way we planned.

According to financial and estate planners, lawyers, accountants, and everyone else involved in the future planning business, the most common excuse for not making a Will is the fear of not getting it right. Indecision can paralyze even those with the best intentions. In trying to make perfect decisions, we risk indefinite delay. Perfection equals postponement. Doing our best is as perfect as it will ever get.

Plans evolve

Personal Future Plans will change as circumstances change. It takes time for your dreams to evolve. You can always update and revise it. In fact, you should expect to make changes along the way. We all get wiser as we get older, don’t we? You can expect to gain insight and pick up tips.

None of us can predict the future or anticipate all eventualities. The truth is that we often have to proceed as best we can without all the answers. Hindsight is the only guarantee of perfect vision.

Thoughts on putting it off

- We're not in crisis yet. We still have loads of time.
- The process is too costly, both financially and emotionally.
- I don't know whom to turn to. My community of support is too small.
- I'm worn out from too many previous battles. I just need a break.
- We're still young.
- The future is too hard to contemplate.
- I'm a procrastinator. I have a reputation to live up to.

What is a personal future plan?

A Personal Future Plan is a written summary of your plans for the social and financial well-being of your family member with a disability.

We have learned that the most effective question when making a Personal Future Plan is: What is a good life? Families tell us that a good life for their relative should include the following elements:

- caring and loving relationships
- a place of one's own

- choice
- contribution
- financial security.

The Worksheets at the end of each chapter will assist you with answering this question for your family's unique circumstances. To download a copy, please visit www.plan.ca and click on the Safe and Secure Worksheets.

If music be the food of love, play on

GARLAND COHEN was in her eighties when she and her son David joined PLAN Vancouver. She had been pushing the future to the back of her mind for a long time, hoping for a miracle. Garland wasn't afraid of dying; she was afraid of leaving David alone.

David had an apartment in the basement of the house where he and his mother lived for 20 years. While he knew many people in the community, none of them knew one another. Garland's health was failing and she feared that David was growing increasingly isolated and might slip through the cracks.

With the help of PLAN, Garland set up a trust and started a network for David. Soon after, she was diagnosed with cancer. David's network provided the support she needed to die at home. After she passed away, the network helped David move into an apartment of his own.

In the years since Garland's death, David has said that the network gave him a sense of security about living in the community, and that he didn't feel alone. Over time, the network helped him tackle issues like employment, using computers, and going back to school. "They're very wonderful people," he said of his friends, and they said the same about him. John Meyer, an early network member and advisor to Garland in setting up a trust for David more than 12 years ago, observed that if Garland could see how David has thrived, "She'd be tickled pink."

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At the age of 61 when David was diagnosed with brain cancer, his

At the age of 51, when David was diagnosed with brain cancer, his friends rallied round. Weeks later, on a December evening, he and more than **75** others gathered in a room filled with Christmas cheer to celebrate his extraordinary life.

David's dedicated patronage of the musical arts was evident among the guests. Canada's first lady of opera, Judith Forst, related how, for decades, David had been coming back stage after every performance to compliment her. "When David loves something," she said, "it isn't **50** per cent, it's **100** per cent." Linda Lee Thomas, lead pianist with the Vancouver Symphony Orchestra, said, "A concert of the VSO is not complete without David Cohen. He comes back stage and always has that wonderful hand extended and shares his generous thanks."

David was also well known in political circles. He inherited his mother's passion for peace and social justice, and his letter writing for Amnesty International is legendary. During civic elections, David volunteered his time and rarely missed a local political meeting. At the party for David, Vancouver mayoral candidate Jim Green, out of the country at the time, sent a letter recalling how David's presentation on a panel about the opera, *Of Mice and Men*, moved a tenor in attendance to tears.

Others spoke of David's kindness, the thoughtful way he thanks people, and his generous spirit. Lyle Lexier, a member of David's network, said, "David Cohen has been my friend for **15** years. We talk about opera and human rights and the release of political prisoners and how to end capital punishment." Longtime friend Owen Underhill disclosed, "I don't think I've ever felt so affirmed in my life as when David left me a telephone message about my work as a composer, a conductor, a father, and a friend."

Network member **Barrie Vickers** spoke for everyone in the room when he addressed the guest of honour, “It is a wonderful gift you have given us David, and we’ll live out the joy that you’ve given to us.”

When David took the microphone, he said, “Thank you for your beautiful words.” Then the whole room joined in a rousing verse of *Hark the Herald Angels Sing*. A long line formed at David’s side, and for the next hour he graciously greeted friend after friend.

SANDRA SHIELDS

Post Script

David Cohen passed away peacefully and surrounded by friends. Some of his friends smile in relating how very fitting that the end of David’s life should fall on Mozart’s birthday—amid magnificent musical tributes. PLAN Vancouver staff shall miss David’s daily phone calls that kept everyone up-to-date on current events and local performing arts schedules. As one of the people on David’s network remarked, “He had a good life and a good ending. Really, what more could anyone ask for?”

Kathy Bromley

Time

TIME. It means something different to everyone. For us, a family of four and a dog, it is something we never have enough of.

We have been moving along at a pace that seems a little crazy at times. A pace that doesn't always let us sit back and relax, visit with friends when we feel like, or even eat at a decent hour.

Although we are just another family to some, we are, in fact, a family trying desperately to keep up the pace—not with the Joneses but with the clock, the timepiece that controls what time we wake up and go to sleep, what time we start work, and how much quality time we have with each other.

We are not a typical family at all. Our family is made up of my husband Rob and me, Michael our son, who recently moved out, and our 18 year old daughter who will never make the decision on her own to move away from home.

Our beautiful daughter, Shannon, is unable to dress or feed herself, and she needs help to brush her hair and her teeth. She has an amazing smile and has made my husband, my son and I better people, people with patience and understanding, but also people with very little free time.

I Am Me

Watching, always watching,

People just pass by.

Oh, they notice alright,

But what they see is not me.

They see a wheelchair,

They see a body that to them is hopeless

They see a body, and then they say, "Oh, poor thing."

They, society, have not seen me.

I am a person who thinks, feels and lives.

I am a writer.

I am a student.

And when given a chance, I am a friend.

I am a person like you.

I cry, laugh and get mad.

True, I do need some extra help but I am still a person.

When you look at me, look at the person.

I am not a wheelchair.

I am not handicapped.

And I am not an object for display.

I AM A PERSON.

I AM ME.

KIRSTEEN MAIN

To download a copy of all Worksheets, visit www.plan.ca and click on Safe and Secure Worksheets.

Worksheet 1

After you're gone: clarifying your vision

It's the day after your death. Describe what a safe and secure life will look like for your relative.

List **10** words to describe a typical day for your relative, in the **best** of all possible worlds.

Use some key words to describe your worst nightmare for your relative after you're gone.

What is the most important message you want to leave your relative with a disability?

What do you want your survivors to help with after you've gone?

When your executors/trustees meet, what do you want them to do first?

What are the three priorities you want future caregivers to remember about your relative?

1.

2.

3.

What are the important arrangements you've made to ensure a good life for your relative?

How do you want to be remembered by your relative?

Worksheet 2

A family portrait

Use this Worksheet to develop a portrait of your relative as it will be an important record to pass on to your survivors.

Health

List names of current doctors, specialists, and health practitioners:

List current health concerns:

List current health treatments:

List current health precautions and alternatives:

Briefly describe key features of your relative's medical history:

Education and work

List your relative's current educational and/or work activity:

What are their future dreams in this area? What other possibilities

would they like to explore?

What are some highlights from your relative's school experience? What did they like about it? What didn't they like about it?

Who are the people from the past that your relative would like to connect with?

Who are the people with whom your relative still has a close connection with?

What are some highlights of your relative's work experience? What did they like about it? What didn't they like about it?

Housing

Describe your relative's current living arrangements:

What are some future housing options/possibilities for your relative?

Summarize their previous living arrangements:

What did your relative like about them, dislike about them?

Who are the people who had a significant relationship with your relative in these previous living arrangements?

Leisure and recreation

List your relative's current social, recreational, cultural, artistic, and athletic activities:

What are your relative's interests and preferred activities in these areas?

What are some future possibilities in the area of leisure and recreation?

What does your relative most like to do?

Personal

How would you describe your relative's beliefs and values?

What customs and traditions are important in your family?

Is spiritual and religious worship important for your relative? Is this an area that could be explored further?

What are (or will be) the significant events, markers, or milestones in your relative's life?

What brings comfort and peace to your relative?

Who has been your relative's greatest source of emotional support other than yourself?

What does your relative gain the most pleasure from?

Who are the most significant people in your relative's life?

What are your relative's favourite possessions?

Worksheet 3

A letter to the future

The last wishes of family members are honoured and respected in our society.

A letter to the future is your opportunity to tell your survivors how you would like to be remembered, and how you would like your relative with a disability to be cared for.

This is not an easy letter to write. Think of it as the letter you might write in the middle of the night when you can't sleep. Be frank about your hopes and fears. Tell those who will survive you what's most important to you.

Dear _____,

With love,

step two

nurture friendship

We spend our free time with friends. We can relax with them and allow our masks to fall. It is all right to be ourselves and we can do what we like, we are not constrained by rules.

But friendship also implies commitment. A true friend feels responsible for his friends, during bad times as well as good, in success and failure, humiliation and sorrow.

JEAN VANIER

The Bromley story

Take THAT, Shannon...

WHEN IT COMES TO DISABILITY, someone long ago decided that there should be another language. Words used such as “toileting” instead of bathroom, “integration” instead of attending class and, one of my favourites, “inclusion” when all we want is for our children is to have friends and achieve a sense of belonging.

Rob and I have worked hard to make sure that others see Shannon as an equal. But we can't control how Shannon's peers treat her on a daily basis.

On the surface, nothing about Shannon seemed open and available to invite friends into her life. With all the equipment and staff attached to her, how can we create a natural environment for Shannon to make friends?

What we have found is that by modeling what we want for Shannon, by continuing to acknowledge her disability all the while sharing her abilities, Shannon has become just another high school student—one with peers, acquaintances and friends. Just one of the hundreds of Grade 12 students working hard to get to graduation.

Shannon has friends that take care of her just like they take care of their other friends. One day, for example, when Shannon showed up at school with her hair a little less than its usual stylish way, a fellow drama student stepped in, gently pulled the elastic out of her hair and had it fixed up in no time. He didn't ask. He just knew it needed to be

done.

For years, Shannon has worn orthotics on her feet—black shoes that were difficult to put on and impossible to kick off. When Shan’s orthopedic surgeon suggested she need only wear her orthotics when she was standing, out went the old and in came the cute flats.

Shannon figured out how to get her flats off by wedging them against her wheelchair and flicking upwards. One morning while Shannon was at her early morning Yearbook Club, she flipped her shoe off one too many times and the shoe came flying right back at her! Shannon’s Special Ed Assistant wasn’t really sure what to make of witnessing another student picking up the shoe and throwing it right back at Shannon. I certainly knew how to react... with a smile.

There’s a level of politeness between people who see each other on a regular basis—people who haven’t spent enough time getting to know each other but know enough to compliment one another and be polite. This is not where friends stay; this is where a friendship begins.

To really know another person means that you can laugh, not just with them but at them as well, in a way that includes mutual respect. I think of the times my friends have laughed at me when I’ve spilled food on myself or tripped on the sidewalk. Only good friends can get away with that.

Which brings me back to the girl in Yearbook Club who threw the shoe at Shannon. It wasn’t a hard throw, more of a toss onto her lap accompanied by “keep your shoes to yourself Shannon!” Only a friend could get away with that behaviour.

Yes, our daughter has peers, acquaintances, classmates and staff but

she also has people in her circle who would gladly call her a friend and treat her with the same caring respect and sense of humour as they do with all their other friends. This is where we want our daughter. This is what inclusion means.

step two

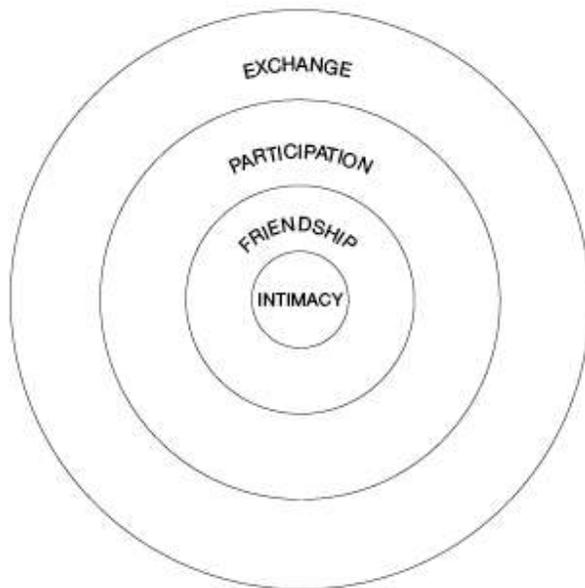
Nurture friendship

THERE is probably no one who can ever look after your relative with the same persistence, interest, and determination as you do. That's a fact. However, unless you've tapped into the fountain of youth, you won't be around forever. That's a fact, too. So what's the next best thing? The best guarantee of a safe and secure future for a person with a disability is the number of caring and committed friends, family members, acquaintances, and supporters actively involved in their life. The real strength of these caring relationships comes not just in their connection to the person with a disability but in their connections with each other. Imagine a spider's web. The strands extend from the centre of the web to the edge. Imagine if there was nothing else holding them together. They would flap in the wind. Their functional value would be minimal. They need to be linked with each other in order to form the web. Otherwise, the spiders would starve. The strength of the web comes when all components are interconnected.

Friends make gifts and gifts make friends.

INUIT PROVERB

Worksheet 4 – Relationship circles



Worksheet 4 provides instructions to complete your own sample relationship circle.

Make sure that the names of the people you place in the circle of participation are there **because** of a common interest, **hobby**, passion, and so on. This will make the chance of people moving into the circle of friendship more likely.

It's the same for our family members. The focus of support for people with disabilities must **be** placed **both** on their individual relationships

and the relationships among the members of the personal network. These interconnections create the web of support that begins to approximate the thoroughness with which families care for each other. PLAN's specialty is facilitating these caring relationships for people with disabilities. We call them Personal Networks.

A Personal Network is a team of people who come together for three basic purposes: the safety, health, and well-being of your relative, the person at the centre of the network. A healthy Personal Network is one where all members are in touch with each other, coordinating their involvement, and staying on top of things. They are united by bonds of friendship, love and trust. This is the sum of everything you embody but won't be able to provide forever.

There is no idea more ancient than a circle of friends.
And there is nothing more predictable than the discovery by such a circle that the one in need is somehow helping the others.

JOHN RALSTON SAUL

The role of friendship in our lives

The oldest literature from all cultural traditions attests to the importance of friendship. Themes about our interconnectedness are but one indication that we are, above all else, social beings. Friendship is a necessity for all of us, as important and essential to life as food and drink.

Aristotle, a Greek philosopher and major influence on Western thought, put it succinctly: "Without friends no one would choose to live, though

he had all other goods.” Perhaps it’s because friendship is so fundamental to our existence that we take it for granted... or we aren’t conscious of its importance until it is brought to our attention.

When asked to boil our life down to its basics, most of us would agree that we are interdependent not independent beings. The impact of this recognition is far greater than our contemporary society appreciates or acknowledges. Understanding this interdependence is critical to our health, our quality of life, our sense of belonging, our peace of mind and our security. And, therefore, it is also fundamental to the future security of our family members with disabilities.

The foundation of this future security is not the size of the estate you leave or whether you have a Will. Yes, these are important factors in building a successful future plan. But they are not enough. We agree with Emily Dickinson who wrote, “my friends are my estate.” Caring relationships and friends provide texture and vitality and make all living worthwhile.

Friendships, ranging from acquaintances to intimate relationships, are formed by choice. They are freely given, based on mutual interests. Friendships are not one-sided. They are reciprocal, a two-way exchange. They are not paid visitors. They are not volunteers. They are not one-to-one workers.

The healing power of friendship

- People with supportive social ties are less likely to become ill
- Social contact helps us to heal more quickly
- Social supports affect the sense of control we have over our well-being and improve our ability to stick with healthy behaviour patterns.

Good friends support us through good times and bad, when we are on our best behaviour, and when we are not. We don't change ourselves to be with friends. Our gifts and our frailties are accepted as part of who we are. Our friends are not expected to fix us. They are just there. Friendships are naturally enjoyable.

When we are truly loved and valued, we gain a sense of belonging. When we feel like we belong, we change for the better. Our confidence improves as does our self-esteem, our sense of well-being and our quality of life. Life takes on new meaning. At PLAN, we have consistently witnessed this transformation.

If you love someone, put their name in a circle, instead of a heart, because hearts can break, but circles go on forever.

AUTHOR UNKNOWN

Caring relationships: a source of support

Think of our own lives. When someone close to us dies, we are not left alone. We still have supportive friends and family. We want this same caring, secure environment for our family member with a disability when we die. This means formalizing the existing relationships of our relative into a Personal Network or creating a new Personal Network around them. It is the only answer to the question, "Who will replace you when you are gone?" Personal Networks can become the next best thing. Personal Networks can become your eyes and ears, arms and legs. Nothing offers peace of mind better than that.

The good feelings that arise from our connectedness to others are an obvious benefit of friendship. However, these good feelings are just the beginning in evaluating the benefits of caring relationships. Investing in an extended network of friends and family for our relative provides both short-term and long-term returns.

When it is time to monitor and advocate, our relatives with disabilities will benefit from the presence of friends and supporters. Individuals who lack supportive ties are vulnerable to a wide variety of negative consequences. If not surrounded by people who have a vested interest in their well-being, our relatives may be at risk for abuse, neglect and exploitation. And, unless friends are present, the needs of our relatives can be ignored by a busy, overworked service system.

Success in school and on the job is directly correlated with the size and health of our social networks. Social networks are also a determinant of health. There is now a mass of evidence to indicate that social ties may be one of the critical factors distinguishing those who remain healthy from those who fall ill. Did you know that the health risks of being isolated are as detrimental as cigarette smoking? Clearly, friendships are necessary for good health.

Reciprocity

Personal Network members often describe how meaningful their relationship is with the person at the centre of the network. They talk about getting as much as they give. This is called reciprocity.

A few years back, we commissioned a study to document the experiences of Personal Network members. The results were impressive and confirmed our belief: People with disabilities make a real difference in the lives of Network Members. We also confirmed that the relationships between people with disabilities and Network Members were mutual. In the context of relationships, our family members are contributors.

The power and potential of Personal Networks have far exceeded our expectations. Over the past quarter century, we have seen members of PLAN's Personal Networks:

- monitor the formal programs and services that our relatives receive
- become effective advocates
- serve as executors and trustees or as advisors
- act as supportive decision-makers and members of Representative Agreements
- respond promptly and effectively to crises

- solve problems and handle the unexpected
- carry out the wishes of parents.

Maria has shown me how to appreciate the little things in life. My faith in humanity has grown.

THOMAS, A PERSONAL NETWORK MEMBER

Stages of a personal network

PLAN hires a Community Connector, who works an average of two to six hours per month, to create and nurture its networks. Vickie Cammack, Co-Founder of PLAN, Founder of Tyze, and a co-author of this book, developed this program. She advises that community connectors should “do as much as necessary and as little as possible.” Personal Networks take time, sometimes as long as one to two years before they have “legs,” as Vickie describes it, or until the network members develop a close and tight caring relationship with each other and with the focus person.

Personal Networks go through three stages:

STAGE ONE: EXPLORATION This is the time for the individual, family, and the community connector to get to know each other; it’s the time to focus on interests, passions, and possibilities for meeting others. At the end of this period, the community connector will provide a set of objectives, a time line of activities, and a list of potential network members.

STAGE TWO: DEVELOPMENT This is the time when all the leads and possibilities are followed up, contacts are made, and invitations

extended. The goal in this stage is to recruit network members and to introduce them to each other. Practical strategies are developed.

STAGE THREE: MAINTENANCE By this time, caring relationships have formed and networks meet regularly. The network settles in for the long run. As new interests emerge—and they often do—new connections are made. The network gets stronger and becomes more dynamic.

The art of making friends

Did you know that over **50** per cent of the first attempts that pre-schoolers make to join in a group with other children are rejected? They must keep trying before being accepted by their peers.

In other words, the first step in meeting another person is a learned skill that comes with practice. This is a skill that most of us take for granted and which developed more or less naturally for most of us. Research has shown that children with disabilities often do not experience this trial and error process. He suggests that there are three skills that very young children develop while playing with each other:

1. They learn how to initiate contact with peers;
2. They learn how to maintain play. These are the skills we learn to keep the interaction or relationship going;
3. They learn conflict resolution. Inevitably in any caring relationship, we have to learn to negotiate, to share and to compromise.

Friendships rarely develop by chance. We cultivate them as carefully as we nurture a job or a family, a talent or a hobby. Some of us may think that friendships happen naturally and that if they don't occur, there is nothing we can do about it. Not true. There appears to be a certain

skill set associated with initiating and developing our acquaintances and friendships.

Qualities of community connectors

PLAN's talented Community Connectors share similar characteristics. They:

- recognize and nurture the capacities and gifts of everyone
- pay attention to detail
- are great event planners
- are creative, pragmatic, and reflective
- know their community and use their connections.

The ability to make friends may have to be relearned for some people. As a result of an accident or injury, their friends may have drifted away and their social circle changed dramatically. They may have had limited opportunity for socializing as a result of institutional living. They may be surrounded by staff who don't recognize the importance of friendship or don't know how to facilitate it. They may have tried to make friends, were rebuffed, and then became discouraged from trying again. They may lack or have lost confidence. They may believe that no one would want to be their friend.

Friends, by sharing time with us, are saying that we are worth the gift of time.

I am excited to be a Community Connector because I can be a part of creating this opportunity in someone else's life.

JOSHUA

Because friendships do not always develop naturally for some of our family members with disabilities, it is often necessary to approach the development of caring relationships in a focused and strategic manner. PLAN hires a Community Connector to assist with developing and maintaining our Personal Networks.

What we've learned about personal networks

- They take time, about two years on average, to become a smoothly functioning team.
- It is important to focus on people's interests, passions, and what they can do. There are enough people focusing on what they can't do.
- Connections among and between network members are as important as their relationship to the person at the centre.
- There are more people interested in developing a caring relationship with your relative than you may think!

How caring relationships challenge families

While many families recognize the importance of caring relationships in their relative's life, they often feel some ambivalence when it comes to actively seeking opportunities for these relationships to form. From our experience, there are three challenges that families face: asking, opening, and believing.

ASKING To ask is to make ourselves vulnerable. There is always the possibility of refusal. Yet reaching out and asking is integral to developing and deepening our relationships. Friendships often form because we ask others to participate in a shared activity. We invite

acquaintances over for tea to get to know them better. We ask neighbours to help us with building a fence. We ask friends to give us a hand with setting up for a party. Each of these casual invitations presents an opportunity for the relationship to grow into a caring one. This process is not as easy when it comes to reaching out on behalf of our family members. We grew up with the unwritten expectation not to complain and to take care of things ourselves. We are fiercely and justifiably proud of our self-sufficiency.

I let go and trusted. We moved fast and wild. I had no idea what it looked like, nor did I care. The dancer inside me was out.

BONNIE SHERR KLEIN

We may feel that extending even a casual invitation is risky. We worry that others will feel obliged—or worse—that they might be saying yes because they feel sorry for us or for our relative. This worry speaks to how deeply many of us have been hurt by negative cultural stereotypes about disability. It makes us forget the gifts our relative has to offer. It makes us forget that others may indeed care.

We need to remind ourselves of the beauty and richness our family member has added to our lives and to the lives of those around them. We often hear stories from ordinary people attesting to how their relationship with our sons and daughters has brought meaning to their lives. These are often people who wanted to reach out but did not know how. Each invitation we offer is an opportunity for others to extend their community and to broaden their relationships.

OPENING In order for others to come into our lives, there needs to be a place for them. It is impossible to meet people or deepen a friendship if we have no time to spend with them. This is an issue for many people with disabilities. Virtually all areas of their lives may be programmed. From an outsider's perspective, there is no apparent need for a friend. Our relative may be too scheduled for friends and acquaintances to spend time with them. We may need to give up a program or change schedules to create the space that would allow for others to engage with our relative.

On a more subtle level, some of our own actions might inhibit the involvement of others. Over the years we may have become used to doing many things for our family member. The presence of others changes our routines too. The involvement of somebody new might be threatening. Shouldn't we be doing it all ourselves? That's good, old fashioned guilt talking. We can do it better. But what if they do it better? What will they think of us? That's letting fear do the talking for us. As we feel ourselves losing some control, we may resist or undermine the contributions of others. We need to ask ourselves honestly and courageously what we are willing to let go of in order to make room for others to become active and involved in the lives of our relatives.

When you really think about it, this process of letting go is our lifetime task. It is why you are reading this book. Friendships provide a catalyst to accomplish this task. Our family members grow richer from having experiences outside of their immediate family. Their friends can inspire and encourage them to participate and contribute to society.

BELIEVING Of the three challenges, this may be the greatest. We worry that the distinctive traits or history of our relatives may make

them unloveable to everyone, that is, but us. We remember the absence of invitations to birthday parties or sleepovers. We notice, yet again, someone staring in the supermarket or when we receive a look of pity from a passer-by. We feel hurt by these things and we ache for our relative. Our overwhelming desire is to protect, and we cannot find it in ourselves to truly believe there is a caring community of people available to befriend our relative. This lack of belief affects our ability to be open to others, and to trust in their integrity.

The heart keeps looking for itself.
It knows and does not know where it belongs.

JAN ZWICKY

After a quarter century of nurturing Personal Networks at PLAN—and in dozens of locations around the world—we can assure you that no disability can prevent a caring relationship from forming. No previous experience, no characteristic, no behaviour, not anything. And we don't just believe this, we know this. The proof is in the hundreds of friendships that have developed within our Personal Networks.

In spite of the negative view of an uncaring society profiled regularly in the media, people do reach out to each other. PLAN's experience bears this out. People are genuinely hospitable and eager to become part of our relative's life. Often they just need to be asked.

Our challenge as parents and families is to not let our fears dominate the opportunities for friendship.

Significant contributions

Personal Network members make significant contributions because they:

- see the gifts and abilities of our relatives
- validate our relatives by letting them know they are valued
- help our relatives develop their talents
- create opportunities for our relatives to make contributions.

Relationships and contribution

Relationships play an important role in enabling our sons and daughters to contribute their gifts. From the comfort of supportive friends, family, and Personal Network members, people with disabilities can find opportunities to work, volunteer, create, inspire, care, serve, and contribute.

Our family members make contributions in two ways:

CONTRIBUTIONS OF DOING These are the action-oriented contributions we are most familiar with such as volunteering and working.

CONTRIBUTIONS OF BEING These are contributions made by the majesty of our relative's presence. Being present is an important way for our family members to make their contribution. The exchange is fellowship and communion. Our relatives offer grace, caring,

attentiveness, wonder, acceptance, silence, receptivity, compassion, inspiration, pleasure, gratitude, loyalty and friendship. These gifts—often overlooked in our society—are critical to society’s well-being. In fact, they are a necessary antidote to “too much doing.”

Identifying the gifts and contributions of our relatives leads to meaningful relationships. See Worksheet 5.

For more on the relationship between contribution and citizenship, see the Philia dialogue.

No disability precludes relationships.

VICKIE CAMMACK

That’s what friends are for

There is something about being human that makes us yearn for the company of others, to be with and to be touched by our family and friends. Isolation and solitude are devastating by-products of having a disability. We believe that these by-products are disabilities in and of themselves.

Loneliness can weigh even heavier when a person with a disability is served by a large impersonal service delivery system which has little time or resources to focus on friendships. The only way to truly diminish this loneliness is by paying attention to caring relationships. Even though this may be challenging for both our family member and for us, it is critical for their future security and well-being.

The keys to creating these connections are first, our willingness to let them happen and second, our effort to make them happen. All the

riches of the world will not compensate for the security of being cared about. That's what families do. That's what friends are for.

Reflections of a PLAN community

connector

I'M PRIVILEGED to have been a community connector for several PLAN networks. For some networks, the role simply involves planning a few gatherings a year. Everyone just shows up with their casseroles or salads, with stories to tell and contributions to make.

There are other situations where I need to figure out ways to invite more people into the network. In these cases, I must be creative and resourceful in my invitations and the places to go to meet new people.

Brad is one of the people I work with. When Brad joined PLAN, the only potential network member we had was his mother. Because Brad has no short-term memory, meeting new people is challenging. He can't remember with whom he has last spoke, what they have told him about themselves, and what stories he has already told them.

We went to Brad's old high school and were able to look through old yearbooks to see who he knew as a teenager. Because Brad's long-term memory is much better than his short-term, we hoped that he would recognize faces and names. He did, and now I'm trying to track down contact information for a couple of people.

One unlikely connection we have made is with Brad's dentist. Brad doesn't speak highly of anyone, except his former dentist. Recognizing how exceptional this is, I asked Brad for permission to contact the dentist. I discovered that Dr. Wincott drops by to visit Brad every few months! He is now part of the network.

.....

We recently connected with the company **Brad** worked for when he was **17** years old. Two of his old co-workers had lost touch with him several years after his accident. Soon we will all **be** meeting for coffee. As we talk **about** ideas and tell each other stories, I am learning more **about** some of the people **Brad** used to know. Now that he has come to know and trust me, **Brad** is comfortable with me finding these people.

Brad and I are still at the **beginning** stages of **building** a network, **but** it is growing in small steps. We **both** look forward to seeing what happens as more people come into **Brad's** life.

TINA DAM
PLAN Family Liasion



Tyze is a private, online service that works to create and maintain Personal Networks and is based on the proven PLAN network facilitation model.

Tyze brings everyone on the same page to create the best possible outcomes and to highlight reciprocity, exchange and meaning. Please visit www.tyze.com.

Nick's network

WITH SUPPORT from his friends, family, and caregivers, as well as his Tyze network, Nick goes to concerts, reads computer magazines, and even has a blog called *The Hockey Ambassador*. When he found out that some retired NHL players were going to be visiting his home town, he invited them over for a beer and used the internet to special order some Molson Canadian for the occasion. Nick has a vibrant life studying Information and Communication Technologies. Despite being largely bed-ridden with chronic pain, he lives an extraordinarily rich life. With support, Nick is able to study at the university. His team of friends and caregivers know when his assignments are due and are available to help him write reports and tests. He relies on his caregivers—some of whom only work once in a while—to book transportation to and from concerts, record NHL games, and bring him to hospital appointments.

It's a lot to remember, and a lot to coordinate. And that's where Tyze comes in.

Nick's parents, friends, and caregivers have come to rely on his Tyze network as a critical part of how they manage his care. Nick's parents—along with his live-in caregiver and other agency coordinators and professional caregivers—login to Tyze on a regular basis to see what medications and side effects they need to be aware of, what transportation might be required that week, and what personal projects Nick has on the go. Donna, Nick's Mom, tells us that they need to run a "faultless system that allows staff to coordinate everything in Nick's

life” which is a considerable task, given how busy he is.

Before they started using Tyze, there was a white board in Nick’s room with information for the current day as well as the four days prior, but the caregivers just didn’t read it. Donna still had to verbally communicate all the critical elements of Nick’s day and medical needs to each new caregiver as he or she arrived, and she worried that things would fall through the cracks.

With Tyze, communication is now ongoing and Nick’s caregivers have access to the information they need, whenever they need it. Tyze commands their attention in a way that the white board did not, in part because they are young and they understand computer communication, but also because the information is timely and relevant. Every time an entry is made regarding Nick’s care and schedule, his caregivers receive a message. Each caregiver knows that they have to start their shift by logging into Nick’s Tyze network to stay current.

Some of the caregivers access Nick’s Tyze site using their iPhones, so that they can send and receive messages while they’re on-the-go. Passwords, medication information, social activities and doctor’s appointments are all stored within Nick’s private, Tyze network so that his team of caregivers can share information and stories, and deliver the best possible care.

Nick is a sports fan, technology enthusiast and indomitable spirit with high hopes for his future. He’s curious about the world, and fearless when it comes to using technology. With the support and involvement of his friends, family and caregivers, Tyze is playing a significant role in helping him to achieve his dreams. It provides seamless

helping him to achieve his dreams. It provides seamless communication for all the people who have Nick's care as their common objective.

DONNA THOMSON

Shannon's smile

WHEN HIGH SCHOOL BEGAN, we suggested Shannon sign up for dance. We were told that there had never been a student in a wheelchair in that class before, and they weren't really sure how to include her.

I went into the first class with Shannon, introduced myself to the teacher and introduced Shannon to the class. A few of the students had gone to middle school with Shannon but for the others, meeting Shannon was a brand new experience.

It was an amazing year and the teachers have asked for Shannon to return. They say she brings a presence with her that changes the dynamics of the class, that the students are kinder and more patient when Shannon is nearby.

At the end of the term the teacher has the students write notes to each other. One of my favourites to Shannon was "your smile brings the room together."

Friendship

Some friendships last for several years.

Friends share the good and bad times together.

Friendship is about helping people by
being there for them when they are in trouble.

Friendship is about helping friends
deal with difficult situations.

Friends should always stay in touch with each other.

Friends should care about others enough
to try to support them in times of crisis.

When you are down, a friend can lift you up.

Some friendships last a lifetime.

JENNY BAKER

About Jenny...

In addition to writing poetry, Jenny enjoys shopping, hanging out with her sister, photography, Christmas and her birthday, and anything vampire.

To download a copy of all Worksheets, visit www.plan.ca and click on Safe and Secure Worksheets.

Worksheet 4

Relationship circles

For most of us, relationships with family and friends are what keep our lives on track. We have a whole range of relationships—family, partners, lifelong friends, work colleagues, neighbours, people with whom we share an interest, right through to people whom we pay to provide services.

For people with disabilities, these relationships are equally important but can sometimes be challenging to create.

We needn't leave friendships and relationships to chance. We can be really intentional and make it easier for people with disabilities to strengthen their networks. We can do this by enabling them to go to places where they can engage in existing or new interests, hobbies and passions, and have the opportunity to meet people who share these interests.

Use the relationship circles tool to look at the people your relative already has in their life. It will help to map out their community as well. It can be completed one-to-one, or with family and friends, or even brought to a network meeting to complete as a group.

In the relationship mapping diagram, the concentric circles are used to plot out relationships. Marsha Forest, Jack Pearpoint and Judith Snow describes these circles as:

- the circle of intimacy

- the circle of friendship
- the circle of participation
- the circle of exchange.

CIRCLE 1 The circle of intimacy is concerned with loving relationships and the anchors in your relative's life. In here, go the people your relative cannot imagine life without. Typically Mom, Dad, partner, closest friend, children. Your relative doesn't need to get along with them all the time!

CIRCLE 2 The circle of friendship is concerned with the friends and allies of your relative. Good questions to ask your relative are: Whom do you call/text when you've got good news? Who do you moan to when you've had an argument with your partner/your parent(s)? Who do you draw strength from, share a laugh with, and share your dreams with?

CIRCLE 3 The circle of participation is concerned with shared interests and a neighbourhood connection. In here are people your relative knows from clubs, committees, work, and so on. **NOTE** This circle is particularly important because it is the building block for circles 2 and 1. The more connections made in this circle will increase the likelihood of building meaningful connections in circles 2 and 1.

CIRCLE 4 The circle of exchange is concerned with paid relationships. In this circle are people like your relative's doctor, dentist, window cleaner, hairdresser, taxi driver, and so on.

What will emerge when your relative's diagram is complete is a picture of how your relative's network is or isn't in balance. For example:

- many people with disabilities have the same number as other citizens in Circle 1, but few in Circles 2 and 3 and markedly more in Circle 4

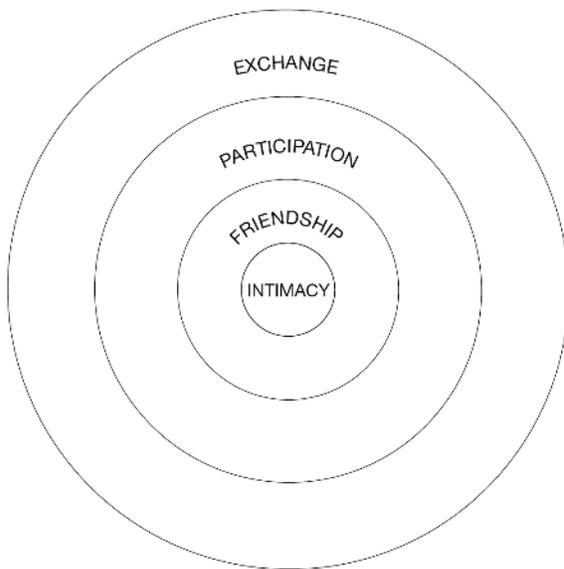
- some people with disabilities spend most of their lives with people who are paid to spend time with them, that is, those in the outer circle, the circle of exchange.

The main strategy for strengthening the inner circles is to bring people in to Circle 3, the circle of participation. These are people who spend time sharing an activity of mutual interest—anything from working together, playing a sport, sharing an art or craft activity, to going out for a meal together or going to the theatre.

Through participation, people become friends over time.

We also know that people don't come straight into Circle 2, the circle of friendship. Friendship doesn't happen instantly.

Relationship circles



Worksheet 5

Contribution

The following questions may help you identify the various ways your family member makes or could make a contribution.

We suggest you answer these questions and then share with your family member and others who know them well.

What contribution does your relative make to your family?

What are the three activities they love the most?

What are their passions?

What gives them the greatest joy and pleasure?

Who are their heroes?

What famous public personality (singer, actor, athlete) do they like?

What are their gifts of doing?

What are their gifts of being?

What would they like to learn?

What could they teach others?

What have you learned from them?

What positive attributes do others like about them?

What is the greatest accomplishment of their life so far?

What job or volunteer position would best suit their interests and personality?

Worksheet 6

Spirituality

Those who have a religion or spiritual world view may use this Worksheet to reflect on the things that make a good spiritual life for their family member with a disability.

Faith communities can provide a starting point for building relationships or networks. Whether we practice spirituality formally or informally, the human spirit always needs to be nurtured.

We hope this Worksheet will help put the pieces together to answer the question, “Who will ensure that the beliefs that our family member has developed over the years are continued when we are no longer around?”

Is going to a place of worship important to your family member?

How often do they like to go?

Do they need support to get there?

Where is that place?

Who is the main contact person?

Name and contact details

Is there any other organization connected with their faith that they wish to be a part of?

Do they need support to do this?

Who is the main contact person?

Name and contact details?

Does your relative's spiritual belief system involve any special dietary requirements?

If so, please explain.

Are there daily habits, for example prayer at mealtime, that are important to your relative?

What kind of support is needed to make this happen?

Are there any icons or pictures that should be with your family member, either in their house or carried or worn by them to keep their faith alive?

Are there any special days or festivals that should be celebrated?

How should this be done?

Is there anything else about your relative's spiritual belief system that should be noted?

Is there anything needed to make communication easier at the place of worship?

Is your family member accepted by the other worshipers?

Are there any physical barriers that prevent full participation?

If you are not around at the time of your relative's death, have you left instructions about the wishes for the type of funeral it should be?

step three

create a home

Home is the source of life itself.
Home is the garden where our dreams,
strengths and relationships evolve,
grow and flower in our journey of life
within our community.

Good times or bad,
there is no place like home.

ARTHUR MUDRY, PLAN PAST-PRESIDENT

The Bromley story

Dreams for Shannon include a home of her own

FROM THE DAY our son Michael was born, he began working on his independence. As a toddler, he would prefer to do things for himself rather than rely on us. As he started school and began playing team sports, he developed his own friendships and became even more independent.

Michael recently moved out and is doing well. He is happy, finishing up a four year program at BCIT, working and saving his money so one day he too can have a home of his own.

Shannon is completely dependent on us and always will be. At 18 years old, she has not started to pull away from us nor does she show any signs of independence. It will be up to us, the people who love her most, to make these difficult decisions for her: When will it be time for her to move out and begin her independent life?

We know that one day in the not too distant future, Shannon will need to move out of our family home, but where will she go?

We have always made plans for Shannon in keeping with the plans our son has made and, although he made his own decision as to when to move out, we will need to work with Shannon to find the right time.

We want to make sure that when the time comes for Shannon, it will be a permanent place for her to live. That, along with people that care for her she will have the choice of where to live and for how long

for her, she will have the choice of where to live and for how long.

Staff will come and go but if her home remains in her control then she will have consistency and familiarity, two things that will bring us all comfort.

In order to give Shannon the feeling of security, we will need to find the resources to purchase a home for her, one that is big enough to accommodate not just the staff she requires but also the roommates who will add to her social life.

Creating a good life for Shannon equates to good planning. We have to plan ahead when taking Shannon out for the day, and we certainly have had to plan ahead for her life yet to come.

We have worked with a financial planner to save, to make wise decisions with our investments, and have opened an RDSP to ensure Shannon's savings are available as she gets older.

We have gone through many scenarios of where Shannon will live and how we will find the funds to make it happen.

We bought our home 25 years ago. If we decide to sell it, we could put money towards two smaller condos, which would mean downsizing for us and independence for Shannon.

We would love for Shannon to continue to live in the only community she knows, where so many people already know her. We live in a city full of hills so it is important to us to find an area that is downtown, away from the hills, so Shannon can continue to get outside, to volunteer and to visit with people in her neighbourhood.

We also feel it is important that there are activities Shannon will enjoy nearby, such as parks where children play, theatres and a coffee shop

or two.

Shannon's decision-making skills are very limited so most of the major decisions will be left to us but we are very aware of the things she likes.

As far as decorating goes, in order to keep her space young and lively we will make sure to include both Shannon and a number of her close friends, a group that has grown up with her. These girls will definitely speak up on her behalf if we make choices based on what we like, rather than what Shannon would enjoy.

step three

Create a home

A HOME of one's own. This is the universal dream, occupying a powerful place in our individual and collective psyche. Home as haven and home as hospitality convey the intangible aspects of home. Home as feeling—the feeling you get when at the end of a long day you open your front door and exhale, Ah, I'm home.

In my book, *A Good Life*, I write about the essence of home having nothing to do with wood, nails, bricks, and mortar. Rather, it's about sweat and laughter, bruises and tears, stains and cobwebs, flowers and slammed doors, failures and promises, kisses and fingerprints. Home is where we can just be, where we become, where we belong. Home is not a program or a service—it is our haven and sanctuary, whether it be owned or rented.

The word “home” comes from a Sanskrit root meaning a safe place to lie down; a separation of outside from inside, defined by a threshold. Isn't that the kind of place we want for our friends and family members with disabilities? A place that provides continuity and security? A place that ensures privacy and reflects the personality of those who live there?

Only when you discover yourself can you be secure.

DAPHNE ODJIG

Making a house a home

Parents the world over rank a stable and hospitable living environment as a high priority for their sons and daughters. A house, however, doesn't become a home by accident. It requires thoughtfulness and care. It starts by understanding the meaning of home to your relative. What are they used to? How can you recreate that? How do you guarantee that a heap of living will take place there? See Worksheets 7 and 8 at the end of this Step to help answer these questions.

Some of our sons and daughters will want to have their own place. They'll want to live on their own or with people they know and like. They'll need very little staff support. Others will need intensive staff support.

Once this sense of home has been clarified, you can examine the type of tenure and other technical details that best suit your relative. For example, at the end of this chapter in Jackie's story, we will describe how the assets in an RDSP can be used to purchase a home.

Home can exist wherever you live and regardless of who owns or manages the building, house, apartment or room. The key to creating a home is to:

- have control over the home environment
- make sure it reflects your family member's personality
- ensure that your family member chooses their own roommates.

One of our past-Presidents is very satisfied with the group home her son lives in, and we have to say we agree with her. Every time she visits Peter there is laughter—surely one of the languages of home. Regardless of where our relatives live, we want them to have choice. We want our relatives to live in a place that respects their choices, a

place where their personality shines through.

Many of us cannot afford to assist our family members in purchasing their own homes because we're still paying down our own mortgages. There are alternatives to private home ownership, however, that will provide long-term stability. Housing cooperatives and land trusts, for example, have many of the advantages of home ownership. So does home sharing; that is, living with others who do not have a disability. If these options are not available or appropriate, we suggest you consider renting.

If mealtime is a renewable resource, then food is a social lubricant that can keep the machinery of involvement and interaction running between people with and without disabilities.

KAREN MELBERG SCHWIER AND ERIN SCHWIER STEWART

Rental accommodation—particularly rent to own—can allow people to establish a sense of their own place and to maintain control of their living environment. It may not be for everyone but being a tenant provides your relative with the flexibility to try different living arrangements, particularly when they are starting out and first leave home.

We see no reason why people who live in group homes and who need staff support for their personal care should be denied the benefits of living in a home-like setting. This may not be easy, but it is definitely possible. Not every agency appreciates the difference between house and home. You may have to search for the right agency. You may have to advocate. You may have to change your relationship with the

current service provider.

These options are more feasible now. The existence of microboards and the promotion of individualized planning and funding demonstrate a respect for the individual's wishes and a commitment to personalized, customized supports rather than catering to the needs of the group.

Home ownership means:

- control over where you live
- stability of tenure
- the opportunity to build up equity
- privacy
- a sense of place
- choice
- ability to offer hospitality
- security
- safety and comfort.

Limitations of current housing options

Governments spend millions of dollars every year on housing for people with disabilities. That's a good thing. The challenge for advocates and parents alike is to ensure that control of the home environment doesn't rest exclusively with the agency or service provider. The progressive agencies out there today are both responsive and sensitive to making genuine homes out of their group living arrangements. But families still worry. What if there is a change in staff,

the home supervisor or in agency leadership? What will happen if there are funding cutbacks?

It's not that group homes, semi-independent living, and other residential options are wrong. But they do have their limitations. In our conversations and meetings with families, the following concerns about the current residential service system for people with disabilities surface repeatedly:

- there is no control over where their relative lives
- individual needs may be secondary to those of other roommates
- someone else decides who your family member lives with
- the personality of the home is often shaped by the people who work there, not by the people who live there
- some group homes may not welcome the involvement of family and friends
- there is no security of tenure
- families fear the loss of caring and understanding staff and home supervisors, as these types of changes have an immediate impact on their family members.

As a result, more and more families are looking for alternatives that provide flexibility, continuity, and greater control.

Home ownership

Home ownership for many of us is the fulfillment of a dream, even if we have a hefty mortgage and are borrowing money from a financial institution. Home ownership can also be a good investment and a

hedge against inflationary times.

Many of us hope to own a home at some point in our lives. Until recently, this has not been the case for people with disabilities. In the past, it was a dream they and their families dared not consider. As our families members become more self-sufficient and as our plans to secure the future become more focused, home ownership for people with disabilities is becoming an option of interest. In fact, it is an option that more parents are exploring, more financial institutions are supporting, and governments are welcoming. If you are interested in exploring home ownership options, PLAN can put you in contact with families that have already done so.

Whether the home is owned directly by your relative, owned jointly with you or others, or owned by their trust, for as long as they like, your relative will have a choice in where they live, whom they live with, and in the staff they hire. As one mother put it, “Roommates will come and go, support services will change, that’s a given. But whether I am around or not, I know that the house—or I should say the home—will be there for my daughter.”

Critical components of home ownership

As you might expect, making arrangements for home ownership for your family member can be complicated. The mix between financial and legal matters, health and safety concerns, and social support adds more considerations. It means paying attention to a number of critical components.

FINANCING THE PURCHASE Unless you are independently wealthy, this is a major challenge. The Registered Disability Savings Plan (RDSP) provides families with a means to begin saving for the

purchase of a home. The matching Canada Disability Savings Grant, the Disability Savings Bond, and compound interest will increase the size of the capital your relative will have available. Details of the RDSP are discussed in Step Five.

Other financing options used by families include:

- re-mortgaging the family home to access additional capital
- forming a partnership with other parents to purchase a home
- taking out a reverse mortgage
- working with local developers who, in return for zoning concessions from municipalities, will make affordable housing available
- earmarking part of their estate to establish a housing trust exclusively for the purpose of purchasing a home
- purchasing life insurance to finance a home or establish a housing trust renting out the other bedrooms to help finance mortgage payments.

ASSISTANCE WITH RENOVATION The Canada Mortgage and Housing Corporation (CMHC) under two programs—the Residential Rehabilitation Assistance Program (RRAP) and the RRAP-D program—offers financial assistance to homeowners and landlords to improve their dwellings so they are more accessible to persons with disabilities. The amount you receive is based on the cost of mandatory repairs and the area in which you live. Currently, the maximum loan amounts range from \$16,000 to \$24,000. A certain amount of the loan may be forgivable, depending on income. Higher amounts of assistance may be available in more remote areas. For further information, see

Resources in order to contact CMHC of BC and the Yukon.

OWNERSHIP Here are some home ownership options you may want to consider for your relative:

- they have direct title
- they co-own the house with another person (for example, their spouse or a family member)
- you own the house together
- at least two families own the home
- your family member lives in a housing co-op that can build up equity
- your family member rents to own
- you arrange financing for your family member to live in a co-housing development. All financing (for each unit and the common areas) comes from the owners of all the units
- the house is owned by a trust in your family member's name (or by joint trusts if two or more people with disabilities are involved).
The trust(s) can be established:
 - while you are alive; or
 - through your estate after your death.

The future has already arrived.
It's just not evenly distributed yet.

WILLIAM GIBSON

TYPES OF CO-OWNERSHIP If more than one individual or family owns the home, you must choose one of these legal co-ownership options:

- joint tenancy; or
- tenancy in common.

HOUSING TYPES Just about anything is possible:

- single family
- condominium or row housing
- housing cooperative unit
- co-housing
- apartment
- mobile home
- infill housing (for example, converting a garage into a small housing unit)
- renovation of an existing house
- purpose-built housing designed for your relative's needs; for example: shared kitchen, dining and lounge areas.

ONGOING MAINTENANCE If you purchase a house, you will need to

make arrangements to cover:

The ongoing mortgage payments

- Will government income assistance be enough? If not:
- When you are alive, will you supplement the mortgage payments out of a living trust, from family resources, or from some other source such as the RDSP?
- After your death, will the payments come out of a trust?

The major maintenance, repair and insurance costs as well as property taxes

- Will you pay for these costs yourself while you are alive or will you establish a living trust for this purpose?
- Will you establish a trust to cover these costs after your death?

NOTE It is critical that you consult with a knowledgeable lawyer to establish the trusts referred to above. For example, you may want to ensure that you do not jeopardize your relative's entitlement to government benefits. BC disability assistance benefits have a housing cost component which is dependent on costs incurred. You may want to structure payments with this amount in mind.

Joint tenancy

Property owned jointly by two or more persons in which the surviving joint tenant(s) becomes the owner of the entire property when one of the joint tenants dies.

Tenancy in common

Property owned jointly by two or more people. Upon the death of one of the tenants-in-common, ownership of the deceased's shares is transferred to that person's estate, not to the other joint owner.

The minor, ongoing maintenance

While this can be done by yourself in the short term, you may want to consider contracting with a property management company to provide this service. In addition, this may be a service you will need to request your trustee to provide. If your relative lives in a condominium or a housing cooperative, property maintenance is already built into the housing agreement.

NEGOTIATING FUNDING FOR PROGRAM SUPPORT STAFF

Unless you have the private means to pay for staffing supports, you will have to negotiate funding from government. Generally speaking,

government is becoming more interested in supporting people to live in their own homes. After all, it represents a big savings if the capital costs of the home are not its responsibility. We suggest you use this argument when negotiating the supports necessary. You can argue that since you are financing the house, the government should finance staff supports.

Everyone benefits when everyone belongs.

SELECTING COMPATIBLE SUPPORT STAFF Not every staff person will be comfortable working in your family member's private home. Many staff will see it primarily as their workplace. We suggest you spend time clarifying in writing the values that are important to your relative. When hiring through an agency, become familiar with their operating philosophy. Interview their executive director. Visit some of their programs. Get to meet the people who receive services from them. Talk to their families.

Do not be afraid to let staff go if it appears they are not compatible with the values established for the home.

CHOOSING A COMPATIBLE ROOMMATE There is no scientific approach to this challenge. Some people are easy to get along with, others are not. Often you won't know until you try. Many of the people who are now living in their own homes first tried living on their own in some form of rental accommodation. Then they invited someone to live with them. This is an excellent way to test the kinds of support you and your relative will need. It also enables people to have a better sense of who they want in a roommate.

TECHNICAL ADVICE FOR CONSTRUCTION AND RENOVATION

We'll leave you to your own devices with this component. You will be able to access building contractors in your area far better than we will. Accessible building design advice is available from local disability resource groups if you would like additional expertise. Other parents are a good connection for families who are considering construction or renovation. Check the Resource section for additional contacts.

Looking to the future

Times are changing. More people with disabilities are gaining a measure of choice and control over their lives that they have never experienced before. When established with due respect and consideration for the issues identified here, home ownership can provide families with a concrete component of their plan for the future. Families see themselves as part of the solution. With tax and trust concessions, more and more families will be willing and able to invest in the housing future of their relatives with disabilities and to partner with government.

This Step, Create a Home, connects with the other steps in this book. Without the existence of a network of personal support, our relatives will be just as isolated in their own place as anywhere else. Similarly, you will need to use your Will and trust agreement (see Step Five) to formalize the arrangements to own or rent, as well as to make provisions for housing maintenance.

In addition, the next Step, Make Sound Decisions, provides an overview on supported decision-making. This Step will assist you to protect your relative against exploitation in their home, to support their choices, and to monitor the home arrangements that have been made.

Aaron

If you can dream it, you can live it

RECENTLY WE HAD a little party, a celebration. We were marking the five-year anniversary of the day our son Aaron moved into his own home. We had the usual dinner, dessert with family and friends and, of course, Aaron, the guest of honour.

It started with a partnership opportunity with Aaron's uncle to purchase a nine-acre farm with a 60 year-old house on it. The property was close enough for us to be available, but not close enough to infringe on the privacy of Aaron or his caregivers. The dream was to plant grapes to help provide an income for the partnership.

Many details later, and soon we owned this dream property. From the very beginning, Aaron was involved and knew that this would be "his" house.

With the help of a Giving in Action Grant, renovations were underway. We added an ensuite bathroom for Aaron's room, redid the original steep stairs to code, added stair handrails, and built another common room so that everyone had a bit more space. We also fenced the yard to keep Aaron safe from the road.

Aaron visited almost daily. We talked a lot about when he would live there, always thinking of how to make this transition as easy as possible for all concerned.

We could see the house from our home and would say, "Aaron, show me where your new house is," and he would go to the window and

me where your new house is, and he would go to the window and point up the road to it.

We put the word out through our family and our network that we were looking for a couple under **30** years old to live with Aaron. Friends of our daughter Lisa were chosen. **Both** had previous work experience with Easter Seals as camp counselors.

After the whirlwind of preparations, the actual move was anticlimactic. Aaron settled in straight away and was thrilled with all the social activities that normally take place in a household of young folks. They held events like spaghetti night in Canada (potluck party), and games and movie nights.

We knew all would **be** well when we picked Aaron up for a family party. We saw him lean in for a kiss and hug goodbye from his housemate. This from a kid you almost have to **bribe** to get a kiss from! When we **brought** him **back** home, we were apparently spending too much time **gabb**ing. He leaned over, opened the front door and, putting a hand gently on my shoulder, said a very clear **“Bye”** and gave me a nudge out the door.

We try very hard to make sure everyone feels well supported and that they know they can come to us when they are unsure or need help. We don't want anyone to **burn** out.

The transition was harder on us than it was on Aaron. Eventually, we adjusted to having an empty nest. And now we sometimes forget to tell the caregivers when we are leaving town **because** we know Aaron is in **capable** hands. Social media certainly helps keep us all connected.

Aaron is a happy, successful young man in his own home and community.

Aaron is a nappy young man, secure in his own name and surrounded by interesting people and opportunities. Over the past five years we have learned some very valuable lessons:

- you can't do it alone. People love to help, so ask for help and support when you need it
- have a good working relationship with the people at Vela Microboards, CLBC, PLAN and any other agencies that support your dream
- to show others what is possible, we share our stories with families at Family Support Institute
- if you can dream it, you can live it. This doesn't mean that it won't be difficult but, when looking back on Aaron's PATH, we are very pleased with all that has been accomplished
- share your successes. People love to celebrate and if there is food involved, even better
- you have to trust your gut feeling with the people you hire and make sure your lines of communication are always open
- last but certainly not least, do not underestimate our sons and daughters! We are sometimes afraid to take a chance but if we listen carefully, they will tell us what they need.

LAURIE PAYNTER

Sean

A rock solid foundation for Sean

SEAN SPENT MANY YEARS in a children's hospital with complex medical needs. As is hospital policy, when he turned **18**, he needed to find an alternative arrangement.

The easiest choice would have been to move him to another hospital. But in a hospital he would be known, for the most part, as "Sean the quadriplegic patient with a tracheotomy who must be turned every couple of hours."

Those closest to him wanted more. The solution was a subsidized co-op apartment that was renovated to suit Sean's needs. The master bedroom was expanded and the closet moved. The doors were widened and hardwood floors were installed.

The bathroom was changed into a shower room with a shower cart, and tracking was installed to help lift him.

Sean's preferences were considered when designing the lighting and acoustics. Since this was Sean's first move out, the government funded **100%** of the renovation. Personal support workers were hired through an agency.

From day one, Sean was thrilled with his new home; he was so excited to be in this new place.

It's not the physical environment that makes this an ideal solution for Sean. His home is an intimate environment where his friends can spend time with him, and those working with him can be sensitive to

spend time with him, and those working with him can be sensitive to his needs and preferences.

The people who help Sean make decisions are really in tune with his body language and the way he is feeling about things so, for example, if he likes something, he'll tilt his head towards it, with a big smile on his face, and looks relaxed sitting in his chair.

Sean doesn't own his apartment, but his tenancy is very secure. The building won't be sold and his rent won't be raised.

Although she was initially apprehensive—as any mother would be—Sylvia is elated with Sean's new life. “Just having regular caregivers so he gets to know each person, and having that one-to-one contact with each individual. Sean gets out into the community...it's very important to let him see what the city—what life—is all about. He's really flourishing in this setting. He's genuinely happy and far more talkative... it's that one-on-one contact with people that is bringing out the best in Sean.”

And 12 years later, Sean is content, very vocal and happy. Sean really benefits from knowing what to expect: a now very familiar and regular routine, combined with familiar people and support staff has created a rock solid foundation from which Sean can enjoy life and his surrounding community.

Greg

Superman settles in

IT TOOK MANY SETBACKS and much heartache before Greg could finally call a house a home.

For years, Greg and his family dealt with the limitations and frustrations of group homes and institutions. According to his brother Scott, “it felt like the family was taken out of the picture. He emphasizes, “actually, it felt like Greg was taken out of the picture too.” Now that Greg’s life is so much more positive, his family and friends want to give other families hope.

Greg was blamed for his so called “inappropriate behaviours” and his inability to cope well in situations that most of us would find very difficult. Sharon Disanto, Greg’s friend and advocate, explains: “It’s not the person’s fault if their home isn’t working, it’s a failure of the system to find the appropriate supports for that person.”

For too long, Greg received mental health services that that weren’t compatible with his developmental needs, and he received services for people with developmental disabilities that lacked understanding of his mental health needs.

Now, he has a private clinical team, separate agencies for “residential services” and “day program,” and a one bedroom house without any roommates, except support staff. Greg’s staff knows him well, and it is clear that he trusts them.

Most importantly, Greg’s new staff recognizes his gifts. Sharon recalls

Most importantly, Greg's new staff recognizes his gifts. Sharon recalls a meeting years ago where Greg's medical team concluded that he had no gifts. "I'd probably yell and scream too," she suggests, "if the people who were supposed to be caring for me thought I had no gifts. Greg's family helped carry the memory of what Greg was like when he was well and, after many difficult years, his brother Scott smiles, "Now we can hang out. He talks to my kids, and asks me how I'm doing," explains Scott. "The old Greg is back."

Scott and Sharon credit Greg for having gotten through many extremely difficult experiences. "We helped, but Greg is the one who got through this," says Sharon, "he is a survivor."

As Scott reflects on his brother's difficult journey, he smiles, "You know, for years Greg has always tried to convince us that he was Superman... I think he's kind of proven to us that he is."

ERIN HOLLAND

Examples of housing solutions

Given the complexity of issues and the unique circumstances of each individual and family, the following examples should serve only as illustrations of what is possible.

EXAMPLE ONE

Starting young: Jackie

Background

All Jackie wants to talk about is her last dance class, the time her choir went to Montreal, and the sleepover with her classmates at the Vancouver Aquarium. Grade 4 is a time of wonder and learning.

Don and Jasvir are more serious. Conversation reflects their concern for her security and continued happiness. “We take our choices for granted. Knowing that Jackie will have enough money to pursue her dreams is important to us,” says Jasvir. They see the RDSP as a way of ensuring that she can make personal choices when deciding her future. They want her to be able to go where she wants to go, to do what she wants to do, and to make choices that make her happy.

Don and Jasvir have discussed the RDSP and are planning to contribute \$150 a month for the next 20 years. Jackie’s grandparents also want to help. They’ve talked about contributing \$25,000 to her RDSP at the start.

When Jackie is 39 years old, her RDSP will be an estimated \$362,000. If she purchases a life annuity, she will have annual income in excess of \$18,000 per year.

Another option is to use a lump sum from the plan to assist their daughter in purchasing her own home. If they withdraw \$200,000 as a down payment when Jackie is 39, she can purchase an annuity that

will pay approximately **\$8,000** per year for the rest of her life.

RDSP Summary:

Family taxable income: over **\$78,130** Annual family contribution: **\$150** a month (**\$1,800** a year) Family contributions from age **9** to **28**: **\$61,000** (including **\$25,000** from grandparents) Value of Grant: **\$45,000** Value of Bond: **\$10,000** Investments: moderate risk. Age to begin receiving from the plan: **39**. Approximate value of the RDSP when payments begin (age **39**): **\$362,000**.

Option A: No home purchase

Annuity payments: approximately **\$18,000** per year.

Option B: Home purchase at age **39**

Withdrawal of **\$200,000** for down payment Annuity payments: approximately **\$8,000** per year.

EXAMPLE TWO

Patricia, living in an apartment

Background

Patricia is a **38**-year-old woman who lives on her own. After sharing a rental apartment with a friend for three years, Patricia moved into a housing cooperative where she stayed for two years.

Patricia's grandmother had left her a large sum of money which she had placed in a discretionary trust. John, Patricia's father, is the trustee. When Patricia decided to move out of the housing co-op, she and her Dad began to look for an apartment unit she could own. They found an affordable one-bedroom unit, centrally located near a large shopping centre, close to major bus routes and a short walk to the Skytrain.

Financing

The apartment unit cost **\$225,000**. Patricia's Dad contributed **\$21,000** of his own money. The discretionary trust contributed **\$135,500** in a no-interest second mortgage. Patricia took out a first mortgage for **\$68,500**.

Features

- Patricia has title to the apartment.
- Since her Dad owns only a tenth of the apartment, Patricia is the principal owner. As homeowner she is eligible for the homeowner's grant. Also since this is her principal residence, the apartment is not subject to capital gains should it ever be sold.
- The fact that Patricia's father owns approximately a tenth of the apartment prevents a dishonest person from persuading Patricia to sell or to order major repairs.
- Should the apartment ever be sold, Patricia's father would get his money back and the amount of the second mortgage would be returned to the discretionary trust.
- The mortgage payments equal the shelter component of the BC disability assistance benefits that Patricia receives.

EXAMPLE THREE

Thomas, staying in the family home

Background

Thomas is a **48**-year-old man who currently lives with his parents. They want him to remain in the family home after they die. When that day arrives, the house will be placed in a trust for Thomas's continued use. To support Thomas, the family has arranged to establish two trusts (a

residential trust and a family trust) and a microboard (see the Resources Section for more information).

Financing

The parents' estate plan provides for the home, including furnishings, to be left in a discretionary trust for the primary use and benefit of Thomas. The family calls this the "residential trust." The trust would have a small amount of funds to cover minor repairs.

A separate discretionary financial trust will provide additional assets to cover maintenance of the home, property taxes, extraordinary expenses, and the quality of Thomas's life. The family calls this the "family trust." Community Living BC (CLBC) will be asked to contribute funding towards the daily support needs of Thomas. For CLBC contact information, see Resources.

Features

- Thomas continues to live in an environment that is most familiar to him.
- There will be a small microboard. This microboard consists of three people (a family member/advocate, a co-trustee, and a Personal Network member) and will have the authority to contract with CLBC. This funding will allow the microboard to contract with service providers. They will also monitor the quality of the care.
- Two or more compatible people will live in the home with Thomas and provide a caring and harmonious living environment. In return, they will live rent-free and enjoy the home as is customary under traditional rental contracts.
- Should it become necessary to sell the home, the Will contains a provision that the trustees can do so and use the funds from this

transaction to acquire an equivalent home for Thomas's benefit. Any surplus funds will be placed in the family trust.

- As the trust owns the property, it will most likely not qualify for the homeowner's grant or supplement.

EXAMPLE FOUR

Surinder, living in a condominium near the family home

Background

The Kalathils live in the Interior. Gopal and Dal purchased a two-bedroom condominium for their 28-year-old son, Surinder. The complex is located within three blocks of the family home.

Financing

Total cost of condominium: **\$170,000**. Down payment from the parents: **\$140,000**. Surinder's monthly mortgage payments are approximately **\$300** over a **20** period.

Features

- Ownership of the home is between the parents and Surinder. As financial protection, Surinder granted his parents enduring Power of Attorney.
- Upon the parents' death, complete ownership of the home goes to Surinder. Surinder's sister and her husband will have Power of Attorney.
- One of the bedrooms will be rented to a roommate for Surinder.
- A team comprised of a representative of the family, the service delivery organization, and the family of Surinder's roommate will oversee the maintenance and operation of the condominium.

It feels like home

MY WIFE AND I live in an intentional community called “cohousing,” a type of collaborative housing in which residents participate in the design and operation of their own neighbourhood. Cohousing offers many creative options for folks in how they choose to live together.

One of the first things we did as a community before the houses were built, was to establish a set of shared values. Our 31 families came to an agreement that diversity would be one of our most important values. Our dedication to diversity and a commitment to supporting each other have been, I believe, very important in creating a nurturing environment for one of our members.

Sophie, a young lady who had recently completed her secondary education, was eager to establish an independent life of her own. For a variety of reasons, her parents weren't comfortable with the idea.

Our cohousing community was in its forming stage at this time and only a short distance from Sophie's family home.

Our values of diversity and mutual support presented a very viable living option for Sophie and her family. They purchased a home where, surrounded by neighbours, Sophie has lived for nine years.

Over the years Sophie has become a solid and contributing member of our community, supporting and being supported by her many neighbours and friends. Her parents are within walking distance and are very active members of our community.

Sophie has volunteered her skills with figures and computers, and

pays our community's many invoices. Through a connection in our community, she augments her pension with clerical work at our local community school. She also has a part-time job at Canadian Tire.

Most importantly, Sophie is a valuable and respected member of our community, and has developed close relationships with several families. In many ways she has achieved her goal of independence.

There is no question that Sophie has flourished here, but so have most of us in one way or another. Over the course of our lives, many of us will experience some form of disability and I feel that the support that is often provided by an intentional community can assist all of us in becoming more able.

Interview with Sophie

How did you come to be in RC Cohousing?

I was 20 and didn't want to live at home anymore. I didn't want to live in a group home and my parents were against me living by myself in an apartment in town. And then we heard about cohousing which was going to be built very close to my parent's. Mom and Dad bought a house and I've been living here for nine years.

What were your first impressions of life in our community?

(S) People were friendly and said hi to me. I met Hilary at a meeting and we became friends.

Do you make friends easily?

No. I'm shy but not as shy as when I was in high school. Working at Canadian Tire helped me to talk to people.

After nine years do you have a sense of belonging?

After nine years do you have a sense of belonging?

Yes. It feels like home.

How do you contribute to the community?

I write out cheques and distribute them to members who have bought things. I also get the cheques signed by people on the finance committee.

GARY KENT

Life Is ...

Life is not easy but it can be

Life is a miracle

We get down sometimes but we do not stay there

When we are up we lift others with us

It really helps to have faith

Life is full of challenges and surprises

There are lots of joyous and precious moments

It is freedom to do certain things with your family and friends

It is about making mistakes

It is full of risks

Sometimes we are sad but sometimes we are glad to know

that we are alive and can feel whether we are sad or glad

So I decided to turn around and be happy instead of sad

When I look at the sun, I remember life has begun with light

JENNY BAKER

To download a copy of all Worksheets, visit www.plan.ca and click on Safe and Secure Worksheets.

Worksheet 7

Welcome mat

These are questions you can discuss with your relative. Have some fun and use a variety of props to facilitate your discussion: perhaps have your relative draw a few pictures or make a collage of cutouts from magazines.

What kind of home would you like to live in?

Would you like to live by yourself or with other people?

Who would you like to help you live in your own home?

What would this person help you with?

Where do you want to live?

Why do you want to live there?

What do you want to live close to? (a park, church, recreation centre, bus route, shops, and so on.)

What is your favourite room?

Do you have a favourite chair? Would you like to have one? Which room would you place it in?

Where would you place your favourite things?

What kind of furniture will you need for your own place?

What furniture from your family home would you like to have in your own home?

Would you keep a pet? What kind?

Would you like a garden?

Do you like to cook? If so, would you like to have a big kitchen?

Would you like to have a quiet room?

Which room would you like to have music in?

Do you like doing dishes?

Do you like to clean the house?

Do you like to mow the lawn?

How would you decorate:

Your living room?

Your bedroom?

Your entrance?

What colour would you paint the outside of your house?

How would you welcome visitors to your home?

When you came home at the end of the day, what would be the first thing you would do?

Worksheet 8

When is a house a home?

Here are some simple guidelines and questions to help you evaluate the home-like quality of residential services.

Whose house is it?

Are the individuals who live in the house the ones to determine its structure and tone or is the house geared to suit the staff hired to provide service?

For example, are there pictures and other personal mementos scattered throughout the house or are these personal items restricted to the individual's bedroom? Do the staff use their computers in the home as if they were working in an office?

Use your home and your own life as yardsticks for comparison. Do not accept, "well, it's better than where they were." Instead, ask yourself, "Is it as good as I have now?" and "Is it as good as I would want for myself?"

Look around

Are there locks where they are not needed; that is, on the refrigerator, on the clothes closets, and so on?

Are there no locks where they are needed; that is, on bathroom doors, bedroom doors, filing cabinets, medicine cabinets, and so on?

Do people have the same amount and variety of possessions and personal articles as other people their age?

What does it feel like?

Are the rooms comfortable? How about the couch? The chairs?
Could you relax here? Does the place feel like a home?

Take a moment to listen

Can you go somewhere for a little peace and quiet? Are there conversations among the people who live here?

Smell

Do you get a scent of home made dinner on the stove or dessert in the oven, or do you smell institutional cleaners and odors?

Taste

Would you enjoy the food that is served or would you merely tolerate it?

Ask

What are the rules? Are they excessive or overly restrictive? Do they make sense to you? Who makes the rules?

Infer

Do the people who live here experience a home with some added support, programming, and needed supervision? Or do they experience an institutional program with a few home-like qualities?

Analyze

What compromises have been made in the name of budget limitations, programming practices, staff needs, and so on? In what ways do these compromises detract from a home-like atmosphere?

Ask yourself

If an opening came up tomorrow, would I ask to move in?

step four

make **sound** decisions

Not being able to speak does
not mean I have nothing to say.

KIRSTEEN MAIN

The Bromley story

A smile that says it all...

SHANNON REQUIRES assistance for all her needs. She is unable to walk or talk, and communication is very subtle. We rely on how we are feeling—hot, cold, hungry, and so on, to make her comfortable.

She is unable to hold onto anything or direct us to what she wants. This means there is a lot of “educated” guesswork involved in Shannon’s daily life. We rely on past experiences for activities that have made her happy.

When Shannon is enjoying something she has the most amazing smile, as noted by her grade 12 peers who selected her as the person with the best smile. When Shannon’s not happy, watch out: her furrowed brow and stuck out bottom lip will quickly let you know. Preparing Shannon for the adult world is quite a process. One of the pieces that took a lot of thought was selecting the people in Shannon’s life who would be willing to help us keep on track, to help us with some of the major decisions that are coming up, and as a way for us to accept individualized funding to allow Shannon options in her adult years.

When making plans for Shannon after graduation, Rob and I looked for a lifestyle that mirrored the activities she enjoyed while in high school. A combination of attending post-secondary and volunteering feels right to us, but we know only time will tell if these decisions will be right for Shannon.

step four

Make sound decisions

WHEN you get right down to it, worrying about the safety and security of our relatives is a paradox. On the one hand, we want to protect them from discrimination, exploitation, abuse, neglect, and injury. On the other hand, we want them to have a good life—a life where they enjoy themselves, where they get to try new things, a life where their choices are respected. We want to teach our relatives how to survive and work through adversity. We want them to learn from their mistakes, as all of us must. We want people to recognize their ability to make decisions and to support them to make sound decisions. This type of self-determination makes a life worth living.

When our children are young, we make the important decisions on their behalf. When they reach the often complex and challenging time of adolescence, however, it is necessary to start thinking about meaningful ways to include them in the decisions that will impact their future lives. Being aware of, and implementing, sound decision-making practices now will create an important strand to your relative's safety net as they make the transition from childhood to adulthood.

It's a delicate balancing act faced by families the world over: Keeping our relatives safe while at the same time respecting their choices. Make no mistake about it. This balancing act is a tough challenge. Families find it difficult. So do service providers. So do government and its institutions.

Do not see me as your client.
I am your fellow citizen.
See me as your neighbour.
Help me learn what I want to know.
NORMAN KUNC

Fortunately, British Columbia has developed a legal option which enables our adult family members to get the support they need in order to make good and safe decisions without taking away their decision-making power which strip them of their rights as citizens.

This Step will describe Representation Agreements, an alternative to adult guardianship. For those with young children, this discussion about Representation Agreements won't be relevant until your relative turns 19. For information on choosing a guardian for your minor children, see Choosing a guardian for children under the age of 19.

Choice is like a muscle: if not exercised, it will atrophy.

It starts with choice

A good life includes honouring the choices of our relative. This means recognizing their tastes, preferences, and values; it also means acknowledging our relative's ability to discriminate, to select, and to choose. We know how determined our relatives can be to express their approval or disapproval. We know they often are aware of their limitations and exercise prudent judgment in the face of it. We know

they have views and opinions on a variety of topics. Unfortunately, not everyone is aware, understands, or accepts the capability of our family member.

The assumption of others that our family members don't have opinions or cannot make decisions is an added hindrance. This can lead to ignoring their wishes and eventually making all decisions, big and small, on their behalf.

We want the people involved with our relative to see what we see: A person capable of making their intentions known. We want the people in their lives to be patient, to be willing to listen and to watch, and if necessary to be willing to learn our relative's unique and perhaps non-verbal communication style. We know that all behaviour is a form of communication and we want our relatives surrounded by people who will take the time to search for that meaning.

We are wary of people who won't make an effort to learn how our relatives express themselves, who are too busy, or who ignore—and perhaps worse—think they know what is best for our relative.

Once there is recognition of their choice-making ability, we can turn our attention to supporting our relative to make decisions. This may mean, in certain circumstances, speaking or making decisions on their behalf. We do this informally when we set up a joint bank account or when we accompany them to a medical appointment. This type of supported decision-making is formally recognized in British Columbia when our relative creates a Representation Agreement.

We believe in nurturing the decision-making ability of our relative rather than giving someone else the power to make decisions on their behalf. The decision-making ability of our relative can be nurtured by:

- respecting their inherent decision-making **ability**
- enabling their own, authentic decision-making **voice**
- presenting them with genuine choices
- helping them to sort out and understand the options, and
- supporting them in making the actual decision.

In reality, many people with disabilities are offered few choices in their lives, which can lead to them becoming passive and submissive. By contrast, when we surround them with people who respect their capacity to make decisions, we also create the conditions for our relative to become a self-advocate. This reduces the risk of exploitation, neglect and abuse. Ultimately our relatives are safer when they are able to speak for themselves.

Is offering choice too risky?

How big a risk are you prepared to take?

Can you balance safety with choice?

Whom do you trust?

Take Tim's situation, for example. When we first met Tim his caregivers made all his decisions. They decided what he should wear, what he should do during the day, what time he should have dinner, and so on. These decisions were based on what suited his caregiver's schedule. Tim was never consulted. For example, Tim loved country music but his caregivers didn't so he never had the opportunity to listen to the country music station.

Over time, Tim retreated so far into the background of his own life that

he might as well have disappeared. Fortunately Tim and his family joined PLAN. As his Personal Network developed, so did the relationship between Tim and his staff. Eventually new caregivers were hired based on their willingness to learn Tim's communication style.

Change is a constant

It is hard to predict what we or our relatives will have to adjust to, and what critical decisions will have to be made in the future. We can make educated guesses about some of the areas we want protected for our relative, but there are no guarantees. Rather than wasting our energy on trying to control the uncontrollable, we suggest you prepare for any eventuality by providing your relative with the best possible people to assist them in making their own decisions.

Supported decision-making for our relative means:

- they actively participate
- their views are sought and taken into consideration
- they are surrounded by caring, knowledgeable, trustworthy people who can assist with their decision-making and communicate their decisions
- their needs are the primary consideration, not the needs of staff or the service system
- the focus is on their abilities and wishes
- all their choices and options are considered
- their tastes, preferences, motives, and ability to discriminate are taken seriously
- their risks, failures, and mistakes are recognized as learning opportunities.

Relationships are the foundation of sound decision-making

By now it should come as no surprise that relationships and Personal Networks have additional benefits—they enable good decision-making

and assist to protect and keep your relative safe.

The first order of business, therefore, is to consolidate your relative's friends and supporters into a network. Members of a network can monitor the services and programs your relative receives; they can also advocate to ensure the quality of those services and programs.

Network members are often more than willing to support good financial, health, and personal care decision-making for your relative.

Some network members are willing to be appointed as

Representatives in the Representation Agreement your relative creates.

In some cases, the creation of a Representation Agreement can be the spark for establishing a Personal Network for your relative.

Progress always starts with bold ideas.

Representation Agreements: supported decision-making

Representation Agreements enable adults to get decision-making support without having to go to court or without having to be declared incapable. This is an exciting, practical, and low cost option for your relative.

It is important to recognize that a Representation Agreement belongs to your relative and not to you. You can help your relative create one, but it is a legal plan signed by your relative conferring authority to representatives they choose to assist them to manage their own affairs. If you want a Representation Agreement yourself, and that would be advisable, you should create your own.

There are two types of Representation Agreements: Standard (Section 7) and Enhanced (Section 9). The Standard Agreement covers routine financial, health, and personal care authorities and is more than adequate to provide support for most of the decisions our relatives will make. See Enhanced (Section 9) Representation Agreements.

The Representation Agreement Act recognizes all forms of communication, verbal and non-verbal, and assumes your relative is capable of making a Representation Agreement unless the contrary is demonstrated.

This means there are no specific requirements with respect to capability to create a Representation Agreement with standard powers. However, there is always the possibility that your relative's capability to make an Agreement could be challenged by a bank, a hospital, or someone who is not familiar with people with disabilities making their own decisions.

It is prudent to be transparent and thorough when you assist your relative in creating a Representation Agreement. For example, you can describe the ways your relative communicates their likes and their dislikes.

Should it ever be challenged, two important factors in determining capability include:

- the existence of a trusting relationship between the adult and their representative(s); and
- evidence the adult demonstrates choices and preferences, and can express feelings of approval and disapproval of others.

Standard Representation Agreements cover:

- personal care: diet, exercise, living arrangements, maintaining spiritual and religious traditions, arranging home support, caring for pets
- routine management of financial affairs: banking, applying for and dealing with benefits, insuring or selling motor vehicles, managing existing loans and insurance, dealing with income tax, making or disposing of investments, and so on
- major health care: surgery, general anesthetic, kidney dialysis, chemotherapy
- minor health care: medical examinations, immunizations, medications.

The Standard (Section 7) Representation Agreement does not require a lawyer or a notary, although you can retain a lawyer if you wish. Otherwise, the Agreement can be prepared by your relative in conjunction with you and other supporters.

The Nidus Personal Planning Resource Centre provides a self-help kit and will assist you through the process of developing a Representation Agreement for your relative.

A good life includes honouring the choices of our relative.

The Benefits of Representation Agreements

An attractive feature of a Representation Agreement is its adaptability. It can be tailored to suit the exact circumstances of your relative. Representation Agreements are accessible to all adults.

Representation Agreements have been developed for most PLAN members, regardless of the nature and extent of their disability and vulnerability and regardless of how they communicate.

We have got to put our human spirit on the line if we hope to communicate with others at all.

Maybe that is when people feel cared for, when they feel that sense of human spirit.

MARGARET SOMMERVILLE

Representation Agreements:

- strengthen the voice of our relatives and ensure that their views, values, and beliefs are front and centre
- look at the person and how they are capable
- provide a test of capability that reflects the abilities of our relatives. The test of capability to sign personal planning documents like an Enduring Power of Attorney, for example, takes a traditional view which requires that everyone meet the same standard of understanding the nature of their affairs and the effect of giving someone authority to take over their affairs
- look at the person and how they are capable
- acknowledge that there are other ways of “knowing” including social capability; that is, the ability to relate to others and convey trust. Representation Agreements acknowledge these factors. In addition to the traditional intellectual factors, Representation Agreements also include trusting relationships as an important

consideration in determining capability

- give status to friends, family members, and members of Personal Networks. Many of us don't realize that when our sons and daughters turn **19** we are no longer their legal guardians. Representation Agreements give status to family, particularly parents
- create an opportunity for serious discussion about basic safety and security concerns for our relatives
- create a vehicle for formalizing existing relationships and forming a network of support
- create the means for a working partnership among caregivers, professionals, government workers, friends, family members, and our relative
- lastly, Representation Agreements provide parents with peace of mind.

Basic facts about Representation Agreements:

- anyone over the age of **19** years can make a Representation Agreement even if they cannot currently manage their affairs or sign a traditional contract
- Representation Agreements authorize people to assist your relative in managing their affairs without your relative losing their own decision-making rights
- everyone is assumed to be capable of signing a Representation Agreement

- all forms of communication are accepted, verbal and non-verbal
- to prevent abuse and exploitation of an adult who creates a Representation Agreement, a number of safeguards are available:
 - all agreements must be witnessed
 - a monitor must be appointed for routine management of financial affairs or at least two representatives must act jointly for finances
 - representatives must sign a certificate to certify they agree to follow their duties as set out in the *Representation Agreement Act*
 - the actions of representatives may be challenged, and
 - the Office of Public Guardian and Trustee has the authority to investigate complaints.

Nidus Personal Planning Resource Centre and Registry

The Nidus Personal Planning Resource Centre and Registry is a non-profit, charitable organization that provides information and assistance with Representation Agreements and other personal planning tools.

Nidus offers a Self-help Kit for Representation Agreements for supported decision-making. Nidus also operates a centralized Registry for personal planning documents. Visit the Nidus website for more information at www.nidus.ca.

Section 9: Enhanced Representation Agreements

Enhanced (Section 9) Representation Agreements covers all health and personal care decisions, no matter how complex.

Most lawyers will suggest that their clients use an Enduring Power of Attorney for legal and financial matters and a Standard (Section 7) Representation Agreement for health and personal care matters. The test of capacity for signing an Enhanced Representation Agreement or an Enduring Power of Attorney is higher than for the Standard Representation Agreement.

Summary of legal options

- Standard (Section 7) Representation Agreement: covers routine financial affairs, legal affairs, minor and major health care, and personal care decisions
- Enhanced (Section 9) Representation Agreement: covers the broadest health care and personal care matters, including refusing life support
- Enduring Power of Attorney: covers the broadest financial and legal affairs, including dealing with real estate, but not health care or personal care matters
- Temporary Substitute Decision-Maker: used to seek permission for health care when a Representation Agreement or Committee does not exist.
- Committee of the estate and of the person: authority to make financial, legal, health, and personal care decisions on behalf of another person.

Because the heart is bigger than trouble.
And the heart is bigger than doubt.
But the heart sometimes needs a little help to figure things out.

CONNIE KALDOR

Should I consider legal guardianship?

Traditional legal guardianship permits another person to take over the affairs and decision-making for an adult who has been declared

incapable by the courts. That guardian is called a Committee (pronounced Kaw–Mit–TEE with emphasis on the last syllable). A legally appointed Committee has complete power to make financial, medical, and legal decisions for the person. There are two types of Committee:

- committee of the estate: authority to make financial and legal decisions, and
- committee of the person: authority to make health and personal care decisions.

Representation Agreements were developed as an alternative to this type of guardianship.

We have reservations about Committeeship:

1. Most guardianship orders are blunt instruments. Even though adults may only need help in certain areas of decision-making, the guardianship orders are not easily tailored. All of a person's financial and personal decision-making power may be removed. The adult can no longer assist with the decision-making process. In the eyes of the law, they are no longer a capable person.
2. Obtaining a guardianship order is costly, intrusive, and time-consuming.
3. Guardianship doesn't allow for joint or supported decision-making. It's an all or nothing proposition.
4. People with intellectual impairments and other noticeable differences are usually presumed to be incapable which makes it even tougher to assert their capability.
5. The appointment of a Committee involves the Office of the Public Guardian and Trustee (OPGT). The OPGT typically reviews the

adult's financial records annually. This potentially adds another layer of complication and paperwork.

Few people with disabilities will ever need this form of guardianship. In the past, some parents applied to the courts to become Committee of their adult son or daughter assuming this would give them enhanced status when dealing with government or service providers.

Unfortunately, this proved to be both frustrating and costly and, in many cases, failed to adequately address the specific needs of their adult children.

A Representation Agreement is an economical alternative to protect a vulnerable person without declaring them incapable. It also gives status to caring, trusted friends and family members. Traditional legal guardianship and Committeeship should only be considered as a last resort.

We become what we behold.

We shape our tools and then tools shape us.

MARSHALL MCLUHAN

Types of decision-making

There are three broad areas of decision-making that affect your relative's life:

1. Health/Medical Decisions
2. Financial Decisions
3. Personal Care Decisions Personal Networks and Representation

Agreements are critical to each. Combined with a number of non-legal

options, they offer further assurance that decisions will be made that protect and enhance the quality of life of your relative.

1. HEALTH/MEDICAL DECISIONS You can divide this into emergency and non-emergency decision-making.

Families want assurance their relative will receive medical treatment in the event of an emergency, especially if the doctors are unable to obtain legal consent. You need not worry. Doctors and hospitals in British Columbia can and do provide emergency medical treatment when it is needed regardless of whether consent can be obtained.

For non-emergency health care, the experience is more varied. Many adults with disabilities enjoy a long-standing relationship with their family doctor. They know each other's abilities and communication styles. In these situations, the capacity of the person with the disability to give consent is simply not an issue. The physician is willing to take the time to give the individual the opportunity to express their wishes. In other situations, it has become common practice for the doctor or health care provider to consult with parents or other close relatives around health care treatment for the adult with a disability. The medical profession has long recognized relationships of trust and caring.

In these situations, supported decision-making is already working. It is best to formalize these relationships by having your relative create a Representation Agreement.

If you do not have a Representation Agreement or Committeeship and your relative is found to be incapable, then their doctor, health care provider or hospital must find someone to give consent for health care. There is provision in statute to appoint a Temporary Substitute Decision-Maker (TSDM). The health care provider chooses from the

TSDM list in the following order:

- spouse, including common law and same-sex partner
- adult child
- parent
- brother or sister
- another relative by birth or adoption.

Summary of legal options

Enduring Power of Attorney: covers financial matters, but not health and personal care decisions.

Personal Directive: covers health and personal care decisions but not financial matters.

Supported Decision-Making Authorization: permits the designation of a supporter to help make personal decisions

Co-Decision-Making Order: formal Court Order which specifies personal decisions which an adult is required to make in conjunction with a designated co-decision maker.

Specific Decision-Maker: person designated by a health care provider to make a one-time decision on behalf of an adult who requires a time sensitive decision relative to health care (where no Personal Directive or Guardianship Order exists).

Substitute Decision-Maker: used to seek permission for health

care when a Personal Directive or Guardianship Order does not exist.

Temporary Guardianship and/or Trusteeship Order: a temporary Court Order appointing a person to make decisions on behalf of an incapacitated adult who is in imminent danger of death, serious harm, or financial loss.

Guardianship and/or Trusteeship Order: a formal Court Order granting authority to make guardianship (health and personal) decisions and/or trusteeship (financial) decisions on behalf of another person.

The TSDM must be over **19**, capable, and know the person. The TSDM must have been in contact with them in the past **12** months and must not have had a dispute with them. This list is focused on family. If no family member qualifies, the Public Guardian and Trustee has the power to choose someone and can authorize a friend.

If there is no family involvement or you would prefer someone you trust to help with health care decisions, then it is best to make a Representation Agreement.

2. FINANCIAL DECISIONS There are a number of legal and non-legal options to protect the financial assets of your relative, prevent exploitation, negligence or impulsive purchases, and to ensure good financial decision-making.

The first, of course, is a Standard Representation Agreement. Have a look again at the list of routine financial decision-making options. Depending on the circumstances, an Enduring Power of Attorney

might be useful.

An Enduring Power of Attorney is a written document that allows a person to confer authority to someone else to make financial decisions on their behalf. When you confer this authority on someone else you don't lose your own authority. The Enduring Power of Attorney can be revoked at any time by the person who conferred it.

Both Enhanced (Section 9) Representation Agreements and Enduring Powers of Attorney have a higher, more traditional legal test of capability which your adult relative may not pass.

Trusts are another option used by families to protect the financial assets of their relative and to ensure the funds are used in their best interest. Step Five explores this option in more detail. Trustees can be appointed at any time to manage trust funds.

In the past, many families considered becoming Committee in order to protect, manage, and invest the financial assets of their adult relative with a disability. This procedure has a number of disadvantages:

- obtaining Committee involves the courts and is time-consuming and expensive
- reporting on the management and expenditure of money is tedious and costly
- guidelines to protect and invest the assets may be too conservative for productive money management.

Other practical approaches used by families to safeguard their family member's assets include:

- establishing a joint bank account with your son or daughter

- purchasing property in joint title (see Patricia's story in Step 3).

3. PERSONAL CARE DECISIONS This is an area of decision-making that is by far the most elusive because the forces are largely out of our control. Our relatives will likely be dealing with paid caregivers or service providers and educators for the rest of their lives. These paid staff and professionals make daily decisions which will impact the lives of our relatives.

We can't predict the future of government funding for these critical supports and the repercussions on the quality of programs and services. We are pleased that regulations and policy set standards for service providers. And we acknowledge the value of accreditation and formal evaluation. But we know this doesn't go far enough. These tend to focus on broad system standards. They don't address the personal daily circumstances of each of our relatives.

Monitoring is a natural extension of our parenting skills. While we are alive we can engage with service providers. We know how important it is to maintain a relationship with them. We have a good idea of how much work this requires and how much time it takes. If there is a concern we can do something about it. Many of us join an agency's board of directors or we can create our own society.

Choices

We suggest that you support your relative to make good decisions by asking yourself the following questions:

- What choices do they have now?
- What experience do they have with decision-making?
- What decisions can they make independently?

- What decisions will they need help with?
- What informal arrangements can be made to assist with decision-making?
- Would they benefit from a Representation Agreement?

Supported decision-making for our relative means:

- they actively participate
- their views are sought and taken into consideration
- they are surrounded by caring, knowledgeable, trustworthy people who can assist with their decision-making and communicate their decisions
- their needs are the primary consideration, not the needs of staff or the service system
- the focus is on their abilities and wishes, all their choices and options are considered
- their tastes, preferences, motives, and ability to discriminate are taken seriously
- their risks, failures, and mistakes are recognized as learning opportunities
- all their methods of communication, both verbal and non-verbal, are recognized as valid.

Conclusion: the secret to good decision-making

There is no magic to the task of keeping our relatives safe while at the same time respecting their choices. A tilt in the direction of over protection could lead, at the extreme, to a barren existence. A tilt in the direction of complete autonomy could lead to abuse and exploitation. The secret is balance. And checks.

And the best way to do that is by assembling the best people and resources. A Personal Network—combined with a Representation Agreement, control over the funding, and ongoing advocacy—is the best safety net we know.

Diving

WHEN I wrote this fictional meditation, I had not yet read Jean-Dominique Bauby's extraordinary book *The Diving-Bell and the Butterfly* (see Resources). His story is better known now as a result of the movie of the same name.

At the age of 45, French journalist Bauby suffered a massive stroke that left him without speech and movement. He was, as he says, "like a mind in a jar." Patiently, letter by letter, Bauby tells his story, using one eyelid to signal at what point in the chorus line of letters his friend is to stop transcribing. Bauby's reality is bright, vivid, and compelling. What would you do in a similar situation?

You are heading to the grocery store on a sunny Saturday morning. You are a careful driver but your mind is elsewhere—on automatic pilot. Suddenly an approaching car jumps lanes and heads towards you. In a terrifying instant your life changes. After the impact you lose consciousness.

You wake up in the hospital. The pain is excruciating. You are unable to move your arms and legs. Then you discover you can't speak. A doctor and a nurse are hovering over you. They are asking a lot of questions. They want to know your blood type. You aren't able to respond. For one thing, you are in shock. For another, they aren't watching your facial gestures and you have no other way of communicating. They are now explaining what needs to happen to you.

... ..

No one seems to notice the fear in your eyes. You hear medical terms you don't understand. You're scared and all alone.

Where is your wife? Have they tried to reach her? Suddenly you are placed on a stretcher and rushed down the hallway into an elevator, then down another hallway and into an operating room. Your last thoughts before the anesthetic takes hold are of ...

Who would you think of? Your spouse, your children, your parents, your brothers and sisters, your friends? Or your lawyer, your mechanic, your dentist?

You do survive.

The hospital is crowded but they manage to find a semi-private room for you. And they locate your spouse. She comes in several hours after you return from surgery. She immediately understands your terror.

You are covered with blood. The needle from the IV tube is already causing noticeable swelling and bruising. Your wife calls a nurse. They respond immediately. They are cooperative and friendly. They didn't expect you to wake up so soon. They were busy elsewhere.

The IV tube is adjusted and they give you a warm sponge bath. Eventually you drift off to sleep, comforted by the presence of your wife. At least you are not alone. When your wife and friends are around, you feel safer and your needs are met. They notice when you are uncomfortable. They do all the little things that make your stay tolerable.

On one occasion you had to contend with an inexperienced intern who insisted on giving you a needle in your arm even though he couldn't find a sizable vein. You were helpless to protest. Your arm became a

personal challenge to him. When a colleague from work arrived, it was bruised and bloodied.

Within minutes he had your wife on the phone. She spoke to the charge nurse and a notation was made on your chart. It won't happen again, they promised. It doesn't.

What keeps you safe during your hospital stay? Is it hospital rules and regulations? Is it the professional training of medical staff? Is it the nurses and doctors? Or is it friends and family?

Friends and family remove the cloak of anonymity. With them you become a person again. It's not that professional paid care isn't important; it's just that you are more than the sum of your health needs. Make no mistake about it, this move from being an object of service to a real person depends on your relationships.

Why would it be any different for people with disabilities? It isn't. However, we often make the error of assuming professional paid care is all that is necessary to keep people with disabilities safe and guarantee choice.

Programs, professional supports, rules, and regulations have their limitations. Paid service should supplement—not supplant—good, old-fashioned human contact, warmth and love.

AL ETMANSKI

Choosing a guardian for children under the age of 19

It is difficult to discuss who should take care of our children under the age of **19** should we die unexpectedly.

Unfortunately it does happen leaving the surviving children, remaining relatives, and friends in legal limbo. The courts become involved and a judge makes a custody order. You cannot assume grandparents, godparents or other choices you think are obvious will automatically be given responsibility. More than **40** per cent of Canadian parents have not legally appointed a guardian for their children.

NOTE Contrary to popular belief, you cannot appoint a guardian for your adult children in your Will. See Step Five for more details.

You must add a guardianship clause to your Will. One of the toughest decisions faced by parents is determining who to appoint as legal guardian of our minor children. To ease this emotionally difficult process and to prevent further upset, here are some suggestions to assist you in choosing a guardian:

- list your parental values, your aspirations for your children, as well as any religious, financial or cultural concerns;
- choose the person who comes closest to your parenting style and who would guide your children the way you intend to guide them. A child's aunt or uncle is a common trusted choice, followed

by close family friends. Trust in that person's judgment is paramount;

- try to select someone close to your age rather than someone of your parent's generation. Your parents may be excellent grandparents but they may not be able to manage another set of children, especially through the teenage years;
- becoming a guardian adds additional financial as well as emotional responsibilities. In recognition of this, some parents take out a life insurance policy naming the guardian as beneficiary;
- parents of other children with disabilities are a good source of advice. Because of their common bond, parents often choose each other as guardians.

Starlight over the new forest

Starlight over the new forest

in a time without end

the trees are turning to stars

and the stars are turning to trees

the time that went is no longer now

the time to come is no longer still

the time I had is a time of sorrow

the time I stayed to the time I left

the time I took was the thing I lost

the thing I took was the time it cost

I no longer know what the time is

when the time itself is the thing I lost

the thing I took was the time it cost

and now I know what to take from loss.

KIRSTEEN MAIN

To download a copy of all Worksheets, visit www.plan.ca and click on Safe and Secure Worksheets.

Worksheet 9

Use this Worksheet to organize your supported decision-making choices. After completing this Worksheet you will be able to assist your relative in drafting their Representation Agreement. We suggest you contact PLAN or the Nidus Resource Centre for further assistance in drafting and activating a standard Representation Agreement.

This Worksheet does not give any legal advice. A Representation Agreement is a legal contract which must be drafted in accordance with the *Representation Agreement Act*. The representatives and monitors appointed under the Agreement are accepting responsibility and liability from the adult, so it is important that they understand their duties and responsibilities.

A. Checklist

MEDICAL DECISION-MAKING

YES__ NO__ I have discussed issues of medical consent with my relative's doctor.

YES__ NO__ The doctor accepts consent from my relative for medical treatment.

YES__ NO__ The doctor accepts my consent for medical care on my relative's behalf.

FINANCIAL DECISION-MAKING

YES__ NO__ I have set up an income trust.

YES__ NO__ I have set up a discretionary trust.

YES__ NO__ My relative has a RDSP.

YES__ NO__ My relative has a bank account.

YES__ NO__ Withdrawals from that bank account are protected by:

- joint signature for withdrawals
- my family member is well known to bank employees
- funds in the account are kept to a minimum
- don't need to be protected.

PERSONAL CARE DECISION-MAKING

YES__ NO__ My family member has an advocate(s).

YES__ NO__ The services my relative receives are monitored by a separate and independent agency.

YES__ NO__ Housing supports are kept separate from other services.

YES__ NO__ Staff understand and support the importance of family involvement.

YES__ NO__ Staff understand and welcome the involvement of spouses, friends, and members of the Personal Network.

YES__ NO__ Service and program staff recognize the importance of offering and respecting my family member's choices.

YES__ NO__ Family and friends provide support by reviewing services and programs on a regular basis. (**NOTE** This is different from the service plans developed by service providers.)

YES__ NO__ Members of the Personal Network are familiar with the personal care issues.

B. Information

GENERAL

Who does my relative trust?

Who would I trust to assist my relative with decision-making?

Who understands my relative's communication style?

MEDICAL DECISIONS

Who is my relative's doctor?

What assistance would they need to make medical decisions?

Who would my relative accept to assist with medical decision-making?

What aspect of their medical care do I think my relative might understand?

What formal arrangements do I need to make to ensure medical care is easily available to my relative?

FINANCIAL DECISIONS

My relative's trustees are:

My financial advisors are:

My relative has the following bank accounts:

Signing authority includes:

Who would be willing to assist my relative in making financial decisions

I have asked the following individual to monitor the trust I have set up for my relative:

PERSONAL CARE DECISIONS

My relative's advocate is:

The independent agency that monitors services is:

Who would be willing to assist my relative in making lifestyle and personal care decisions?

step five

achieve financial security:

wills, trusts, and
the RDSP

Having children
makes you aware
of your mortality;
having grandchildren
gives you a sense
of immortality.

THE RIGHT HONOURABLE
ADRIENNE CLARKSON

The Bromley story

Saving for three

Financial security is of utmost importance. The RDSP is one of the tools we have embraced as a family to save for Shannon's future.

AS A FAMILY, we have volunteered with a variety of organizations to ensure that Shannon's life includes a sense of contribution. My son and I trained and became ski instructors with Vancouver Adaptive Snow Sports, Rob is the past-Chair of PLAN, and has chaired the Canadian Angelman Syndrome Society.

We have had Shannon involved in baseball and youth programs and do our best to include a family holiday every couple of years that is focused on activities that we can all enjoy. It is a lot of work on our part to make sure Shannon enjoys her life to the fullest.

Keeping Shannon busy and engaged costs money and we know that we must work with more than an RDSP and a trust. We must also make sure our Wills and life insurance policies are kept up-to-date.

We need to pay attention to ways to provide a financially secure future for Shannon. Yes, we must save for her future, but we must also make sure the right people are put in charge of handling her money.

We want the same for our daughter as we do for our son. Just because she was born severely disabled, unable to brush her own teeth or put on her coat, doesn't mean she shouldn't have a good reason to wake up every morning. We want Shannon throughout her adult life to be able to contribute to her community, to have friends and

adult life to be able to contribute to her community, to have friends and to enjoy a great life.

The reality is, Rob and I have three people to save for in retirement.

Where many people are struggling to save enough for themselves, we need to make sure to save enough to last Shannon's lifetime as well.

The RDSP has made other family members aware of Shannon's lifelong financial needs and as a bonus, they have contributed as well.

We have found that people want to help us with Shannon but don't have the skills to be able to take her out on their own. Contributing to Shannon's RDSP has become another way for friends to participate in Shannon's future.

step five

Achieve financial security: wills, trusts, and the RDSP

THIS step will provide you with an overview of how to plan for and protect the financial well-being of your family member with a disability both now and in the future. While we are still able, we can help our relatives out in many ways, although we must keep BC disability assistance rules and other policies in mind.

NOTE BC disability assistance is the financial assistance that our relatives receive from the provincial government. You may have seen it as “disability benefits” or as “GAIN” in the past. It is provided through the BC Employment and Assistance program, which also provides supplementary benefits such as medical and dental. For contact information, see Resources.

Step five highlights

This chapter highlights the key tools at your disposal to plan for the financial security of your relative. These include:

- Will and estate planning
- discretionary trusts (also referred to as Henson Trusts)
- the Registered Disability Savings Plan (RDSP).

This information will help with your preparation but is no substitute for legal advice.

We worry most about what the future will hold. We want to put enough money aside to handle emergencies and unforeseen circumstances. Many people with disabilities live at or below the poverty line. We don't want our relatives to just get by. Simply existing is not enough; we also want our family members to have a good life.

PLAN's Toll-Free Hotline is now available: 1-844-311-PLAN
(1-844-311-7526)

Most of us are not sufficiently wealthy to leave enough money in our estates to cover the costs of everything that our family members might possibly need. Until recently, there were limited options or tools we could use to deal with this challenge. If our family members relied on

government benefits, there was little we could do to supplement their income without it being clawed back by the provincial government. Fortunately, this is changing, particularly in British Columbia where the government is not only committed to assisting people with disabilities to receive financial help from their families, but is also committed to assisting families build up savings. Some penalties and disincentives are being eliminated. For example, the money received from the RDSP will NOT be clawed back (see detailed discussion of the RDSP in Section 2, and for ongoing updates please visit www.rdsp.com or www.rdspresource.ca or call PLAN's Toll-Free Hotline 1-844-311-PLAN (1-844-311-7526)).

These changes signify that we are approaching a new partnership between families and government, a partnership based on shared responsibilities which acknowledge the commitment that families have always made to the safety and well-being of their relatives with disabilities.

And if I had a million dollars
Well, I'd buy you some art: a Picasso or a Garfunkel.

BARENAKED LADIES

This chapter is divided into two main sections:

SECTION ONE Wills, discretionary trusts, and estate planning

SECTION TWO The RDSP.

The information contained in these two sections will:

- provide you with general information on drafting a Will and

planning your estate

- highlight the importance of trusts, particularly discretionary trusts
- introduce you to the RDSP
- discuss the relationship among government benefits, the RDSP, and discretionary trusts
- overall, help you plan for the financial security of your relative.

Assuming financial security for your relative need not be complicated, particularly if you have thought through the issues raised in the preceding steps. Yes, it's technical but Worksheet 10 will help. Once you have completed it, there are lawyers, accountants, financial and estate planners, and wealth management specialists to help you finalize your plans.

This chapter won't replace the need to make some tough choices. The professionals you will choose should be highly skilled, but they rely on the clarity of your vision, your plans and your details in order to make the right plan for your family.

Fortunately you are not alone. You can use PLAN as a back-up resource. Our advice has been sifted through the experiences of thousands of individuals and families we have supported over the past quarter century. We've learned from them all. Even those of us with little disposable income or limited assets can still leave something to help our relatives.

We pass on this accumulated wisdom knowing that being better prepared will:

- save you time and money

- assist you in selecting the right course for your relative
- make it easier to complete your Will
- leave you with peace of mind.

You'll feel a great sense of accomplishment and relief when you've finally done it!

Do not **b**e intimidated **b**y legal language. All professions have their **j**argon. Some of the key words and phrases you'll encounter in this section are summarized in Demystifying Definitions near the end of this Step. And for **a**dvice, call PLAN's Toll-Free Hotline at **1-844-311-PLAN (1-844-311-7526)**.

SECTION ONE

Wills, trusts, and estate planning

In praise of the imperfect Will

You've heard the facts before. Too many Canadians die without a Will. Many others die with a Will that's out-of-date. In a public opinion survey of 1,000 adults, 31 per cent of respondents said they have never broached the subject of life insurance with their partners and 59 per cent said they had never even thought about it! You want to avoid joining their ranks. But you don't have all the answers. You still need to work out a few more details. You're just about there... maybe after reading this chapter.

Well, we're sorry to disappoint you. This chapter will not help you create the perfect Will. Neither will any other book, or person for that matter. So don't make the same mistake too many others have made. Don't wait for something that will never happen.

Now is the time to develop and execute the "imperfect" Will. It is one of the biggest gifts you can give to your family and to yourself. We feel so strongly about this that we might call our next book, "In Praise of Imperfection."

What's so great about perfection anyway? Where did we get the grandiose illusion that we humans can either be perfect or get things perfect? The perfect meal or the perfect day? Maybe. But the perfect body, perfect looks, and the perfect job while living in the perfect house? Not likely. Perfection is an illusion which adds unnecessary pressure and can make us feel guilty for never measuring up. Surely,

absolute perfection is the **job** of divine personalities, **beyond** the scope of mere mortals. Few, if any of us, **ever** attain these standards. Yet we still manage to get on with our lives.

And that's precisely what we want you to do with your Will. Get on with it! Preparing and completing the imperfect Will is not the least you can do, it's the **best** you can do.

Surely the true definition of courage is to do the thing you are afraid to do.

GEORGIA BINNIE CLARK

Beginning to create your Will and estate plan

Before you create your Will, you must **be** clear about the details. Every family situation is unique. You are going to rely on your family after you are gone, so it's a good idea to discuss things with them now. If the person you want to **be** your executor is intimidated **by** lawyers or has never invested money, now is the time to find out.

There are other **valuable** resource people you might consider talking to: **extended** family, friends, **members** of your relative's Personal Network, other families in similar circumstances, and so on.

In our **experience**, it helps families clarify their **objectives** **by** talking to others in similar circumstances. The more open and forthright your discussions are, the more clear your **objectives** will **be**. This will make for a more meaningful and more efficient relationship with your lawyer, accountant, and estate planning specialist. When seeking advice on estate planning, tax planning, or wealth management strategies, see **Questions to ask an Advisor**.

Eight key objectives

Most people want their Will and estate plan to:

1. pay their debts, taxes, and other liabilities
2. provide a separate, independent income for their spouse
3. distribute their assets according to their wishes
4. maximize the size of their estate for their children
5. protect the financial security of their relative with a disability (the RDSP and discretionary trusts are the basic tools for this)
6. ensure that there is a guardian for their children under the age of 19
7. avoid delays, family strife, needless taxation, costly legal challenges, probate fees, and government involvement
8. allocate a portion of their estate to the charities and causes they are passionate about.

Tips from Jack Collins for securing the future

JACK COLLINS—one of PLAN's co-founders and a co-author of this book—knows much about the legal and financial elements of securing the future. After he retired, he dedicated his time to learning everything possible about the technical aspects of Will and estate planning and how they can be coordinated with government benefits. Although he is a lay person, lawyers, financial and estate planners rely on his insights and advice.

His credibility among families is legendary. They like his plain

speaking, no nonsense style. They trust him because he is one of them. Culled from his vault of expertise and its application to thousands of families, here are tips from the master:

- Get a basic Will as quickly as possible. I have seen what happens when a parent dies without a Will.
- Review your Will every two years and update it when something in your life changes. Additions and amendments (called codicils) are not costly.
- Life insurance is a good way to finance a discretionary trust. For a small monthly premium you can finance a policy. After you die the proceeds can be placed tax free—and without probate costs—into your family member’s discretionary trust.
- Appoint executors and trustees who will outlive you—in other words, appoint someone younger than you—and appoint alternates just in case.
- The year of your death will likely be your highest income year because most investments are deemed sold on the day of your death and any remaining RRSPs or RRIFs get added to your income. Tax and estate planning—including donations to charity—will reduce the tax bite.
- Most of us want the trust capital as well as income to go entirely to our relative. To do so, your trust document must specifically exclude the “even handed rule” so the trustee(s) do not have to consider the rights of residual beneficiaries. If such permission is granted within the trust document then the trustees will be

encouraged to spend down the capital as well as income. Please consult your lawyer on this technical point.

- Grandparents often look for ways to help secure the future of their grandchildren. Suggest they create a discretionary trust—or contribute to an RDSP—for their grandchild with a disability.

NOTE the generosity of a grandparent in setting up a trust (either discretionary or non-discretionary) for a grandchild may result in that grandchild’s BC disability benefits being eliminated.

Grandparents are cautioned to thoroughly discuss this eventuality with both their lawyer and the parents of the grandchild that they are intending to “benefit” before creating any trust.

Basic questions about Wills, trusts and estates

Once you’ve added your own personalized objectives to the eight general objectives described above and you are comfortable—well, reasonably comfortable—with your answers, you are ready for the technical solutions. Here are some questions and answers to start you on your way.

NOTE For a complete list of legal terms, see “Demystifying definitions that could definitely derail you” near the end of this step.

WHAT IS A WILL? A Will is the legal document that tells people what to do with your estate once you die. It helps makes life easier for those left behind by providing a plan for them to follow and by naming who is in charge.

WHAT IS ESTATE PLANNING? Estate planning is quite a broad term. It includes such things as:

- preparing your Will
- preparing either a Section 7 or a Section 9 Representation Agreement
- preparing powers of attorney and personal directives or personal declarations about end of life decisions
- deciding upon issues such as executor and trustee appointment, and finding ways to minimize probate fees
- calculating your estate needs and determining the amount of life insurance needed to meet those needs
- looking at strategies to reduce income taxes at death
- advising about a trust for you or a trust for your relative with a disability.

Family is not an important thing, it's everything.

MICHAEL J. FOX

WHAT ARE THE BASIC THINGS I NEED TO THINK ABOUT? During the course of designing your Will and planning your estate you will need to:

- appoint an executor to ensure that the instructions in your Will are carried out
- divide your estate among family (spouse and children), charities,

and others

- create a trust, usually a discretionary trust, for your relative with a disability and identify a trustee and perhaps co-trustee(s) to manage the trust
- appoint a guardian for your children who are under the age of 19 years.

If you die without a Will, you have no control over how your estate is divided .

WHAT HAPPENS IF I DIE WITHOUT A WILL? If you die without a Will, provincial laws set out how your estate will be distributed. Under the *Estate Administration Act* (BC), the Court will appoint an administrator, and your estate will be divided according to a specific, legislative formula. This means you will have no control over how your estate is divided. Further, you will not be able to protect the inheritance you want to leave to your relative with a disability. The Public Guardian and Trustee holds your relative's inheritance until they turn 19 years, at which time they will receive their total inheritance outright. This situation may disqualify your relative from receiving BC disability assistance.

If you die without a Will and you have children who are under the age of 19 and there is no surviving parent who is the legal guardian, then the government will become guardian of those children.

HOW MUCH WILL MY CHILDREN GET IF I DIE WITHOUT A WILL?

If you die without a Will, the *Estate Administration Act* directs:

- the first **\$65,000** of your property goes to your spouse, plus the household furnishings, and the right to live in the family home until death
- one-third of the remainder of your estate goes to your spouse and the remaining two-thirds is divided equally among your children
- your next-of-kin will have to go to court to be allowed to deal with your estate

NOTE For minor children, the Public Guardian and Trustee becomes guardian of the estate whether you have a Will or not unless you have created a trust.

The mind is not a vessel to be filled, but a hearth to be lighted.

IRENE PARLBY

DOES THE WILLS VARIATION ACT MATTER TO ME? Yes it does.

This Act requires that your Will provide adequately for your spouse and for your children. The definition of spouse in the Act includes an individual of either gender who has lived with and cohabitated with you for at least two years in a marriage-like relationship. If a spouse or children feel you have not provided adequately for them in your Will, they can ask the court to change your Will to get a larger share of the estate. This must be done within six months of probate.

If you do not leave your child with a disability (either an adult child or a minor) a fair share of your estate, it is likely the Public Guardian and Trustee will intervene on their behalf and try to change the Will.

WHO IS THE PUBLIC TRUSTEE? The Public Guardian and Trustee is responsible for protecting the interests of both children who are under the age of 19 years and dependent adults. Your executor is required to send a copy of your Will to the Public Guardian and Trustee after you die if you have children under 19, or if you have a child or other beneficiaries who have or may have mental disabilities. The Public Guardian and Trustee will examine the Will to see if you have made adequate provision for your children under 19 and any spouse or adult child with a mental disability. If you have not done so, the Public Guardian and Trustee may contest your Will on their behalf.

BC DISABILITY ASSISTANCE The BC Employment and Assistance is a provincial government program that provides financial assistance (BC disability assistance) as well as supplements such as medical, dental, optical, and pharmaceutical benefits to people with disabilities. To be eligible, a person must meet both the test for the Persons with Disabilities designation and the asset and income test. For contact information, see Resources.

Some people who do not qualify for BC disability assistance may qualify for income assistance as a person with Persistent Multiple Barriers; this type of assistance, however, provides somewhat fewer benefits.

At the time of writing, a single person on BC disability assistance receives up to \$906.42 per month for shelter and support while a single person receiving income assistance as a person with Persistent Multiple Barriers receives up to \$657.92 per month. People on BC disability assistance can apply for an annual bus pass for \$45 per year. People receiving income assistance as a person with Persistent Multiple Barriers are reassessed at least every two years for eligibility.

We don't have to choose; we have to talk to each other about what concerns us deeply.

HAROLD RHENISCH

Once people are **18** years of age, they are entitled to **BC** disability assistance if:

- they qualify as a Person with Disabilities under the rules in the Employment and Assistance for *Persons with Disabilities Act* and Regulations
- they have less than **\$5,000** in liquid assets; that is, things a person owns including money, property, and investments.

If an individual on **BC** disability assistance has assets of more than **\$5,000**, they will be cut off until their assets are worth less than **\$5,000**. **NOTE** the RDSP is not considered an asset.

Individuals on **BC** disability assistance are also entitled to own certain exempt assets which do not count as part of the **\$5,000** limit. This includes a home they live in and a motor vehicle they use.

Individuals on **BC** disability assistance are entitled to have an RDSP of any amount, a non-discretionary trust of up to **\$200,000** or to be the beneficiary of a discretionary trust of any amount of money. **NOTE** the Minister responsible for **BC** disability assistance has the discretion to exempt an amount higher than the **\$200,000** for a non-discretionary trust, if lifetime disability-related costs will be higher.

The *Employment and Assistance for Persons with Disabilities Act*, Regulations, and policies change from time to time. Check the

Resources Section for contact information or check the Ministry of Social Development and Social Innovation's website for regular updates by visiting <http://www.gov.bc.ca/hsd/>.

How BC Disability Assistance is affected by income

EARNED INCOME

Persons on BC disability assistance are able to work and earn income. A single individual is allowed to keep the first **\$800** of income without affecting their benefits. A family unit with two individuals on disability assistance has a combined exemption of up to **\$1,600**.

NOTE Beginning January 1, 2013, the Annualized Earnings Exemption came into effect. People already on BC disability assistance whose earned income fluctuated were given the option to use their earnings exemptions on an annual instead of a monthly basis. The annual exemption for a single person is **\$9,600**; the annual exemption for a family unit with two individuals is **\$19,200**. This program will begin to be opened up to all people on BC disability assistance in a phased approach.

I wear my shadows where they are harder to see, but they follow me everywhere. I guess that should tell me I'm traveling toward light.

BRUCE COCKBURN

UNEARNED INCOME

This is income from term deposits, bank interest, rental income,

RRSPs, and so on, which has not been earned by working. Unearned income is deducted dollar for dollar from BC disability assistance. If a person receives \$300 in unearned income, then their next month's payment will be reduced by \$300. **NOTE** Income from a RDSP is exempt from this provision.

HOW BC DISABILITY ASSISTANCE IS AFFECTED BY INCOME SUCH AS AN INHERITANCE If people on BC disability assistance receive income from an inheritance, a life insurance payout, an ICBC payout or other financial windfall, they will be cut off BC disability assistance until they have less than \$5,000. To avoid this from happening, they can place up to \$200,000 in a non-discretionary trust, \$200,000 in an RDSP without affecting their BC disability assistance, and/or purchase a motor vehicle or primary residence. Getting timely advice is critical to minimize the risk of being cut off.

NOTE While there is a ceiling of \$200,000 for non-discretionary trusts (without special permission from the Ministry), there is no ceiling for discretionary trusts. That is why we strongly recommend you set up a discretionary trust for your relative as part of your estate plan. The non-discretionary trust can only protect \$200,000 of the assets from an inheritance or settlement. A trust can be set up that either comes into effect during your lifetime or after your death; however, different income tax rules may apply. See below for a discussion about discretionary trusts.

WHAT BENEFITS DO MY RELATIVES QUALIFY FOR ONCE THEY TURN 65? When your relative reaches the age of 65, they will move from provincial income assistance to federal seniors benefits: Old Age Security (OAS) and Guaranteed Income Supplement (GIS). Together, these two benefits provide at least as much as BC disability

assistance.

Old Age Security is not asset tested, but it is income tested at a relatively high threshold.

The GIS is the seniors' program that helps low income seniors. It is not asset tested, but it is income tested at a relatively low threshold. If your relative has no other income source, they are likely eligible for the GIS.

The good news for holders of RDSPs is that the GIS will not be affected by income received from an RDSP. In other words, RDSP income is exempt.

For advice, contact PLAN's Toll-Free Hotline: 1-844-311-PLAN (1-844-311-7526).

CAN I SET UP AN RDSP AND A DISCRETIONARY TRUST? You can set up both an RDSP and a trust. There are benefits to each and you may want to do both. In general, the RDSP is designed to build savings and can be used while parents are still alive. Discretionary trusts are typically designed to manage the inheritance you leave for your relative. A discretionary trust in your Will becomes operational only after you die. Discretionary trusts can also be created as inter vivos trusts that take effect while you are still alive.

WHY SHOULD I SET UP A DISCRETIONARY TRUST? A trust may be advisable for many reasons:

- to ensure the availability of ongoing government benefits such as BC disability assistance
- to help your relative with a disability during their lifetime and then to pass on funds that remain to another generation or a chosen charity

- to protect a vulnerable relative from being taken advantage of by those with bad motives and also those with good intentions but limited skills or judgment
- to provide ongoing financial management of assets
- to take advantage of special tax treatment
- to give some protection of assets if a relative goes through a marriage breakdown or has creditors.

WHAT PROVISIONS SHOULD I ADD TO MY WILL TO BENEFIT MY RELATIVE WITH A DISABILITY?

You can set up a trust in your Will for the person with a disability. The best course of action is to talk to a lawyer who has expertise in providing Wills and estate advice to families of people with disabilities.

There are two common trusts used by families of people with disabilities: non-discretionary trusts (also called income trusts) and discretionary trusts (also referred to as Henson Trusts).

Lost and Found

Man finds gold. Man loses gold. Man finds time. Man loses hair. Man finds dream. Man loses dream. Man finds laughter. Man loses time. an finds meaning to life. Man loses life.

TOM KONYVES

NON-DISCRETIONARY TRUSTS

A non-discretionary trust means that the beneficiary of the trust has or had some control over the assets in the trust—for example, they can

request payment of funds out of the trust and the trustee has no discretion. The trustee must pay out the requested fund, as opposed to a discretionary trust where the trustee has the right to refuse payment out of the trust.

A non-discretionary trust can be set up in two ways. One way is by a friend or relative of the individual with a disability. The other way is by the individual with a disability, as long as the person has the capacity to gift the property.

Regardless of who sets up the trust, as long as the amount of money in the non-discretionary trust is under **\$200,000**, it will not be treated as an asset for individuals on BC disability assistance. It is important to note that these trusts are reviewed by the provincial government and need to be designed properly in order to be approved. For example, although not supported by law, Ministry policy states that the beneficiary cannot be the sole trustee.

If the total of the capital contribution to the non-discretionary trust exceeds **\$200,000**, then the individual will no longer be eligible for BC disability assistance, until either the trust limit has been increased by the Minister of Social Development, or if the individual can demonstrate more than **\$200,000** in lifetime disability-related costs.

DISCRETIONARY TRUSTS

Most families of people with disabilities choose to set up a discretionary trust in their Will. To do this, you appoint a trustee, and possibly co-trustee(s), as the person(s) who will be in charge of the trust. You give the trustee(s) the discretion—or power—to decide when and how much of the trust fund will be used from time to time for the beneficiary, in this case your relative with a disability. Your trustee(s) can then gauge your relative's changing needs over time

and adjust disbursements accordingly.

HOW DOES A DISCRETIONARY TRUST AFFECT MY RELATIVE?

Most important, a discretionary trust allows the beneficiary to continue to receive BC disability assistance. The trustee(s) will buy our relative what is needed. The trustee(s), not your relative, will decide how and when to spend money in the trust. That is why a discretionary trust is not normally considered your relative's asset; decisions are made at someone else's discretion.

Under BC disability assistance, discretionary trusts are recognized as an exempt asset. There is no ceiling on the amount that can be placed in a discretionary trust. The trustee can use the trust for anything, but certain payments will be exempt from the Ministry's unearned income rules including:

- medical aids and devices, caregivers, renovations or upkeep of the beneficiary's primary residence, and education and training
- expenses of up to \$8,000 a year on any other item or service that promotes the individual's independence, as determined by the individual or trustees, not the Ministry staff.

We are hopeful that these restrictions will be reduced to make them compatible with the RDSP. Check with PLAN to make sure you and your advisors have current information about these rules, or check for updates on the Ministry of Social Development and Social Innovation's website.

WHAT HAPPENS TO THE MONEY LEFT IN THE TRUST WHEN THE BENEFICIARY DIES?

When you set up a trust, you must also identify who will get what is left in the trust when the beneficiary dies. This could be the beneficiary's spouse, children, siblings, other family

members, charities or others.

You should be careful to avoid a potential conflict of interest when you choose the trustees of the trust you establish for your family member. For example, if the trustee is also the person who receives the remains of the trust when the beneficiary dies, the trustee is placed in the difficult position of choosing between benefiting the beneficiary or themselves. One simple solution to this problem is to appoint co-trustees. We suggest you discuss this matter with your lawyer to avoid the Office of the Public Trustee trying to vary the Will.

WHAT DOES A TRUSTEE DO? The trustee:

- manages or looks after the trust assets
- keeps the trust assets invested
- does the bookkeeping for the trust
- makes the necessary government filings, such as income tax returns for the trust
- makes sure your relative receives trust benefits according to your wishes.

If you decide to set up a trust for your relative, you will need to name the trustee in your Will. Choosing a trustee is one of the most crucial decisions you will make about future planning. The person you choose may have responsibilities as a trustee for **40** years or more.

It is a good idea to have more than one trustee. For example, you may want to have two trustees and two alternates in case the original trustees cannot act or cannot agree. It's also a good idea to choose a trustee who is much younger than you in age. You want them to live as long as your relative does!

WHO SHOULD BE A TRUSTEE? You may want to have one trustee

with financial skills and a co-trustee who has a personal relationship with your relative. Their skill sets may be different and may complement each other. One trustee might make investment decisions, keep accounts, manage tax returns, and so on. The other trustee, a sibling or friend, would be in a better position to advise on how to spend trust funds.

You may consider using a respected trust company as one of the trustees. Some families use a trust company as one trustee and a relative or family friend as the other trustee. The trust company can make sure there is experienced financial help to invest and manage the trust assets. The relative, friend, or personal network member makes sure the funds are spent in the best interests of your relative.

If you name a person as a trustee, then you should also name a successor in case the first person dies, moves, or is otherwise not willing or able to continue. It is best if the trustees are people your relative knows and likes. The trustees and your relative will likely be involved with one another for a long time. A good relationship between them will benefit everyone.

At least one of the trustees should live close to your relative. If a trustee has close contact with your relative, they will understand the needs of your relative better.

Choosing trustees is one of the most crucial future planning decisions you will make.

WHAT ARE THE DUTIES OF A TRUSTEE? The duties of a trustee include:

- deciding how and when to spend funds
- making payments to or for the beneficiary
- managing investments and safekeeping assets
- coordinating any maintenance/repairs of real estate
- preparing trust tax returns
- maintaining records of the trust
- reporting to the beneficiary about the trust.

NOTE you can direct your trustees to consider certain expenditures, for example to support your relative's hobbies, to fund courses they are interested in taking, or even to purchase a home for your relative.

IN BC, DO EXECUTORS AND TRUSTEES GET PAID? You can state in your Will or in a contract (that is incorporated by reference in your Will) how much your executor is to be compensated. If you don't say how much they should be paid, provincial laws set a fee. In British Columbia, executors can charge up to 5 per cent of the capital and income of the estate, and an annual management fee of 0.4 per cent of the total value of the trust assets. Your beneficiaries or the court must approve the fee. The fees that trustees charge are determined by the amount of time, effort, and skill that has been required of them while acting as your trustee.

NOTE If your executor is also administering a trust, they may be entitled to additional compensation.

Somehow, the painting soothed him.

It verified his fears. But it also informed him that fear was wonderful.

TIMOTHY FINDLAY

WHAT INVESTMENT POWERS SHOULD I GIVE MY TRUSTEE?

Trustees are limited by law to investments that a prudent person would make. You may give them greater or narrower investment powers but you must specify it in your Will. Be sure to discuss this with your lawyer.

CAN I APPOINT A GUARDIAN FOR MY CHILD IN MY WILL? If you have children under the age of 19, you should appoint a guardian for them in your Will. You should also appoint alternates in case the first is not able to accept. You cannot appoint a guardian for an adult child even if they have a severe disability. Guardians for adults can only be appointed by a court and are called Committees. Better still, assist your adult relative in developing a Representation Agreement.

WHO SHOULD BE THE EXECUTOR OF MY WILL? The executor is the person who makes sure that the instructions in your Will are carried out after you die. Often people appoint their spouse as their executor, but you may need to appoint someone else or someone jointly with your spouse. You should also appoint alternates in the event the original executor is unable to fulfill the responsibilities of executor. It is recommended that you discuss the proposed appointments with each of the executors you choose before you name them in your Will.

If you have set up a trust in your Will, usually the executor and

alternate executor will be the same as your trustees and alternate trustees. However, in some cases, for example where there is a business to be managed, you may wish to have different executors and trustees. Talk to your lawyer about this.

WHICH OF MY ASSETS DO NOT FORM PART OF MY ESTATE AND PASS OUTSIDE THE WILL?

Any assets held in joint tenancy with another person pass directly to that person on your death and are not governed by your Will. For example, a home and bank accounts held in joint tenancy with your spouse go directly to your spouse on your death.

Life insurance policies with a designated adult beneficiary pass outside the Will directly to that beneficiary.

RRSPs and RRIFs with a designated adult beneficiary pass directly to that beneficiary.

Quite often when a spouse dies, most of the family assets are held in one of these ways and pass directly to the surviving spouse. Assets that pass outside your Will save probate fees.

Assets held in inter vivos trusts, trusts that have been established prior to your death are also not part of your estate.

Be sure to consult your lawyer about putting assets in joint tenancy with your children or anyone else as there are dangers as well as benefits in so doing.

SHOULD I MAKE A GIFT TO A CHARITY THROUGH MY WILL?

Estates often have a lot of taxes to pay. This is because any funds in RRSPs and RRIFs are considered income in the year of a person's death. Other assets are deemed to be sold in the year of the death. Tax is payable by the estate on this income and any earned capital

gains.

When you make a gift to a registered charity through your Will, your estate receives a charitable tax receipt which can be used to reduce the income tax that has to be paid.

If you have supported charities while you are alive, you may wish to consider supporting charities through your Will. You should discuss these wishes with your estate planning professionals. Most charities have planned giving programs set up to be able to respond to inquiries about leaving a charity a gift through your Will. You are also able to leave charities gifts of life insurance, property, RRSPs or RRIFs, as well as through many other innovative vehicles. When you have decided on your charity or charities of choice, you should consider contacting them to discuss the gift.

CAN I MAKE A GIFT TO PLAN IN MY WILL? Many families appreciate the work that PLAN does and support its continued financial independence by making a charitable gift or by leaving a bequest through their Will.

Please contact PLAN to discuss specific programs that you would like to support through your estate. Any request for anonymity will, of course, be respected.

CAN I LEAVE MY RRSP AND RRIFs TO A RELATIVE WITH A DISABILITY? If you have a lot of assets in RRSPs or RRIFs, you may want to consider leaving them specifically for a son or daughter or grandchild with a disability when you die. If you do leave these assets to a child or grandchild with a disability, then the federal government provides a tax deduction equal to the total amount of the RRSP or RRIF going to that beneficiary. This means your estate wouldn't have to pay any taxes on these assets.

This can, however, create two problems. First, if your relative has diminished mental capacity, they may not be able to manage that asset. Secondly, the asset will affect your relative's BC disability assistance. However, if the amount is less than \$400,000, they may be able to put the funds into a non-discretionary trust (\$200,000) and an RDSP (\$200,000). While they will not lose their BC disability assistance, they lose the income tax savings.

RRSPs and RIFs can now be "rolled over" to an RDSP. As of June, 2011, within limits, the proceeds from a deceased parent's or grandparent's Registered Retirement Savings Plan, Registered Retirement Income Fund and Registered Pension Plan can be rolled over into the RDSP of a financially dependent child or grandchild with a disability.

We recommend you discuss this option with your lawyer or check with PLAN for the most current information.

The professionals you choose will be highly skilled but they still need the clarity of your vision to make the right plan for your family.

WHAT IS PROBATE? Probate is the name of the legal process that confirms your last Will. Normally it is the job of your executor to file your Will for probate with the provincial court and pay probate fees. This process can take anywhere from a few weeks to a few months. Until your executor receives the grant of probate, assets of your estate cannot be released.

Probate fees in British Columbia are currently as follows:

- Under \$25,000 No fee
- \$25,000-\$50,000 \$6 for each \$1,000
- Over \$50,000 \$14 for each \$1,000

UNDER WHAT CIRCUMSTANCES SHOULD A PERSON WITH A DISABILITY SET UP A TRUST OR MAKE A WILL?

Many individuals with disabilities do establish trusts and make Wills. This will become even more important for people with RDSPs. The law has legal tests which all individuals, with or without a disability, must meet in order to place their assets in a trust or execute a Will. For example, in order to create a Will, an individual must know what a Will is and know and understand what their assets and liabilities are and their value. If an individual cannot meet the legal tests required, then they would not be able to settle a trust or make a Will at that time.

An individual's capacity, however, is not a static thing. An individual without the legal capacity to execute a Will may, six months later, have the requisite capacity. Furthermore, lawyers vary in their understanding and appreciation of capacity of people with disabilities. You may find it useful to consult with legal professionals who have familiarity and experience working with individuals with disabilities.

An individual on BC disability assistance may need to place up to \$200,000 of their assets into a non-discretionary trust to remain on BC disability assistance. If the individual does not have capacity to create a trust, a lawyer or advocate may be able to assist in finding another way to assist the individual to remain on BC disability assistance.

Questions to ask an advisor

When seeking advice on estate planning, tax planning, or wealth management strategies ask:

1. What is your experience, knowledge, and training?
2. How long have you been doing this?
3. How are you compensated for your advice?
4. Have you worked with other families who have a child with a disability?

Seeking advice from professionals

There are a variety of experienced professionals in the future planning business. There is no substitute for good professional help. There are lawyers, financial planners, accountants, and trust companies that have special expertise in helping plan for the needs of children and relatives with disabilities. They can help you maximize the size of your estate, save you money, and ensure that your instructions are written in proper legal language. They are guided by principles of confidentiality, prudent administration, and sound judgment.

As with all professional services, be a cautious consumer. Always ask the professional their estimated fee before hiring them. You can also ask other parents or check with your local PLAN affiliate.

Life changes

No matter how **exhaustive** your preparation and thorough your study, your Will may never **be** complete and will never **be** perfect. While preparing for this chapter, we were consulting with one of the most prestigious estate planners in the country. He interrupted our interview to visit his lawyer. After over **35** years in the **business**, he is still revising his Will!

Expect to revise your Will as life changes. The act of revision is relatively painless and **inexpensive**. And the peace of mind is **incalculable**.

Eight tips in making your Will if you have a relative with a disability

1. Complete the Will Planning Worksheet. This will give you an idea of your assets and help you make decisions.
2. Decide how you want your estate distributed. For **example**, all to spouse and when spouse dies, split among children in **equal** shares.
3. Appoint an **executor** and alternate **executor**.
4. Decide if you want to set up a discretionary trust for your family member with a **disability**. Ensure there is no conflict of interest. If you do, decide who will **be**:
 - the trustee of the discretionary trust
 - the residual beneficiary of the trust when your relative dies

- the residual beneficiary of the trust when your relative dies.

5. Be aware that the following pass outside the Will:

- life insurance with a designated beneficiary
- RRSPs and RRIFs with a designated beneficiary
- assets held in joint tenancy.

6. If you have children under 19 years of age, decide whom you will appoint as their guardian.

7. Take all this information to a lawyer who has experience in Wills and estates for families and individuals with disabilities. Ask the lawyer to explain the tax and legal implications of your decisions.

8. Discuss your draft Will with your trustees.

SECTION TWO

The registered disability savings plan (RDSP)

Canada is the first country in the world to implement an RDSP. As a result, both the Government of Canada and the Government of British Columbia have now made it easier for families to secure the financial futures of their relatives.

The RDSP is a powerful tool for securing the financial well-being of your relative. Anyone can contribute to an RDSP. And the funds grow tax-deferred. In many situations, the federal government will assist by generously matching your contributions (see discussion on Canada Disability Savings Grant and Canada Disability Savings Bond). **The RDSP will not affect provincial disability benefits.**

The RDSP is a tax-deferred savings plan for which as many as **500,000** Canadians with disabilities are eligible. The RDSP is a financial savings vehicle that can be opened in Canadian financial institutions. Visit www.rdsp.com and click on “Where do I get it?”

PLAN's Toll-Free Hotline is now available: 1-844-311-PLAN
(1-844-311-7526)

Maximum lifetime contributions to an RDSP are **\$200,000**. This does not include any matching Grants and Bonds received from the federal government or any income earned from investments.

Anyone can make contributions: parents, grandparents, other family members, friends, agencies, foundations, and so on. The contributions are not tax-deductible and once contributed into the RDSP, they become the asset of the beneficiary of the RDSP.

2014 Income thresholds

The income thresholds of **\$87,123** for the Disability Savings Grant and **\$25,356** and **\$43,561** for the Disability Savings Bond, respectively, are **2014** figures. These numbers are indexed annually and will change over time. For the most current information, please visit www.rdsp.com or www.disabilitysavings.gc.ca.

When a contribution is made, the Federal government through the Canada Disability Savings Grant will add as much as three times the contribution to your relative's plan. How much, however, depends on your family income, or the beneficiary's income if they are **18** years or older. If annual income is below **\$87,123** the matching is better (as much as three to one) than if annual income is over **\$87,123**. Either way, the Canada Disability Savings Grant allows you to multiply a contribution and it will grow tax-deferred.

In addition, if annual income is under **\$25,356**, then the beneficiary is eligible for the full amount of Canada Disability Savings Bond. If income is between **\$25,356** and **\$43,561**, then a pro-rated portion will be received. The lifetime maximum Bond that can be received is **\$20,000**. When payments are received from the RDSP, the portion of the RDSP that is the Grant or the Bond—plus the accumulated investment

income—is taxable in the beneficiary’s hands, not in the hands of the contributor.

An RDSP is considered an exempt asset by the Ministry of Social Development and Social Innovation’s Employment and Assistance Program. In other words, having an RDSP will not affect your relative’s disability income and related benefits. In fact, RDSP funds can be used at any time for any purpose without affecting BC disability assistance.

Income from an RDSP is also exempt from claw backs against any federal benefits, such as the Guaranteed Income Supplement and Old Age Security. This is important because once your family member turns 65 years of age, they move from BC disability assistance to the Old Age Security and Guaranteed Income Supplement. Currently, any outside income, except payments from an RDSP, is clawed back from the Guaranteed Income Supplement at a rate of 50 per cent.

Income from an RDSP does not affect the Canada Child Tax Benefit, GST credit or Employment Insurance.

Both levels of government have sent a clear message to families: they trust people with disabilities and their families and there is no need to interfere with how families spend their money and how they live their lives.

When we focus on our standard expectations for behaviour and communication in our fast-paced, super technological world, we may miss opportunities to know and understand people who are likely among the most patient and best listeners on the planet.

MARTHA LEARY

Basic elements of the RDSP

If your relative is under **60** years and eligible for the Disability Tax Credit, then they are eligible to open an RDSP. Qualification for the Disability Tax Credit requires a “severe and prolonged impairment.” For details, see Income Tax Form **T2201** available from the Canada Revenue Agency website www.cra-arc.gc.ca/E/pbg/tf/t2201/ or by calling Canada Revenue Agency at **1-800-959-2221**. If you would like assistance in applying for the Disability Tax Credit, the Ability Tax and Trust, a PLAN partner, can provide assistance. See Resources for contact information.

Having an RDSP will not affect your relative’s government benefits .

Features of the RDSP

Features of the RDSP include:

- contributions of up to **\$200,000** can be made to your relative’s

RDSP

- Grant and Bond entitlements can be carried forward up to ten years
- the RDSP grows on a tax-deferred basis
- a beneficiary can have only one RDSP at a time
- contributions can be made by anyone or any organization including, for example, but not limited to: the beneficiary or any family member, friend, a foundation, or a service club
- contributions to an RDSP can be made until the end of the year in which your relative turns 59. Payments from the RDSP must begin once your relative reaches the age of 60, but may begin before at the holder's discretion (the "holder" is the person who manages the RDSP)
- the portion of the RDSP made up of government contributions (that is, the Grant and Bond) and investment income will be taxed in the hands of the your relative when withdrawn; any personal contributions (including those made by friends and family) will not be taxed
- payments from the RDSP can begin at any time. If the plan has received the Grant or the Bond, to avoid penalties, payments should not begin until 10 years after the last Grant and Bond were received (this is referred to as both the "10-year rule" or the "Proportional Repayment Rule")
- lump sum payments of any size are permitted when family contributions exceed government contributions

- an RDSP can be opened at most financial institutions and through many independent financial planners
- an RDSP can be moved from one financial institution to another
- an RDSP can be invested in most financial instruments; for example, T-bills, GICs, bonds, stocks, or mutual funds
- parents and grandparents are able to arrange for some or all of their retirement savings to be transferred tax-free to the RDSP of their financially dependent child or grandchild when they pass away.

Endowment 150

Endowment 150 supports low-income individuals with disabilities in saving for their future. The program offers eligible individuals a one-time \$150 gift to help their Registered Disability Savings Plan (RDSP) grow. Endowment 150 is an initiative of the Giving in Action Society with support from Vancouver Foundation.

The program is available to the following BC residents:

- Adults with a disability, who are under 60 years of age, have received provincial income assistance at any time after January 1, 2008, and have an RDSP with at least \$25 deposited.
- Children with a disability, who are under 19 years of age, have an RDSP with at least \$25 deposited, and whose household receives the maximum federal Child Disability Benefit.

For more information about eligibility or to get an application form, visit www.endowment150.ca, send an email to info@endowment150.ca, or leave a message at 1-888-707-9777 (toll free).

The Canada Disability Savings Grant

The Canada Disability Savings Grant will provide matching contributions of as much as three times your private contributions to a lifetime maximum of \$70,000. The maximum annual Grant is \$3,500.

Your relative can receive the Grant until December 31 of the year in which they turn 49 years old.

FEATURES OF THE CANADA DISABILITY SAVINGS GRANT

Features of the Canada Disability Savings Grant include:

- if annual net income is under **\$87,123**, then the Grant is equal to three times the first **\$500** of RDSP contribution; for example, a **\$500** contribution is matched by a **\$1,500** Grant. The Grant on the next **\$1,000** of RDSP contribution is two times the contribution; for example, a **\$1,000** contribution is matched by a **\$2,000** Grant (see chart later in this step)
- the maximum Grant that can be received in a year is **\$3,500**
- the lifetime maximum Grant is **\$70,000**
- if annual net income is over **\$87,123**, then the first **\$1,000** is matched one-to-one; for example, a **\$1,000** contribution is matched by a **\$1,000** Grant
- the amount of matching Grant or Bond your relative is eligible for depends on your family's annual net income each year until December 31st of the year that your relative turns 18 years old. Starting January 1st of the year that your relative turns 19 years old, their net income is used (and any net income of any spouse or common-law partner)
- if payments from an RDSP are made within 10 years of receiving the Canada Disability Savings Grant or Bond, then a portion of any Grants or Bonds received within the preceding 10 years must be repaid. To avoid repayment of the holdback amount, no payments should be made from the RDSP for 10 years after the last Grant or

Bond is received. For example, if you make 20 years of contributions to your relative's RDSP and it receives matching Grants each year, then payments should not begin for 10 more years

- if you set up an RDSP for your relative and choose NOT to receive the Canada Disability Savings Grant and the Canada Disability Savings Bond, then the 10-year rule referred to above does NOT apply.

Getting money from an RDSP

Here's what you need to know about withdrawals (often referred to as payments), disability assistance payments, and lifetime disability assistance payments:

- the holder decides when withdrawals are made from the RDSP
- withdrawals can be used for anything (there are no federal or provincial restrictions)
- withdrawals can begin any time (even before age 60!) but remember that a withdrawal made within 10 years of the last federal government contribution will trigger the repayment of the holdback amount
- withdrawals must begin at age 60
- you can make a one time withdrawal (a disability assistance payment) or set up regular payments, monthly or annually (lifetime disability assistance payments)

monthly assistance payments,

- when you are ready to set up regular withdrawals, you can use some or all of the RDSP to purchase a life annuity
- if the federal government contributes more than all of your personal contributions, then the total of all withdrawals in any given year will be limited by a formula (approximately the amount in the RDSP divided by the number of years to reach age **83** OR up to **10%** of plan savings, as determined by the value of the plan at the beginning of that given year).

Canada Disability Savings Bond

The Canada Disability Savings Bond is a federal government contribution that is received when the beneficiary or the family of a child has a low income. Personal contributions are not required to receive the Bond.

FEATURES OF THE CANADA DISABILITY SAVINGS BOND

Features of the Canada Disability Savings Bond include:

- the Canada Disability Savings Bond will provide up to **\$1,000** per year to an RDSP for an adult whose annual income is under **\$25,356** per year
- if the adult or family income is between **\$25,356** and **\$43,561**, then they will be eligible for a Bond of a lesser amount
- children under the age of **19** whose family's annual income is over **\$43,561** per year are not eligible for any portion of the Bond
- the Bond is available to a lifetime total of **\$20,000**

- a beneficiary may receive both the Grant and the Bond for a lifetime total of \$90,000
- a beneficiary can receive the Bond until December 31 of the year in which they turn 49
- no contributions are necessary to receive the Bond.

Qualifying for the Canada Disability Savings Grant

This chart illustrates how annual RDSP contributions qualify for a matching Grant based on the amount contributed and annual income.

Income (2013)	Contributions	\$\$ Amount of Grant	\$\$ Annual Maximum	\$\$ Lifetime Maximum
\$87,123 or less	First \$500 – contributions into the RDSP	\$3 for every \$1 contributed	\$1,500	\$70,000
	Next \$1,000 – personal contributions	\$2 for every \$1 contributed	\$2,000	
More than \$87,123	First \$1,000	\$1 for every \$1 contributed	\$1,000	\$70,000*

*If the annual family income always exceeded the threshold, then the RDSP could not reach the legislated maximum.

Qualifying for the Canada Disability Savings

Bond

This chart illustrates that, regardless of whether RDSP contributions are made or not, lower income families and adults may qualify for government assistance in the form of a **Bond**.

Your Income	Contributions Required	\$\$ Annual Bond	\$\$ Lifetime Maximum
\$25,356 or less	\$0	\$1,000	\$20,000
Between \$25,356 and \$43,561	\$0	partial amount based on income	\$20,000
Greater than \$43,561 (or no income tax return)	\$0	\$0 – no bond is available	\$0

Carry Forward of Grant and Bond Entitlements

Any Canada Disability Savings Grant and **Bond** entitlements dating back to **2008** can be carried forward. When a person opens an RDSP, Canada Disability Savings **Bond** entitlements will automatically be calculated and paid into the plan for the preceding **10** years (but not before **2008**, when the RDSP was launched).

GRANT ENTITLEMENTS The government will only pay the Grant on contributions made on or before December **31** of the year in which the beneficiary turns **49**, and will only pay the **Bond** on requests made on or before December **31** of the year in which the beneficiary turns **49**. Thus, a holder must open the plan on or before December **31** of the year in which the beneficiary turns **49** in order to establish any carry

forward eligibility.

To be eligible for the carry forward from any given year, the following test for eligibility must be met:

- the beneficiary must have been a Canadian resident in that year
- the beneficiary must have been Disability Tax Credit eligible for that year (this underlines the importance of asking for Disability Tax Credit eligibility retroactively)
- income tax returns must have been filed for the two years previous so that the government is aware of the beneficiary's family income for that year and can determine the level of eligibility. If income tax returns are not filed for a given year, the entitlement for that year will be 1 to 1 for the Grant and no Bond entitlement.

For example, Pat, a resident of Kelowna, BC, opened an RDSP in 2011 when she was 35 years old. She has been eligible for the Disability Tax Credit since 2008. She applied for the Bond, has filed her income tax returns every year, and has a net income of \$14,256 per year since 2006. Based on this information, the federal government will establish her eligibility for the full Bond for the four years 2008 through 2011 and will deposit \$4,000 into her RDSP.

BOND ENTITLEMENTS To receive any accumulated Bond entitlement, you will need to make a Bond request, and upon receipt of that request, the government will pay all accumulated Bond entitlements including the current year and ten previous years, but not before 2008, to an annual maximum of \$11,000.

To receive any accumulated Grant, a contribution will need to be made requesting the Grant and, upon receipt of that request, the government will pay accumulated Grant entitlements starting with the highest and

oldest matching rate first, to the newest and lowest matching rate last to an annual maximum of \$10,500.

NOTE The RDSP must be registered in order to qualify for any eligibility, including carry forward.

For example, when Pat opened her RDSP, her family made a contribution of \$4,000.

Year	3-1 Entitlement	2-1 Entitlement
2008	500	1,000
2009	500	1,000
2010	500	1,000
2011	500	1,000
Total	2,000	4,000

The table above shows Pat's Grant entitlements.

The \$4,000 will be first applied to her Grant entitlement as follows:

- 3-1: $\$2,000 \times 3 = \$6,000$
- 2-1: $\$2,000 \times 2 = \$4,000$

A total of \$10,000 Grant will be deposited to her RDSP. She will have \$2,000 in 2-1 entitlements remaining.

Combining the three contributions: Family contribution (\$4,000), Grant (\$10,000) and Bond (\$4,000), Pat will have \$18,000 in her RDSP.

RRSP/RRIF rollover to a RDSP

In 2010, provisions were added permitting parents and grandparents,

at death, to rollover their RRSPs and RRIFs to the RDSPs of financially dependent children and grandchildren, on a tax-deferred basis.

A person is generally considered to be financially dependent if their income is below a specific threshold (**\$18,735 for 2013**). A person whose income is above this amount may also be considered to be financially dependent if dependency can be demonstrated.

Normally any assets held in RRSPs and RRIFs become income to the deceased in the year of the death—often leading to a sizeable tax bill. When these assets are passed to the RDSP of a child or grandchild, that tax is waived, leading to sizeable tax savings.

As much as **\$200,000** can be rolled into an RDSP but the amount of the rollover may not exceed the beneficiary's available RDSP contribution room. This means that if contributions have already been made, then the amount will equal **\$200,000** minus previous personal contributions.

The rollover will count as contributions towards the beneficiary's lifetime limit but will not be matched by Canada Disability Savings Grants. The rollover will be considered as a personal contribution for the purpose of determining whether personal or government contributions are greater. But because the rollover will not have been subject to income tax, it will be considered taxable when withdrawals are made.

Before you open an RDSP: three questions you might ask your financial institution

RDSPs may vary from one financial institution to another. Make sure your relative's RDSP has the flexibility to meet unforeseen circumstances:

1. Does the RDSP permit Disability Assistance Payments (lump sum payments)?
2. Can the RDSP be transferred to another financial institution without penalty?
3. Are there penalties if you don't meet a contribution schedule?

RESP rollover to a RDSP

Investment income earned in an RESP is allowed to be transferred on a tax-free basis to an RESP beneficiary's RDSP. In order to qualify for the RESP rollover, the beneficiary must meet the existing age and residency requirements in relation to RDSP contributions. As well, one of the following conditions must be met:

- the beneficiary has a severe and prolonged mental impairment that can reasonably be expected to prevent the beneficiary from pursuing post-secondary education

- the RESP has been in existence for at least **10** years and each beneficiary is at least **21** years of age and is not pursuing post-secondary education, or
- the RESP has been in existence for more than **35** years.

NOTE Only RESP investment income is actually included in the rollover, and these amounts would not attract Grants. RESP government contributions (Grants and Bonds) cannot be transferred to an RDSP.

Personal contributions made to an RESP will be refunded to the beneficiary. At that point they may be then directed to the RDSP—either in a lump sum or over time—at the discretion of the beneficiary, and such amounts would be treated like ordinary RDSP contributions—that is, they would attract Grants.

Tips to get the most out of an RDSP

- start early
- contribute regularly
- maximize Canada Disability Savings Grants
- remember that anyone can contribute to your relative's RDSP
- use PLAN's RDSP calculator to determine your best scenario (www.rdsp.com)
- and for advice, call PLAN's Toll-Free RDSP Hotline: 1-844-311-PLAN (1-844-311-7526).

Now I can sleep at night

JUSTIN WAS THREE DAYS away from his 18th birthday when he suffered a heart attack. He was in the cardiac unit for a long time—they implanted a cardiac defibrillator in his chest, and had to try several kinds of medications before one worked.

Donna, Justin's mother, had recently been laid off a job she had for 17 years. She was holding down two new part-time jobs when the heart attack happened—and lost one of them being at Justin's bedside constantly for the first month of his hospitalization.

Justin and my son were friends. Both have developmental disabilities. A support worker who had a hunch they'd get along introduced them.

Their friendship grew as they really enjoyed hanging out together—meeting at the local pancake house, and then heading to the gym for a swim and a workout (and a great deal of horseplay).

Now, in the hours spent in anxious bedside vigil, I had time to get to know his Mom. A widow, she worked so hard to provide for Justin and his sister, but I could see the growing weight of her anxiety as the days passed and bills went unpaid.

Like many parents of kids with disabilities, we talked of our sons' struggles to navigate through the world, and of their gifts.

Because I had just been through the process with my own son, I helped Justin maneuver through the provincial disability benefits system (PWD), and soon he was getting his own monthly cheque from the province. And now his health care was paid for as well.

Not a minute too soon, as Donna was behind on the rent again. She was terrified they may be evicted and homeless. I was shocked to learn that she had never heard of the Disability Tax Credit.

I explained that Justin's doctor would have to fill out some forms to verify his disability. I would help her fill out other forms to have her taxes re-assessed for the past 10 years once Justin was approved. Because Donna lived in BC, the government would then refund her approximately \$15,000. She shook her head and said that would be like winning the lottery. She really didn't believe me at first. It would take some time—probably six months or more—but that the money would come.

...and it did. About six months later, I met Donna at the mall for coffee and had asked her to check her mailbox on the way. She arrived beaming—grinning from ear-to-ear as she pulled the cheque from her purse with shaking hands to show me.

The next day she called me and said “now I can sleep at night.” She had gone to the bank and paid off all her debts—Justin's braces, overdue bills—everything.

Now that their lives had stabilized, it was time to start saving for Justin's future by opening an RDSP. I explained that you don't need to have any money to open an RDSP. Once you qualify for the Disability Tax Credit, you can just open an account and, if you have a disability and low income, the government will put \$1,000 a year in the account for up to 20 years.

I explained that if Justin (or his family or friends) could afford to put a minimum of \$1,500 a year into his RDSP account, then the

government would contribute up to **\$4,500**, turning Justin's **\$1,500** into **\$6,000** every year until the maximum amount of Grants and Bonds has been received.*

Last week Justin, Donna and I met at the bank and opened his RDSP. Justin will be depositing **\$125** every month. He understands that this is "no touch money," and that if he lets it grow, he will have the secure financial future neither he nor his mother ever dreamt possible a year ago.

SUSAN ANTHONY

TRUST	RDSP
AGE	
<p>You can establish a discretionary trust for a beneficiary of any age. Non-discretionary trusts can also be established at any age.</p> <p>There are no age restrictions on payments from trusts.</p>	<p>You can establish an RDSP for someone until the end of the year in which they turn 59. The Grant and Bond are only available until the end of the year in which the person turns 49.</p> <p>The younger a person is and the earlier the contributions are made, the more that person can benefit from the RDSP because:</p> <ul style="list-style-type: none"> • they have more opportunity to use the matching federal Grant and Bond • the power of compounded income is increased • they can access the funds at a younger age without penalties.
CONTRIBUTION LIMITS	
<p>There are no contribution limits on discretionary trusts. BC disability assistance is not affected by the size of the discretionary trust.</p> <p>BC disability assistance permits a maximum of \$200,000 to be placed in a non-discretionary trust.</p>	<p>The RDSP has a \$200,000 lifetime contribution limit. Combined with the maximum lifetime amount of \$70,000 from the federal Grant and \$20,000 from the federal Bond, the lifetime RDSP contribution maximum is \$290,000. Accumulated investment income can grow the RDSP well beyond this level.</p>

TRUST	RDSP
CONTROL/DIRECTION	
<p>The trustee(s) make decisions about investments and payments from a trust. They have absolute discretion to make these financial decisions if you establish a discretionary trust. Both trustee(s) and alternates can be identified in your Will when you set up the trust. You can also give trustees the power to designate alternates at a later date.</p>	<p>The holder(s) make decisions about investments and payments from an RDSP. Parents or legal guardians must be the holders of an RDSP established for a minor child. Parents can continue in this role once the child becomes an adult. If an RDSP is established for an adult, then the adult must be one of the holders of the RDSP unless there is a Guardian of Property and the Person or a Continuing Power of Attorney for Property.</p>
INCENTIVES	
<p>Setting up a trust for a relative with a disability is done entirely with private funds. Governments make no contributions nor offer any tax incentives.</p>	<p>The Federal government will contribute up to \$90,000 through the Canada Disability Savings Grant (\$70,000) and Canada Disability Savings Bond (\$20,000) to a RDSP.</p>
ELIGIBILITY	
<p>You can set up a discretionary trust to benefit anyone with a disability whether they receive BC disability assistance or not. For people receiving BC disability assistance, discretionary trusts are not considered an asset.</p>	<p>To be able to set up an RDSP, the beneficiary must be:</p> <ul style="list-style-type: none"> • qualified for the Disability Tax Credit • younger than 60 years • a resident of Canada.
INVESTMENT	
<p>Investment of assets in trusts is limited to prudent investor rules as outlined in the Trustee Act unless other investments are permitted in the Will or trust document.</p>	<p>RDSPs are limited to investments that qualify for an RRSP. There are few restrictions.</p>

TRUST	RDSP
LIMITATIONS ON USE OF FUNDS	
<p>Other than the general guidance or direction you give to your trustee(s), there are no limitations on how trustees can use funds from a trust to benefit the beneficiary.</p> <p>If the person receives BC disability assistance, there are some limitations on how funds can be used without affecting BC disability assistance.</p>	<p>There are no limitations on how funds can be used.</p> <p>If the person receives BC disability assistance, then they are free to use funds from the RDSP for any purpose without affecting their BC disability assistance.</p> <p>Funds from an RDSP can be used any time but must begin to be paid to the beneficiary at age 60.</p> <p>There are some limitations on the amount that can be used from an RDSP if government contributions exceed family contributions.</p>
TAX ON INCOME EARNED	
<p>Inter vivos trusts must pay taxes on income earned from investments, unless the income is distributed to the trust's beneficiary. Income subject to tax in inter vivos trusts is taxed at the highest marginal tax rate. Income received from a trust set up in your Will is taxed at the marginal tax rate of your relative with a disability. At present, income taxed in a testamentary trust (one set up in your Will) is taxed at graduated rates applicable to individual taxpayers.</p> <p>Consult with your tax advisor for more details.</p>	<p>RDSPs are tax sheltered. Tax is not payable on investments while held by the plan.</p>
TAX ON PAYMENTS	
<p>No tax is payable when funds are spent from the trust.</p>	<p>Tax is payable on the portion of the payments that are made up of government contributions and interest earned in the RDSP. It is payable in the hands of the beneficiary; that is, at their marginal tax rate.</p>

TRUST	RDSP
WHAT HAPPENS WHEN THE BENEFICIARY DIES?	
<p>When you set up a trust, you identify who will receive the remaining assets when the beneficiary dies.</p>	<p>When the beneficiary of an RDSP dies, the RDSP becomes part of their estate and is distributed through their Will. If they don't have a Will, distribution is determined by the <i>Estate Administration Act</i>.</p> <p>NOTE If the individual dies after the 10-year waiting period, the government Grants and Bonds do not have to be returned. Some or all of the Grant and Bond must be returned, however, if the person dies before the 10-year period is over.</p>

Worksheet 10 – Will planning

This Worksheet will help you clarify your objectives in making a Will. The Worksheet is located at the back of this Section. Take a look at it now. It is based on ones that all lawyers use. You can get a head start by filling out this worksheet in detail. This way, you'll be better prepared for your meeting with your lawyer.

Types of Payments

Two types of payments can be made from an RDSP: Disability Assistance Payments and Lifetime Disability Assistance Payments. Disability Assistance Payments can be of any amount at any time but are only permitted if personal contributions exceed government contributions.

Lifetime Disability Assistance Payments are determined by a formula, which is approximately the amount in the RDSP divided by the beneficiary's life expectancy, or up to 10 per cent of plan savings, as determined by the value of the plan at the beginning of that year.

It is possible to purchase an annuity with any amount of the RDSP. The annuity payments become part of the Lifetime Disability Assistance payments. These payments may begin any time but, once they begin, they must continue. Lifetime Disability Assistance Payments must begin in the year that the person turns 60.

Resources

Consult your local PLAN affiliate on upcoming seminars about RDSPs and Will and estate planning. For information on the RDSP, you can visit www.rdsp.com, where you will find the best—and most current—information in Canada. You will also find our RDSP Calculator and links

to RDSP seminars, such as PLAN's free tele-conference seminars. And when you'd like to hear a friendly voice on the other end, contact PLAN's Toll-Free Hotline: 1-844-311-PLAN (1-844-311-7526).

What happens to minor children when you die without a Will?

If you have young children and you die without a Will, here's what happens.

ONE If there is a surviving spouse they get the first **\$65,000** of the estate, plus the household furnishings and the right to live in the family home until their death. Your estate will be divided according to the Estate Administration Act.

The remainder of the estate is divided as follows: one-third to the surviving spouse and the balance divided equally between any children.

The funds for your children will be held in trust by the Public Guardian and Trustee until your children reach the age of majority.

The surviving spouse will have to apply to the Public Guardian and Trustee's office to access the money held in trust for the use, maintenance and benefit of the child(ren). This holds true for day-to-day expenses as well as any special expenditures.

TWO If there is no surviving parent—that is, you both die—or there is no surviving parent who has legal custody, the Ministry of Children and Family Development becomes the guardian of the

person, and the Public Guardian and Trustee becomes guardian of their estate. In order for another relative or family friend to become guardian, they will have to apply to the BC Supreme Court.

To prevent a costly, complicated, and potentially messy and heartbreaking outcome, you must make a will. If you have children under the age of **19**, you must name a legal guardian for your child.

Where there's a Will, there's a way .

Questions about the RDSP

Why should we open an RDSP if our relative is older?

The RDSP has several advantages no matter how old your relative is. At age **65**, people cease to receive **BC** disability assistance. Instead, they receive the Guaranteed Income Supplement (GIS). GIS income, including income from a discretionary trust, is clawed back at **50** per cent. Payments from an RDSP, however, are exempt. Further, the RDSP grows tax-deferred while income in non-registered trusts is taxable.

Therefore, even though your relative is older and they may not receive much, if any, of the Grant or **Bond**, it is still to their benefit to have an RDSP. It is important to remember that contributions to an RDSP can be made until December **31** of the year in which your relative turns **59**.

Can we use an RDSP as a short-term savings plan?

Yes! As indicated above, an RDSP is still beneficial when your relative is older. Families who want the flexibility to allow their relatives to use the RDSP right away should forego the Grant and **Bond** in order to have the freedom to start receiving payments today. If your relative is older, then you don't have the option of saving over many years. In this situation, the RDSP can be used as a short-term savings plan. See Alex's scenario for more details.

What happens to my relative's RDSP when they die?

Assets in a person's RDSP become part of the person's estate and are distributed in accordance with their Will. If they don't have a Will, then their assets are distributed according to provincial laws.

If the individual dies after the 10-year waiting period, then the government Grant and Bond does not have to be returned. Some or all of the Grant and Bond must be returned, however, if the person dies before the 10-year period is over.

What happens to my RDSP if I lose my Disability Tax Credit (DTC) status?

Currently, if a beneficiary's condition improves such that they do not qualify for the DTC for a taxation year (that is, a full calendar year), the RDSP must be terminated by the end of the following year. No further contributions may be made to, and no Grants or Bonds may be paid into, the RDSP once the beneficiary is DTC-ineligible. In fact, the previous 10 years' worth of Grants and Bonds must be returned to the government and any assets remaining in the RDSP must be paid out to the beneficiary.

There may be some RDSP beneficiaries, however, who have ceased to qualify for the DTC, but have a disability that makes them likely to become eligible for the DTC again, such as individuals with episodic illnesses. For these individuals, government allows an RDSP to remain open but "dormant" up to a maximum of five years after the beneficiary ceases to qualify for the Disability Tax Credit. Written certification must be obtained from a medical practitioner that states that the beneficiary, because of their condition, likely will be eligible again for the DTC in the foreseeable future.

NOTE An episodic disability is a long-term condition that can cycle

between periods of good health and periods of disability. The periods may vary in length, severity and predictability from one person to another. Some common examples of episodic disabilities can include various mental illnesses, multiple sclerosis, interstitial cystitis, arthritis and diabetes.

During the dormant period, no contributions to the RDSP will be permitted, including rollovers of RESP investment income. However, a rollover of proceeds from a deceased individual's RRSP or RRIF to the RDSP of a financially dependent infirm child or grandchild will still be permitted. As well, no new Grants or Bonds will be paid into the RDSP. If a beneficiary dies after an election has been made, all Grants and Bonds from the last 10 years must be repaid. Finally, withdrawals from the RDSP will be permitted, and will be subject to the ten-year or proportional repayment rule, as well as the proposed maximum and minimum withdrawal rules as applicable.

Who oversees my relative's RDSP?

The person who manages an RDSP is the holder. Parents are the holders when their child is a minor. When their child turns 18, the parents may continue as the holder, or they can pass the responsibilities on to the beneficiary, an adult trustee or a power of attorney.

Between June 29, 2012 and December 31, 2016, the definition of who may be an adult beneficiary's plan holder has been expanded to include the beneficiary's spouse, common-law partner, or parent. Although this is a temporarily measure, any plan already opened by a family member before the end of 2016 may continue as is.

NOTE Powers of Attorney can only be appointed if the person has

legal capacity to make such an agreement. When a plan is opened for a person who is **18** or older, that person must **be** a holder unless they assign the responsibility to a designated attorney under a Power of Attorney.

What you need to do now!

- ensure your relative has a Social Insurance Number
- establish your relative's eligibility for the Disability Tax Credit (Income Tax Form T2201 or www.rdspresource.ca)
- file your income tax returns until your relative is **18** (and the income tax returns of your relative if they are **16** years or older) for the current and previous year
- if the beneficiary is a child, make sure you apply for the Canada Child Tax Benefit.

NOTE We estimate that thousands of people in Canada are eligible for the Disability Tax Credit but do not apply because they have no income. Now they have good reason to apply because eligibility for the Disability Tax Credit automatically makes your relative eligible for the Disability Savings Grant and Bond.

RDSP SCENARIOS

The power of the RDSP

The following scenarios illustrate the potential of the RDSP. We have summarized our assumptions in each situation. Results will vary with different assumptions and your personal circumstances.

For illustrative purposes, we have estimated the rate of return for the scenarios below at 5.5 per cent. Interest rates go up and down. To calculate the interest rate you expect, see PLAN's RDSP calculator: <http://www.rdsp.com/calculator/>.

The RDSP and young children

Families with young children usually have a list of competing financial priorities. The RDSP represents an economical way for parents, grandparents—and perhaps other family members and friends—to put funds aside for your relative and, and by so doing, have the government contribute as well.

For example, if you have a four year old and are able to put aside \$100 a month (\$1,200 a year) for 20 years and your family's annual income is below \$87,123 (2013 amount), then your child will have over a quarter million dollars when they turn 34. In other words, your investment of \$24,000 will multiply over ten times!

HERE'S HOW IT WORKS:

Family taxable income: under \$87,123

Son/daughter's income at age 19: under \$25,356

Annual family contribution: \$1,200 a year

Total family contributions from age 4 to 24: \$1,200 times 20 = \$24,000

Matching Grant: \$58,000

Bond: \$6,000 (age 19 to 24)

Total Grant and Bond: \$64,000

Value at age 34: \$250,000 (approx.)

If Annual Lifetime Disability Assistance payments begin at age 34, then

the first payment will be **\$5,200**. Over **\$700,000** would be paid by the time your relative reaches the age of **65**.

Alternatively, the funds could be withdrawn at a different age. For example:

Value at age **40**: **\$360,000** (approx.)

Value at age **50**: **\$640,000** (approx.)

There are an infinite number of combinations depending on how much you contribute and when. Please visit PLAN's RDSP calculator at www.rdsp.com.

Teens: Natalie

Natalie's squeals of satisfaction when a teammate scores a run are all the reward that her father, Eric, would ever ask for. "She loves being a part of the team and loves the excitement of the competition," says Eric.

While Natalie, like other teens, may be focused on friends and fun, her mother Karin is aware of the uncertainty of the future. "When I close my eyes, I see us on the calm water above Niagara Falls. What's so frightening is that I don't know what comes next."

"The RDSP is a really concrete way to start preparing for the future today. Financial security allows us to shape the future. We can begin to dream with it," adds Eric. Karin is not currently working outside the home and Eric's annual income is below **\$87,123**; therefore, they will qualify for the maximum annual grant of **\$3,500**. At **47** years of age, Natalie will be able to receive payments without any penalties and the plan will be worth about **\$350,000**. It will pay her about **\$9,700** a year at the beginning and rise to **\$48,200** per year when she is **77** years old.

Karin and Eric think they can put aside **\$125** a month for an RDSP for a total of **\$1,500** per year. They plan to contribute for **20** years.

RDSP SUMMARY:

Natalie's age: **17** years

Family taxable income: under **\$87,123**

Annual family contribution: **\$125** a month (**\$1,500** a year)

Family contributions from age **17** to **36**: **\$30,000**

Value of Grant: **\$70,000**

Value of Bond: **\$18,000**

Investments: moderate risk

Age to begin receiving from the plan: **47** years

Approximate value of the RDSP when beginning payments (age **47**):
\$350,000

Annual Lifetime Disability Assistance payments will approximately begin as follows:

\$9,700 at age **47**

\$16,500 at age **57**

\$28,200 at age **67** and

\$48,200 per year at age **77**.

Transition to adulthood: Darren

Even in a crowded room Darren seeks out people standing alone, latches onto their arm, and guides them into a conversation. It seems no one can refuse his broad smile.

"It's his gift," says his mom Janice, who keeps a watchful eye on him.

"I'm not sure how he will put it to use after he finishes school in June,"

she sighs.

“I like the idea of the RDSP,” she says, “I’m scared to death about the future. But as a single mom, I don’t have much left to contribute after I pay the bills every month.”

Janice plans to open an RDSP for Darren to get the Canada Disability Savings Bond. She’s been to a PLAN Will and Estate workshop and has counseled her elderly parents to put the share of their estate they plan to leave for Darren into a discretionary trust. If he’s still young enough, the trust can make contributions to his RDSP. Otherwise, the trust can be used directly to secure his future.

RDSP SUMMARY:

Darren’s age: **19** years

Taxable income: under **\$25,356** (determined by Darren’s income)

Annual family contribution: **\$0**

Value of Bond: **\$20,000**

Investments: moderate risk

Age to begin receiving from the plan: **49** years

Approximate value of the RDSP when beginning payments (age **49**):
\$60,000

Annual Lifetime Disability Assistance payments will begin at: **\$1,750**
and will rise by about **\$170** every year.

NOTE The amount in the RDSP could also change if Darren’s grandparents contribute to his RDSP.

Young adulthood: Maria

“I’m famous! I’m famous!” shouts Maria, surrounded by the cast of the Vancouver theatre production of Beauty and the Beast. She glows

when she is speaking about musicals, the excitement palpable in her voice. If her parents George and Rosa had enough time (and money), this is where she would spend every evening.

Maria's parents are confident that they can provide a good life for her while they are alive and able. The RDSP provides the means for securing the future when they won't be around.

Rosa and George have a big extended family and, at the last gathering, getting an RDSP started for Maria was a main topic of discussion. The family has set a goal of raising **\$25,000**. George has no doubt it will happen. George and Rosa also plan to contribute **\$1,500** a year for **20** years.

RDSP SUMMARY:

Maria's age: **27** years

Taxable income: under **\$25,356** (determined by Maria's income)

Annual family contribution: **\$125** a month (**\$1,500** a year)

Total family contributions from age **27** to **46**: **\$55,000** (annual contribution plus **\$25,000** lump sum amount)

Value of Grant: **\$70,000**

Value of Bond: **\$20,000**

Investments: moderate risk

Age to begin receiving from the plan: **57** years

Approximate value of the RDSP when beginning payments (age **57**): **\$475,000**

If an annuity is bought, annual payments will begin at: **\$24,000** and will rise by an average of about **\$500** per year. Some or all of the funds in Maria's RDSP could also be used to help purchase a house or to deal

with other requirements that may arise.

The future is here: Alex

Tom is a Lifetime Member of PLAN. Tom is confident that Alex's future is provided for. His Will is current and he directs his executor to establish a discretionary trust for his son, Alex. Alex also has a Personal Network who will look out for him when Tom passes away. Alex, who just turned 41, has many interests, including photography and volunteering. His extra time is divided between the local seniors centre and the food bank.

Tom knows that if he capitalizes on the Grant and Bond for the next eight years, Alex won't be able to access the plan until he is 59 years old without paying a penalty. Tom wants him to be able to start using it earlier so he is prepared to forgo the government contribution. What Tom likes is that it will earn interest—on a tax-deferred basis—and that Alex can use it for anything he wants without affecting his BC disability assistance. Tom also knows that, unlike a discretionary trust, Alex's RDSP will not affect his Guaranteed Income Supplement, which will replace his BC disability assistance once he turns 65 years old.

Tom's plan is to contribute \$200,000 as soon as he can and then let it grow for about 10 years.

Tom will still set up a discretionary trust in his Will but the trustee will face more restrictions on spending than the holder of Alex's RDSP. The RDSP and trust combined, however, will provide a good life for Alex.

Tom's plan seems pretty sound. In 10 years, the \$200,000 that he contributes will have grown to about \$350,000. By purchasing a life annuity that is indexed for inflation at 2 per cent, this will provide Alex with an annual income of about \$16,000 per year at age 52, growing

to about **\$29,000** when he is **83** years old, which is pretty good for a **\$200,000** investment!

RDSP SUMMARY:

Alex's age: **41** years

Taxable income: under **\$25,356**

Family contributions at age **41**: **\$200,000**

Value of Grant: **\$3,500**

Value of Bond: **\$1,000**

Investments: moderate risk

Age to begin receiving from the plan: **52** years

Approximate value of the RDSP when payments begin (age **52**):
\$350,000

Life annuity: Approximately **\$16,000** per year, indexed at **2** per cent.

Comparison—RDSP and discretionary trusts

Appreciating the differences between RDSPs and trusts will help you to determine which option is best for your family member. Some families may want to capitalize on the federal government matching RDSP Grants and Bonds; others may see trusts as a more viable option. Still, others may want to do both. Please visit www.rdsp.com or speak with your qualified professional advisor for further assistance.

To download a copy of all Worksheets, visit www.plan.ca and click on Safe and Secure Worksheets.

Worksheet 10

Will planning

This Worksheet is intended to:

- assist you in compiling information to take to your lawyer when you wish to make your Will
- assist in making you aware of decisions you will need to make and to help you make them.

After completing the worksheet you will be ready to contact a lawyer of your choice to make the Will. This worksheet does not give any legal advice. To draft a Will, you need to see a qualified lawyer.

A. Personal and Family Particulars

Date _____

1 Full Name

Address

Occupation

Home Phone

Office Phone

Date of Birth

Place of Birth

Citizenship

Marital Status (including plans to marry)

Date of Marriage

Place of Marriage

Do you have a marriage contract?

Have you or your spouse been married or lived in a common law relationship before?

2 Marriage or Common Law Relationship

Spouse's Full Name

Address

Occupation

Home Phone

Office Phone

Date of Birth

Place of Birth

Citizenship

3 Children (Please list all children of either spouse.

Please note with an * any child of a former marriage of either spouse and with ** any child with a disability. Please include children you have adopted and children of any previous marriages or common law relationships. Have any of your children died?)

Full Name Date of Birth

4 Other Dependents

Is there someone who is dependent upon you for financial support for whom you wish to provide, such as an elderly parent?

If yes, please complete the following:

Full Name

Address

Relationship

5 Other Responsibilities

Are you now serving as the legal guardian or trustee for an adult who has a disability or lacks capacity

If yes, full name, address and relationship to you:

Full Name

Address

Relationship

Relationship to you

B. Will Particulars

1 Appointment of Guardian(s) for Infant Children

Do you have a child under the age of **19**?

It is important to note that you CANNOT appoint a guardian for your child with a disability who is older than **19**.

Who will be their guardian(s) should you die before they reach age **19**?

Name	Address	Relationship to you	Occupation

Who will be their alternate guardian(s) before they reach age **19**?

Name	Address	Relationship to you	Occupation

2 Distribution of Your Estate

(a) Do you wish to leave your estate to your spouse if he/she survives you?

(b) Do you wish to share your estate between your spouse and your children?

If so, how?

(c) If your spouse dies before you, do you wish to leave your estate to your children?

If so, in equal shares?

If in unequal shares, what proportion or amount is each child to get?

(d) At what age(s) do you wish your children to receive their share?

(e) If any child fails to survive to that age, do you wish his or her children to receive the share?

(f) If one of your children dies before you do, who do you wish to receive his or her share of your estate?

(g) If your spouse and children all die before you do, who do you want to receive your estate?

3 Discretionary Trust for someone receiving BC Disability Benefits

(a) Do you have a relative who is in receipt (or likely in the future to be in receipt) of BC Disability Benefits? Yes No

(b) Do you wish to set up a trust for this relative? Yes No

(c) Do you wish it to be a discretionary trust? Yes No

(d) Who do you wish to be trustees of this trust?

Name	Address	Relationship to you	Occupation

NOTE You may have any number of co-trustees. You should discuss with your lawyer whether you want each trustee to be a co-trustee or an alternate trustee. You should also discuss with your lawyer the ability of your named trustees to appoint additional or successor trustees.

(e) Who do you wish to be alternate trustees if any of the ones you have named are unable to serve?

Name	Address	Relationship to you	Occupation

(f) Residual Beneficiary

When you set up a trust you must specify what happens to the

assets left in the trust when the person whom the trust was set up for dies.

Who do you want to receive the assets left in the trust when the person for whom the trust was set up for dies?

Does this cause a conflict of interest? You should make sure you discuss a potential conflict of interest with your lawyer.

(g) Trustee Powers

Do you wish your trustee to be able, if it becomes necessary or desirable, to buy, sell, rent, lease, or mortgage a residence for your relative with a disability?

If so, make sure you discuss your wishes with your lawyer. They will need to ensure they give the powers you want to your trustees.

Do you wish to give your trustees unrestricted investment powers to allow them to make any investment they think is appropriate?

Or

Do you wish them to be restricted in what they can invest?

It is important to discuss with your lawyer the powers you wish to give to your trustees.

Do you want to leave a particular asset to a particular person? This includes clothing, jewelry, art, etc. If so, describe below.

Do you want to give a cash gift to anyone? If so, describe below.

Do you want to give cash or another gift to charity? If so, describe below.

You must be aware that some assets can pass outside of your Will. Have you filed a beneficiary designation with the plan issuers for your:

a) RRSP Yes No

b) RRIF Yes No

c) Pension Plan Yes No

d) Life Insurance Policy Yes No

If so, these items will pass outside of your Will. Yes No

Do you own any other assets, for example property, bank accounts, etc. jointly with another person? Yes No

If so, these items will pass outside of your Will. Yes No

4 Additional Support for your relative

Do you wish PLAN to provide support for your relative when you are no longer able to do so? If so, contact PLAN to discuss incorporating appropriate clauses into your Will that will enable PLAN to assist your relative.

5 Other Comments or Instructions

This is for additional information, which your lawyer might need to consider.

C. Asset and Debt Summary

(please indicate if these assets or debts are not in British Columbia)

Hers His Both

a) Cash and Term Deposits \$ _____ \$ _____ \$ _____

b) Life Insurance

Insurance Co	Owner of Policy	Designated Beneficiary	Amount
--------------	-----------------	------------------------	--------

\$ _____

\$ _____

\$ _____

c) RRSPs

RRSP Institution	Owner of RRSP	Designated Beneficiary	Amount
------------------	---------------	------------------------	--------

\$ _____

\$ _____

\$ _____

Her name His name Joint Names

d) Stocks and Bonds \$ _____ \$ _____ \$ _____

e) Pension Plans & Annuities \$ _____ \$ _____

\$ _____

f) Describe any interests you may have in any proprietorships, partnerships or private companies.

g) Real Estate

No.1 No.2

Address

Registered Owner(s) _____

Joint Tenants? _____

Estimated Value \$ _____

\$ _____

Mortgage Balance (estimated) \$ _____

\$ _____

Mortgage Life Insured? Yes No Yes No

Approximate equity \$ _____

\$ _____

h) Personal Effects

Approximate value of household goods, furniture, jewelry, boats & automobiles: \$ _____

Are any of these articles owned jointly with someone else? Yes No

i) Miscellaneous

A) Interest in any existing estate or trusts:

B) Other substantial assets:

C) Do you have any real or personal property outside of BC? If so, please specify.

D. Summary of Debts (other than mortgages previously noted)

Creditor Life Insurance Amount

_____ Yes No \$ _____

_____ Yes No \$ _____

_____ Yes No \$ _____

Estimated Net Value of Estate

Her name His name Joint Names

Total Assets _____

Less Total Debts _____

Less Estimated Tax _____

Liability _____

Total Net Value of Estate \$ _____ \$ _____

\$ _____

Demystifying definitions that could definitely derail you

BC Disability Assistance Financial support plus medical, dental and pharmaceutical benefits provided to people with disabilities in British Columbia.

Beneficiary A person to whom you leave things or who is entitled to receive things through a trust (money, gifts, insurance policy, RRSP, trust).

Bequest A gift of a specific item of property or a specific amount of cash identified in your Will.

Co-Decision Maker The person appointed by the Court, with the express agreement of an adult suffering from a significant impairment, to assist that adult in making health care or other personal decisions.

Codicil A legal document used to amend portions of your original Will and requiring the same formalities of signing and witnessing needed for a Will.

Discretionary Trust (or Henson Trust) A trust in which the choice as to how to spend the interest and principal is completely in the hands of the trustee.

Enduring Power of Attorney A written document giving someone else the power and authority to conduct and manage your financial affairs even if you become incapable.

Executor (or Personal Representative) The person or professional named in the Will who is responsible for ensuring that the wishes in your Will are carried out.

Grant of Probate A court order which is the executor's proof they

can act as your executor.

Guardianship The authority to make health, and personal care decisions on behalf of another person.

Holdback Amount The total of government Grant and Bonds paid into the plan (or into any previous RDSP of the beneficiary) in the immediately preceding 10-year period, less any amount of Grant and Bonds paid in that 10-year period that has been repaid to the government.

Inter Vivos Trust A trust that comes into effect during the lifetime of the person who established the trust. Also known as a Living Trust.

Intestate A person who dies intestate dies without a valid Will.

Life Interest Benefit given to someone in a Will which allows that person to have the use of specific property or a certain sum of money only for the lifetime of that person. The remainder goes to someone else when the person with the life interest dies.

Non-Discretionary Trust A trust in which the beneficiary may have some control over the provisions of the trust, including how to spend the principal and interest.

Non-Probate Assets Assets that pass outside of the Will. For example, joint tenant ownership of real estate and bank accounts, RRSP/RRIF, life insurance, and annuities if beneficiaries have been designated.

Personal Directive A written document giving someone else the authority to make personal care decisions on your behalf should you not have the capacity to do so.

Probate The procedure by which the Will of the deceased person is legally approved by the court and documented. It also confirms the

appointment of your **Executor**.

Representative The individual appointed by an adult with disabilities to help them make financial, health and other decisions of a personal nature. **NOTE:** PLAN believes all adults regardless of disability have the capacity to make a Representation Agreement.

Revocation Cancelling parts of or all of an existing Will.

Settlor The individual who establishes a trust.

Specific Decision-Maker The person appointed under the Adult Guardianship and Trustee Act to give or refuse treatment on behalf of another person when a Personal Directive or guardianship order does not exist.

Testator That's you, the person who makes the Will.

Testamentary Trust A trust set up in a Will that only takes effect after your death.

Trust A legal arrangement in which one person (the Settlor) transfers legal title in certain property to a Trustee to manage the property for the benefit of a person (the **Beneficiary**).

Trustee The person or company that manages the trust according to the instructions in the trust agreement or Will.

step six

advocate with empathy

When we support one another,
we are stronger.

When we talk about our
experience, we find meaning.

When we reflect on the meaning of our
shared experience, we form a movement.

When we realize that we are a
movement, we know we are
not alone and that we are powerful.

When we feel powerful,
we can carry on taking care.

DONNA THOMSON

Peggie

Abuse, neglect and exploitation

IT IS HARD to believe, but Peggie spent her childhood living in the extended care ward of a hospital. If it wasn't for friends of Vickie and Al, she might still be there. The friends were visiting their grandmother and noticed that Peggie was much younger than everyone else. They also noticed she was always alone and that people often yelled at her to 'shut up' because of the high pitch sounds she made.

Peggie had lived in the hospital since the age of two. She had received a severe brain injury as a result of a car accident and was immobile. Her family, unable to care for her, had eventually stopped visiting. Peggie had no other companions. Her only stimulation was a TV that she could not see. Most of the time she lay on her back, unable to move or to communicate. She was clearly isolated, lonely and bored. With the tacit support of the hospital, PLAN agreed to help.

The immediate challenge was to get to know her. PLAN hired a Community Connector who observed her love for music. Soon there were four network members taking turns visiting Peggie and inviting her to local music events. Before long, the hospital became defensive. It might have been because Peggie's new acquaintances began asking questions about her care and inquiring why, at her young age, she had to live in an extended care facility. In turn, the hospital demanded to know the qualifications of the people visiting Peggie.

Matters came to a head when a network member overheard someone

on staff mention that ‘administration’ had decided to pull all of Peggie’s teeth out. Apparently, Peggie was not cooperating during mealtimes. She resisted food being shoved down her throat and in response, clenched her teeth. Consequently, it took too much staff time to feed her. They thought it would be easier on staff and quicker to feed her pureed food if she had no teeth. PLAN was able to use its influence with the Ministry of Health to stop that decision.

Eventually senior officials were persuaded to examine community living options for Peggie. With the active presence of friends and visitors, Peggie’s life began to brighten. Contact was made with her family. Government agreed to consider Peggie for placement in a group home they were developing.

Today Peggie is a completely different person. She lives in the community. Her Personal Network is strong and active. Her eyes sparkle and she has put on weight. Our favourite picture shows Peggie dressed in a beautiful black dress outside a downtown Vancouver restaurant just prior to attending a concert by her favourite singer, Celine Dion.

We don’t intend to dwell on the sad and disturbing fact of life that many people with disabilities are at an increased risk of neglect, abuse or exploitation. There are enough studies and experiences to confirm that reality. Whether someone lives on their own or in a facility, they may be vulnerable.

We definitely want agencies to have safety rules and procedures in place. However, the best protection is a network of caring, trusting friends. They are the people whose instincts are finely tuned to the

well-being of their friend. They pick up on what others may miss. Despite taking every precaution, bad things occasionally happen. When they do, you want a knowledgeable team who will rise to the occasion, move quickly and get results.

step six

Advocate with empathy

IT IS A FACT of life that most people with disabilities will require the services and supports of paid staff. Actually, it is a fact of life for all of us. We rely on the services of dentists, doctors, accountants, computer technicians and car mechanics. We may secure a cleaning service for our family or engage a home care service for our ageing parents.

There are two main differences between our engagement with professionals and paid services and that of people with disabilities: We choose which services we use and who will provide them. We can go somewhere else if we don't like the quality of the service or how we've been treated; and our use of services is usually occasional and intermittent.

Alas, the opposite is true for our family members and friends with disabilities. They often have very little choice about which services they receive, and little influence or power to change things if they are not satisfied. And paid professional service providers are typically a constant presence in their lives. If they are not careful, their life, and yours, will be defined by the services they receive leaving little room for pursuing their dreams, being with friends or making a contribution to the world around them.

“One’s dignity may be assaulted, vandalized, and cruelly mocked, but cannot be taken away unless it is surrendered.”

MICHAEL J. FOX

If services and programs are essential for people with disabilities so is keeping them in perspective. Programs and services are meant to be a means to an end. And the end is unique to each person. Their lives should unfold according to their personalities and interests, rather than the priorities of funders and service providers.

This Step discusses:

- ensuring services support rather than supplant a good life for people with disabilities
- creating an effective working partnership with social, health, and education professionals, and three types of relationship-based advocacy: self-advocacy, personal advocacy and public policy advocacy.

Don’t look back. Don’t say you’re sorry. Let them hear your noise.

NELLIE MCCLUNG — PIONEER CANADIAN FEMINIST

Supporting not supplanting a good life

We’ve seen it happen before. An innovation is launched that is intended to make life better. Then, before we know it, the innovation

starts to control our lives. Some would say that's true of smart phones. These seemingly harmless devices have insinuated themselves into every aspect of our lives—at dinner time, during conversations, even while driving. It requires discipline to minimize the intrusion of any technology whether it is a communication technology or a social technology.

Community-based programs and services started out in the same benign way. After the Second World War, families in many parts of the world came to the same conclusion that it was natural and preferable for their sons and daughters with disabilities to live in the community with them rather than in institutions. One of their big challenges was the lack of community services. All the funding was going to provide institutional care.

So families did what they always do. They rolled up their sleeves and developed the needed supports themselves. They took over church basements, used discarded textbooks, raised funds to cover costs and started their own schools and other programs. Over time they were able to hire staff. By 1955, there were seven parent-run, non-profit organizations and a provincial association in British Columbia. By the 1980s, there were hundreds of organizations and dozens of provincial federations offering a comprehensive community-based system of programs and services.

But here's the rub. While great programs have been developed, the pendulum has shifted to the other extreme. So pervasive are these services that, unless we are careful, they will overshadow everything else about the person with a disability. The people we love have to fight to be seen as human beings with unique and varied needs rather than as objects of service.

Despite their benefits and the best of intentions, community services and programs, like our smart phones, have unintended consequences. Too often disability is equated with needing services and not much else. The average person might develop the impression that you must be trained to have a relationship with an individual with a disability. This becomes a barrier to developing friendships. As a result, people become isolated inside the service delivery system. And perhaps worst of all, people with disabilities and their families begin to think that services are ‘all there is.’

These are some of the reasons why PLAN stopped asking the question: ‘What kind of program and service do you need?’ We noticed that this question always led to more service and program solutions. Instead, we started asking: ‘What’s a good life?’ This question unleashed answers that had very little to do with services and programs.

The ingredients of a good life are the same elements of the Personal Future Plan we discussed in Step One (a network of caring friends and family; a place of one’s own; support to make decisions; a life of meaning; and financial security.) Take a moment to revisit Step One and your answers to the two Worksheets. That vision is your North Star. That vision illuminates the destination for you and your relative. That vision will help you determine where services can help and where they can hinder.

Ted’s tips for monitoring and advocacy

- **Trust in the care of others** One of the greatest challenges of parents of a vulnerable individual is to trust that others can love and

care for our relative as richly as we do. I've discovered over the years that many people have 'fallen in love' with my son. I can see how their faces light up when they see him and the joy he brings. It's best for us to allow others in when we are still around, so we can monitor and assist with the transition to the care being provided by others.

- **Holding on in a different way** Letting go of the care of our loved one is challenging. Many years ago we offered a workshop at PLAN called 'Letting Go.' It was intended for senior parents who need to transition the care of their son or daughter to others. No one attended. When we inquired as to why families didn't attend, they responded that they couldn't let go. When we re-titled the workshop to 'Holding On In A Different Way,' families came. The fact is, we never really let go while we are still alive, but we need to hold on in a different way, a way that allows others to care for our relative too.

- **Invite others to help with monitoring** Extended family, friends, and network members can provide another perspective on whether our relatives are well cared for. What do they see? What clues or behaviours are they noticing? Sometimes our extended family and friends can see more clearly than we can. I've learned that collective wisdom is richer than individual wisdom.

- **How does Josh respond?** I've learned to trust Josh's response to those I've entrusted to care for him. Is he glad to see them? Does he smile? Does he reach out and invite them to hold his hand or sit beside him? While his verbal skills are limited, his body language speaks volumes. Josh also has an uncontrolled seizure

disorder. I've discovered that when he is well cared for, well nourished, sleeps well, and is relaxed, his seizures are less frequent. For Josh, the rate of seizing is a good indicator of whether he is happy and healthy.

- **Would I be happy?** One of the most basic questions I ask when I'm evaluating the quality of care being provided by others is to ask – 'Would I be happy here?' and 'Would I want to live here?' I've witnessed homes that are essentially small institutions. There is nothing to indicate this is someone's home. And I've witnessed homes that truly feel like a home—a sanctuary that is warm, personal and inviting. If we wouldn't be happy in a 'care facility,' then it's not likely our relative will be happy there either.

- **People are doing the best they can with what they know** I trust that caregivers are doing the best they can with what they know. Everyone wants to do a good job. And I've also learned that most of us have lived in communities that, until fairly recently, segregated people with disabilities. As a consequence, many people don't know how to be in relationship with our relatives with a disability. I see that I have a role to play in inviting them into relationship with my son and teaching them that his needs aren't 'special' at all. That he has the same needs as you and I—to be loved, cared for, have his choices honoured, security and safety, and dignity. I've also learned that different resources have different strengths and limitations and my job is to find those who are the best fit for my son.

TED KUNTZ, PLAN CHAIR

Developing a partnership with the service delivery system (schools, service provider agencies and government funders)

In PLAN's early days, we felt we were playing teeter-totter with an elephant. The service delivery 'elephant' seemed too big and dominant. In order to give ourselves the time and space to develop our model, we tried to ignore the service delivery system. Most of our energy was invested in demonstrating that personal networks were important. However, it wasn't long before families began asking us to advocate on behalf of their family members. Since the reason to intervene was because something had gone wrong with the services they were receiving, our mindset was reactive, combative and suspicious. There was nothing positive or generative about our relationship with service providers.

Today, the value of personal networks to improve our social and physical health is well understood. Even the term 'network' is familiar, thanks to Facebook. As a consequence, PLAN's mindset has shifted. While a 'warrior' mentality is necessary in certain circumstances, for example, when there is abuse and exploitation, in the long-term, an adversarial relationship is corrosive. It entrenches positions. Furthermore, a prolonged atmosphere of conflict is not in the best interest of our family member.

Services are one tool in creating a good life. A personal network is another. The key is to understand what each tool can do and what it can't do. For example, networks can tap into the hospitality and goodwill of the community. Services rely on a regulated system of trained staff. Networks take their cue from the passion and interests of

the individual. Services focus on needs. Networks are flexible. They can arrange hockey games one week, a birthday party or coffee outing the next. Services are based on standards and routines. Networks explore possibilities. Services strive for predictability.

The best approach to maintain the quality of the programs and services your sons and daughters receive is to develop an authentic partnership with the providers. More and more service providers agree. PLAN now has great working relationships with a number of agencies in British Columbia. We've learned to recognize each other's strengths and limitations.

Most agencies know they can't develop and maintain personal networks for their 'clients.' No matter how hard they try, the priorities of service provision always get in the way. Instead, these service providers focus on creating the conditions for friendships to develop, making sure their regulations and practices don't unintentionally get in the way. And, they ask PLAN to do what it does best: Network development.

Service providers are also undergoing a mind-shift. No longer do they see themselves as the experts providing 'one size fits all' solutions. The work of Eddie Bartnik in Western Australia demonstrates the most advanced understanding of this changing relationship between parents, people with disabilities and the service delivery system. There are links to his writing in the Resources section.

Eddie identifies five elements of a genuine partnership between service providers and families:

CAPABILITIES – their focus is on the gifts and strengths of the individuals, not their needs

COLLABORATIVE – they actively involve individuals and families in

designing new approaches

CUSTOMIZED – their programs and services are tailored for each individual

NETWORK CENTRIC – they recognize the individual cannot be supported in isolation from their family and friends

RESULTS ORIENTED – they measure success by whether the individual has achieved their ‘good life’ goals, not whether the agency has satisfied its funding contract.

Relationship-based advocacy

Advocacy is part of the job description for people with disabilities, their families, friends and networks. Social, educational and health services are human creations and therefore by definition, imperfect. There is often a gap between what people want and what service providers, funders and government offer. Things can and do fall apart.

Government funding is not always sufficient or allocated to the right priorities. A remedy must be sought. A solution must be advocated.

One of PLAN’s specialties is advocacy. We are often called upon to support an individual, family or personal network as they advocate for change and improvement in a program or service, or indeed, for new funding.

We have bundled our cumulative advocacy experience into an approach we call relationship-based advocacy. Relationship-based advocacy has two objectives:

1. pursuing solutions while
2. strengthening relationships with those who work inside systems.

Perhaps where ‘relationship-based’ advocates differ most from

traditional advocates is their focus on ‘means’ as well as ‘ends.’ They want results but they also want to improve relationships among all the players, to attract new allies, and to build the base for resolving the next set of challenges. They create the conditions for joint problem solving. They practice civility and respect, addressing the problem and not the character of the individual.

Mindset is important. Certain ways of thinking can derail your intentions. Righteous indignation is one. There is a danger your anger may undermine your effectiveness. You may expend your energy explaining why you are right and leave little time and room to pursue solutions. Absolute certainty is another. You may become so preoccupied with your solution, you may miss perfectly acceptable alternatives. Defensiveness doesn’t help either. Sometimes perfectly reasonable questions from a funder or provider are perceived as threats undermining any chance of a constructive discussion. Demonizing those who disagree with us or those who are unable to help us is another trap.

It will come as no surprise that PLAN supports a relationship-based model of advocacy, since relationships are at the core of our beliefs. There is also practical value in this approach. The reality is that many of the people we meet in various systems today will be there tomorrow. Whether we like it or not, we are in this together and for the long haul!

Three Types of Advocacy

1. Self-Advocacy

There is no substitute for speaking up for yourself. People with disabilities describe this as self-advocacy. In Step Four we discussed a

variety of ways to support people with disabilities to make decisions. One of the key areas of decision-making is knowing what to do when something is wrong or doesn't feel right. In other words, finding your voice, learning to say 'no,' learning to complain and learning to ask for help.

A popular slogan among self-advocates is; 'Nothing About Us Without Us.' This phrase has two important meanings: presence and participation. First of all, we must make sure that people with disabilities are present when discussions and decisions affecting them take place. Even in circumstances when the individual doesn't communicate or interact in traditional ways, their very presence changes the conversation. It reminds people they are making decisions that will affect the lives of others and to be careful about making assumptions.

Self-advocacy

Self-advocacy is nurtured **by**:

- **believing** in an individual's capacity to speak for themselves
- practicing opportunities to make daily decisions and learn from mistakes
- joining a self-advocacy group
- high self-esteem and confidence
- a network of family and friends.

The second meaning of the phrase is more **obvious**. It is critical to ensure the active involvement of people with disabilities in decisions that affect them. None of us likes a professional who tells us what to do and won't ask questions. No matter how awkward or time consuming, the point of view of people with disabilities is mandatory. Self-advocacy can **be** a challenging concept for some parents. It is our 'job' to speak up for our children when they are young. It is our 'job' to protect them. As our children get older, we naturally continue to advocate for them. At the same time, they need to develop the confidence to **become** their own advocate. Otherwise, their vulnerability only increases when we are no longer around. We need to strike a **balance** **between** our natural instincts to speak on behalf of your son or daughter and their right to **express** themselves.

There are a number of self-advocacy groups and plain language resources in British Columbia where people can learn about their rights and responsibilities and how to speak up for themselves. We've listed them in the Resource Section.

2. Personal Advocacy

Advocacy is more of an art than of a science. It improves with practice. Nevertheless, there are key approaches we have learned over many years, actually many lifetimes, if you count the accumulated experiences of the authors of this book. Aside from the mindset discussed earlier in this Step, here are three basic tips.

a) Don't do it alone: Make sure there is at least one person who accompanies you to meetings, takes notes, compares impressions and with whom you can bounce off ideas. People who know our relatives make for the best advocates. They may not know all the details of service provision and funding, but they are grounded in what is best for our relative and will fight on their behalf. One of the biggest gifts we can give our son/daughter is to teach their personal network everything we know about advocacy and to provide them an opportunity to learn the advocacy ropes themselves. So take one or two of them along with you. After all, you won't be around forever.

b) Take a bite-sized chunk: Don't try and boil the ocean and seek remedies for all your concerns. Make your request clear and concise and focused on your immediate challenge. Avoid moralizing or expressing your political opinion about elected officials. Stick to your issue. One of the ways we've found to help people stay focused is to practice writing their 'ask' in 25 words or less. Try to frame your request in positive, non-judgmental language but with a clear

expectation of the action you expect.

c) Keep your momentum: By definition, you are advocating for something that government or service providers don't want to give, or haven't thought about. Otherwise you wouldn't need to advocate! You seldom will get a positive response the first time. That doesn't mean it is hopeless. Far from it. In fact, often when it seems the most hopeless, things start to turn around. Systems, institutions and big organizations take longer to change course or to change their minds than individuals or small groups do. Set yourself a goal of initiating one or two actions every week in support of your advocacy goal; for example, make a phone call; follow-up on a meeting; send an interesting study you have just come across. If you remain thoughtful and helpful, you will eventually expand your team to include champions inside a system who will become your internal advocates.

Effective advocates

An effective advocate and monitor is someone who:

- knows your family member well
- has good problem solving and negotiating skills
- is self-confident and willing to be polite but assertive
- neither seeks out conflict nor shies away from it.

3. Public Policy Advocacy

PLAN is involved in personal advocacy for individuals and families on a daily basis. This gives us a broad and well-informed view of the issues. We bundle the most common issues together and they become our public policy priorities. For example, many years ago the BC Government wanted to claw-back expenditures for discretionary trusts. PLAN rallied families all over British Columbia and alerted the media. We met frequently with the Minister and her senior staff. We held a big event in Robson Square. Eventually the government relented. This preserved discretionary trusts as an important tool in securing the financial well-being of people with disabilities and set a standard for the rest of Canada.

There will always be a gap between our expectations of what public services ought to be for people with disabilities and the reality of what is actually available. The main reason families created PLAN was because government and service providers had not yet realized that our sons and daughters were outliving us in greater and greater numbers. That's why we proposed the Registered Disability Savings Plan. None other than Prime Minister Harper praised PLAN for its public policy advocacy to usher the RDSP into existence.

Public policy advocacy is often called lobbying. Regardless of the terminology, there are a lot of myths about it. For one, governments think and act differently than they used to. Governments today are more resistant to public pressure, able to expertly bat away even well funded major lobby campaigns. For another, government is more cautious. Everything they do is under 24-hour scrutiny. They are less willing to take chances or create precedents others will take advantage of. It is much harder than it used to be for new ideas to gain a foothold. Of course there are exceptions and hard edge advocacy sometimes

works. The trouble with using that approach is that issues are easily polarized and relationships become acrimonious. Sooner or later you have to walk through the door and sit down with the people you have been fighting with. It is very important to be strong and assertive when the need arises, as long as you focus on the issue, not the people. In the long term, PLAN believes relationship-based advocacy serves the best interests of people with disabilities and their families.

The advice we offered about personal advocacy in the previous section holds true for public policy work as well. You shouldn't do it alone, stay focused and maintain momentum. Here are two additional tips.

a) Strategic inquiry: Governments today set a small number of priorities at the beginning of a mandate and stick to them. It is very hard to change their course. Hard but not impossible. A long time friend of PLAN and many other non-profits is Sean Moore who many consider the 'dean' of Canadian lobbyists. He is fond of quoting the Roman statesman Cicero who wrote: 'If you wish to persuade me, you must think my thoughts, feel my feelings, and speak my words.' Sean believes that before you propose a solution to government you should understand their policy priorities and determine how you might link your issue to their priorities. The best way to learn the language, deadlines, formats and priorities of those you are trying to influence is to ask them. Sean calls this strategic enquiry. Strategic enquiry requires you to become a listener rather than a broadcaster. Sean recommends you listen 80 per cent of the time! You can sketch your big idea in general terms, but should resist the impulse to overwhelm them with details before you understand where they are coming from.

Strategic inquiry helps you establish credibility, learn the politics of the

issue and perhaps even discover potential allies and champions inside the system. Ultimately, strategic enquiry helps you shape a realistic 'ask' that relates to one of government's priorities.

b) Do it yourself: As strange as it may seem, government's capacity to receive and implement good ideas has been curtailed. They don't do as much public policy research as they used to. Public servants tend to focus on the day-to-day challenges and emergencies. You may be advancing a solution for an issue they are not even aware of. Nowadays, advocates have to do a lot more of the heavy lifting if they want to advance their issue in a timely manner. During PLAN's RDSP campaign, one example of 'do it yourself public policy' occurred after the RDSP was approved but not implemented. We realized that every provincial and territorial government would have to change their rules to make sure RDSP assets were not taken away by provincial welfare rules. This is called 'claw back.' The federal government was reluctant to get involved and provinces weren't sure what to do. Time was marching on and PLAN was afraid that poorly thought out rules would be established in some provinces that would undermine the value of the RDSP. PLAN decided to organize its own federal-provincial meeting. We arranged for representatives of the BC government to speak because they had developed a clear set of favourable guidelines. To our surprise, most of the provinces attended and most adapted BC's approach. There is a lot more to learn in order to successfully influence public policy. The principal author of this book, Al Etmanski, is considered one of Canada's most effective advocates. See his blog series *Tips for Solution-Based Advocacy* and his upcoming book, *Impact—Six Patterns to Spread and Share Your Social Innovations* for more ideas. And check out our Resources

Section, particularly Sean Moore's Advocacy School and his team of Instructors which includes Al.

Finding an agency

Here are three tips from Aaron Johannes for finding an agency willing to partner with you and your relative.

1. Shop around: There are many different kinds of agencies these days, so check out at least three. Other families are the best source of information.

2. Ask lots of questions: How do staff interviews happen? Can I be part of them? What is the agency working on right now? How does person-centred planning happen? If you can't ask as many questions as you want now, you won't be able to ask harder questions later. See how the agency feels as a 'partner' in a long-term intimate relationship.

3. Bring your network with you: Better to learn sooner than later as to whether they will be welcome. 'We don't have enough chairs' is not the greeting you want. Neither are comments that too many visitors interfere with staff routine. Look for a version of: 'Welcome! How great that you could all be here!'

Aaron Johannes is a PLAN Board member, a Dad, and a co-Director of Spectrum Society, one of the many agencies committed to tailoring services and supporting families.

Examples of new relationships among families, service providers and government

Individualized funding

Most service providers receive their funding under block funding contracts from government. At their best, service providers have a dual allegiance—to their funder and to the individual they serve. Not only can these be in conflict, but usually the funder's priorities carry the most weight. In many communities, one agency provides the full range of services needed by the individual. That is, they own or lease the homes, provide the staff, and offer residential, employment, recreational, and other support services.

While the agencies do their best to tailor the supports for each individual, this is very hard to do if they serve large numbers of people. Often little and big compromises have to be made. Programs are designed to serve groups of people so individual preferences may be ignored. For example, a funder may need to keep a group home full because of their contract with government. In those situations, individuals are expected to live together even though they have nothing in common.

Staff turnover can be high. Staff qualifications and experience is uneven. For example, people who don't know each other or who may not like each other are expected to live together. Or work programs are designed to enable staff to take care of large numbers of people.

This reduces the opportunities for individuals to make genuine contributions and results in boring daily lives. The rules and regulations of an agency can be inflexible. For example, PLAN has been occasionally criticized by agencies for enriching the life of an individual

and exposing the fact that they can't provide the same supports for the other people they serve.

Because people who use these services often have very little say over what happens to them, many parents and individuals are now promoting an approach called individualized or direct funding. They want to design their own services. They want more flexibility and control. And governments are responding. For example, CLBC offers individualized funding on a limited basis to individuals in BC. See the Resources section. In the UK, there is now legislation (thanks to pressure from families) making it mandatory to offer direct funding to all individuals with disabilities in England and Wales, should they request it.

Individualized funding allocates money directly to the individual with a disability (or their family or Representatives) to enable them to purchase the particular supports and services they may require. Individuals, with the help of their supporters, can then choose and negotiate with their preferred agency the amount of involvement they would like to have in the provision of care. For example, this may involve interviewing, hiring and scheduling their staff. Or they can set up their own service and employ their own staff. Individualized funds may also move with the individual as they change providers and their style of living.

Microboards

Imagine a non-profit society that exists only to provide programs and services to your relative. That's what a microboard is. A microboard is a small (hence the name, micro) society with a board of directors. The board of directors is comprised of committed family members and

friends (no less than five and no more than eight). This board of directors receives funding from government on behalf of the person with a disability and negotiates with service providers to provide the support services. The board of directors, along with the person with a disability, directs and customizes these support services. Microboards are a successful variation on individualized funding and personalized services. Microboards serve a variety of other purposes as well because they create opportunities for relationships of support to flourish. Overall, they allow people to achieve greater control over their personal support needs. The Vela Microboard Society pioneered microboards in British Columbia and around the world. It is an excellent resource. For more information see the Resources section.

Choices in Supports for Independent Living (CSIL)

Another example of individualized funding in British Columbia is the Choice in Supports for Independent Living Services (CSIL). CSIL is available through the Ministry of Health Services to “give British Columbians with daily personal care needs more flexibility in managing their home support services.” CSIL is a self-managed model of care. Individuals receive funds directly to purchase their home support services. They assume full responsibility for the management, coordination, and financial accountability of their services. Participants recruit, hire, train, supervise, and schedule their own staff. Anyone needing help with those responsibilities can arrange for a Client Support Group (five people chosen by the participant who register as a non-profit society) to manage the support services on their behalf. For more information, see the Resources Section.

“I do not ridicule or bewail,” said Spinoza, “I try to understand.”

Social Innovation Labs

A new approach to developing public policy is emerging. It is called a ‘social innovation lab.’ These labs, like all labs, are places to experiment under controlled conditions; to try out new ideas; and to bring all the key players from inside and outside together. These labs provide government staff with a safe place to examine new ideas and to consider the best way to implement them. The labs follow the same format used by the tech, business and health sectors to develop new devices, products and treatments. Social innovation labs have been organized around a variety of topics, from ageing, children in care and caregivers. PLAN has created a social innovation lab on the topic of social isolation and belonging and another one related to housing.

Conclusion

This Step builds on all the previous steps. The Worksheets in those steps will help you become more specific about the quality of services, programs and supports you expect for your family member with a disability. The Worksheets provide the standards you, your family member and their network will use as a monitoring guide. Those efforts may need to be supplemented from time to time by advocacy. The goal should always be to return to a healthy partnership and for your family member to enjoy their good life. Step Seven, Secure Your Plan, adds one additional dimension to the plans you are preparing—

creating a family directed organization with the sole function of providing back up to all the plans you have made.

Accessibility 2024 — Government in partnership

Accessibility 2024 is a 10-year action plan that sets the course for BC to become the most progressive province in Canada for people with disabilities.

Accessibility 2024 is organized into 12 building blocks based on themes that emerged during public consultation, including inclusive government, accessible housing, accessible transportation, employment and financial security.

FINANCIAL SECURITY BUILDING BLOCK

GOAL BC has the highest savings rate for persons with disabilities in Canada by 2024.

MEASURING SUCCESS BC remains the province with the highest per capita number of Registered Disability Savings Plans (RDSPs)

ACTIONS

- declare October as RDSP Awareness Month
- market RDSPs and RESPs through government offices
- work with leaders in financial and disability communities to create a centre for financial expertise for persons with disabilities

- create an RDSP Action Group.

LEARN MORE ABOUT
ACCESSIBILITY 2024

GOV.BC.CA/ACC
ACCESSIBILITY

There is nothing more powerful than groups of families working together to secure the well being of their relatives with a disability.

Disability:

It's ability to have fun

Ability to fall in love

Ability to have freedom Ability to make friends Ability to smile

Ability is a world

Ability to be responsible

Ability to be you

Disability

LIZ ETMANSKI

About Liz...

Liz Etmanski is an artist based in the Lower Mainland. Having won an award for her artistic passions in Secondary School, she went on to become the first person with Down Syndrome to graduate from the Emily Carr University of Art and Design.

Liz also writes poetry, which deals predominantly with the themes of love and overcoming personal obstacles. For more on Liz, visit www.lizetmanski.com.

Whose life am I living?

SHANNON and I were invited to a baby shower and I was excited to be going. When I heard Shannon coughing in bed this morning I wasn't sure we were going anywhere. Before I could make that decision, I needed to give Shannon a bath and get her sitting up, as once she was in her wheelchair it would be easier for me to tell how she was feeling.

With my husband out of town, I had two people to get ready, two people to shower, two sets of teeth to brush, and all the while I still was still unsure whether Shannon would be well enough to attend today's anticipated event. We did manage to get ready on time and once she was sitting up in her wheelchair, Shannon's coughing slowed down. She appeared to be her happy self so off we went.

It's difficult sometimes to know whose life I'm living and today was no exception. It could have turned out differently, we could have succeeded at getting ready only to realize that Shannon wasn't well enough to go. Even as a young adult, Shannon still holds power over my life, often the deciding factor on whether we go ahead with our scheduled plans, modify or cancel them. Today had a good ending.

Rob and I are also very aware that Shannon's life needs to be full of things for her to do, friends to meet up with, and the same applies for us. Shannon has a great group of friends, but activities need to be organized and schedules coordinated. At the same time, Rob and I have friends, and friendships take effort. Sometimes these two worlds collide and we're left with the decision as to who gets to visit with their

Some of the people who get dragged along or, as almost happened today, who needs to change their plans and stay home.

Shannon needs care. We are her parents so we either need to provide the care ourselves or effectively advocate on her behalf to have the resources to hire people who can give us our much needed breaks and Shannon her independence.

The first time I really felt like Shannon's life was taking over my own was when she was leaving youth services and moving towards her adult life. Many of the discussions started by the specialists in the room were about my work. As a teacher I worked three days a week with the summers off. I sat listening to the discussions about my availability and realized that our two lives were becoming even more entwined. It sounded as if the services Shannon may qualify for might be connected with my availability. We were looking to secure Individualized funding so Shannon had choices in how to live her life, but the hours she would qualify for couldn't be decided based on my schedule, could they?

I have always taken a leading role in Shannon's social life but as she grows older I need to be able to step back, let her go off to university without her Mom sitting at the back of the lecture hall. I too need some time on my own, time to read without guilt, go swimming or take a class. I wasn't just advocating for supports for Shannon, I was also advocating for the life I deserve.

Advocating for Shannon's services required us to sit back, listen to what was being offered, and decide how it would affect each of us, individually and as a family. It was a discussion that took time to work

through and it was difficult for us to know what exactly we needed until the discussions began, until I could see my free time slipping away.

Shannon is currently enjoying her time attending SFU, hanging out with her friends and volunteering with children at both an elementary school and daycare. At the same time, Rob and I are working hard to ensure we are able to pursue our own careers and interests during the week.

step seven

secure your plan

My experience in working with PLAN has been both exhilarating and challenging. At first, we had a vision but had no idea of how to reach it. Today, I am satisfied with the knowledge that PLAN has grown to the extent that folks with disabilities throughout the world have become less isolated and their families have peace of mind.

JOAN LAWRENCE, PLAN PAST-PRESIDENT

Why not...university?

WITH THE countdown to the end of high school coming far too fast, we have looked around to see what types of opportunities Shannon will have to keep her active in the community. We know she needs something to do everyday, so why not university? University should provide a continuation of all the things Shannon has loved at school.

The scholarship process requires potential candidates to look through the incredibly long and generous list of donors and include, in a single letter, all the information required for each of the sponsors. With Shannon sitting by our side, Rob and I worked through the criteria, below is the result of our work. Wish her luck!

To Whom it May Concern: Shannon is a member of the Foundations for Success Program. She loves learning new things, the peer contact, and the variety of experiences available to her. The ideal situation for Shannon would be for this learning and socializing to continue in post-secondary school.

Through a program called Steps Forward, students with significant disabilities are given the opportunity to continue on to post-secondary education.

Dance and drama classes have been a big part of Shannon's high school life. She comes alive on the stage and the other students in her classes have stretched their imaginations creating new and innovative ways to include Shannon and her wheelchair into their productions.

Shannon looks forward to continuing her studies in both dance and drama at Simon Fraser University. As well as furthering her education

graduated at Simon Fraser University. As well as partnering for education, Steps Forward assists each of the students find summer employment related to their studies and helps with planning into the future.

Shannon has also enjoyed her part in Rock Solid, an anti-bullying program, touring as part of the team to many of the local elementary and middle schools. She has participated in the early morning Yearbook classes, helping with organizing the pages and taking photos throughout the day with a switch activated camera. Many of her photos have been included in the Yearbook over the past four years.

Shannon started sharing her talents with the community during her Grade 12 year, reading to grade three students in Ms. G.'s class with the use of her technology, an iPad filled with children's books and a Partner Four voice output technology that has allowed her to encourage and complement the children's reading. These students have totally embraced Shannon's style of communication and presence in the classroom and readily approach her when they see her outside of class. Shannon has contributed more than 70 volunteer hours during her four years of high school.

Shannon is very involved in community activities outside of school. She proudly took part in the Paralympic Torch Relay in 2010. She has also enjoyed playing baseball on the Challenger League in Coquitlam. She is an active member of Disabled Skiers Association of B.C., which has allowed her to take part in the Vancouver Adaptive Snow Sports Sit Ski Program for the past four years. Shannon has enjoyed time on a Special Olympics bowling team, summers exploring the Lower Mainland with Simon Fraser Society's Youth Group, and was part of Girl Guides for many years.

Out of school, Shannon enjoys keeping in touch with her friends, in person and via technology. Shannon has kept a group of friends together, friends that met when they were in Mrs. O.'s class so many years ago. They enjoy movie nights, shopping and celebrating milestones together. She also spends her time watching musicals and playing with her dog.

Due to Shannon's severe disabilities, her limited income and savings are dictated by the Provincial Government and saving for school will be difficult. With her limited abilities and resources, your financial support in the form of a scholarship or bursary would be extremely helpful for Shannon's future goals, which are to be as independent as possible.

This information letter was written on behalf of Shannon by her parents. We appreciate your consideration of Shannon for this award.

Sincerely yours,

Shannon Bromley

PS Shannon received an email from SFU congratulating her on acceptance. And not only that, Shannon received a scholarship that would cover the tuition for her first term on campus. Well done Shannon!

step seven

Secure your plan

ACHIEVING a good life and a secure future for your relative requires careful attention to a number of key elements:

- a vision with as much detail as you, your relative, and close family and friends can muster
- a network of caring, committed friends and family
- a house that becomes a home
- trusted friends and family to assist with decision-making and advocacy
- a properly drawn and executed Will
- a financial strategy which includes an RDSP and a discretionary trust

This is a long list to add to your already busy life.

We would be upset if after reading ***Safe and Secure***, you concluded it is overwhelming. So let us be clear. First, it is too much for one person or one family to do on their own. Second, you don't have to do everything at once. Most of us have put our plans together over a number of years.

Thirdly, trust other families in similar circumstances. That's why PLAN was created.

Our founding families believed in families helping families, particularly for that most precious task—taking care of our family member with a

disability when we are no longer able to. They wanted to share family innovation and know-how. This Step will discuss the key ingredients that make PLAN a social innovation. This includes mobilizing family economic power. We will also describe an approach to keeping the many balls you are juggling up in the air, now and in the future.

Even small steps away from segregation lead to a better life, when taken with conviction and respect.

MARILYN DOLMAGE

Flowers and compost

When you think of it, a parent's job description is much like a gardener's: To nurture, to hover, to be alert to changing conditions, to provide shelter from the storm, to fertilize where appropriate, to savour the beauty of the moment, to appreciate the sweat of preparation and to enjoy all stages of growth. You learn a lot about life as a gardener. You learn, for instance, about the interrelationship between flowers and compost.

A beautiful rose that we have just cut and placed in our vase is very pure. It smells fresh, and fragrant. Rotting compost is the opposite. But that is only if we look on the surface. If we look more closely, we will see that in five or six days, the rose will become part of the compost. The truth is, we do not need to wait that long. We can see it now. Take a deep look at the rose. Can you see the compost in the rose? Take another look at the compost. Can you see the rose in the compost?

There is only one question that matters. In whose embrace do you wish to be when you die?

ANNE MICHAELS — THE WINTER VAULT

If you are a gardener, you recognize that you cannot have one without the other. The rose and the compost are equal. The compost is just as precious as the rose.

If you are a parent, you understand that much of the beauty you create arises out of life's darker moments or in response to threats on the horizon.

The family arm of the disability movement arose at the end of the Second World War when families challenged prevailing advice and refused to send their children with disabilities away to institutions. Despite prevailing attitudes and lack of funding they persevered and thrived. Those early seeds of change have blossomed into the most wondrous of gardens—a community-based system of support for people with disabilities.

The disability movement was the first global consumer movement. It led to the creation of the UN Charter of Human Rights for Persons with Disabilities. It has ushered in changes in legislation and funding as well as shifts in attitudes. The job isn't complete but our movement has come a long way.

Looking into the future

The 21st century is yielding a new set of challenges that a revitalized family movement will have to deal with to ensure that supports for

people with disabilities and their families remain a priority.

The following scenarios are speculative. They may not happen.

Something unpredictable may emerge instead. They are worth keeping an eye on because they remind us to be vigilant to changing circumstances.

CHANGING DEMOGRAPHICS Within 15 years, population aging will be a key challenge facing our national and provincial economies. The potential impact is threefold. One, there will be fewer taxpayers as boomers retire. This means smaller operating budgets at every level of government. For example, by 2025 there will be more people over 65 than under 15 in British Columbia.

Two, health care costs are rising. One source suggests if current trends continue, health care costs in BC will account for more than 70% of the BC budget by 2017.

Three, with a smaller fiscal pie and a greater share of the smaller pie going to health costs, there may be fewer resources to respond to social, educational, and environmental issues including financial support for people with disabilities.

WORTHINESS DEBATE Relatives, friends, and supporters of vulnerable people are constantly reminded of how fragile society's support for people with disabilities can be. Debates about right to die legislation, and a reverence for genetic engineering make some of us concerned that a new eugenics movements is emerging. We must do everything we can to uphold the worth and value of all life, particularly people with disabilities.

THE 'X' FACTOR There has been an escalation in the number of unforeseen emergencies and disasters. The Mount Polley dam collapse is a recent example. The Okanagan Mountain Park fires in

2003 is another. Even events that happen on far away shores impact our lives. The global financial collapse in 2008 is still affecting the Canadian economy and government budgets. The earthquake off the coast of Japan lead to a tsunami, which lead to the meltdown of the Fukushima nuclear plant, which lead to nuclear radiation seeping into the ocean. Now there is fear that radiation is affecting fish caught off BC's coast. The only thing predictable about these events is that they are occurring with increasing frequency. And they are siphoning government resources away from other priorities.

While we can't predict the future, we can prepare for it. Our capacity to adapt to the changes and challenges that lie ahead is directly related to our connectedness to one another. Whatever the future holds in store the solution is a united family movement at its innovative best.

All of us are better when we're loved.

ALISTAIR MACLEOD

Families as social innovators

Fortunately, families are used to turning adversity around.

We are confident the natural ingenuity and creativity of families will lead to new solutions for these changing times. They always have.

Families are the original social innovators. Not a day goes by that families or individuals with disabilities aren't figuring out a better way to do something. They are some of the best problem solvers around. In my new book on social innovation, *Impact – Six Patterns to Spread and Share Your Social Innovation*, I refer to families as 'passionate

amateurs.'

Passionate amateurs innovate for two reasons: Love and necessity. Love for their family member. Necessity because if they don't do something about the challenge that their family member faces, no one else will.

Families don't quit. The impossible is unacceptable to them. Their commitment is freely given, beyond the boundaries of job descriptions, office hours, strategic plans, funding, fashion and political priorities. Their creativity accumulates over time. Their breakthroughs are the result of repeated failures and continuous attempts to make things better. Their resources are limited, so they know how to stretch a dollar and make creative use of whatever materials are at hand.

No amount of thought can ever reveal what comes unexpectedly.

ARTHUR ERICKSON

We believe the defining characteristic of families is their innovation not their advocacy. Families became advocates because they wanted service providers and government to adopt their social innovations. Advocacy was simply a means to that end. We know this from direct experience. PLAN has become a vehicle for collaboration among families to spread their innovations. These innovations have reached the four corners of the world and have become official government policy. As a result, hundreds of thousands of people have benefitted. While PLAN itself is a social innovation with over 40 adaptations around the world, PLAN families have been associated with a number

of other innovative breakthroughs. These include:

1. creating a social enterprise model to finance personal networks
2. the world's first Registered Disability Savings Plan (see Step 5, Section 2)
3. introducing a citizen-based theory of disability (see Step 2)
4. The Representation Agreement—a grass roots alternative to legal guardianship (see Step 4)
5. Tyze Personal Networks—a business started by PLAN to spread the value of caring networks via the web (see the Resources Section).

What makes PLAN a social innovation?

There are three distinguishing features of PLAN's social innovation.

One, we ask a different question: What is a good life? This is a unifying question for parents. It opens their hearts, minds and imagination regardless of circumstances, age, beliefs and life experience. Discussions about a good life get at the core of every family's hopes, dreams, worries and fears for their relative. It invites them to think beyond reliance on professional services to important considerations like friends and family, financial security and a meaningful life.

Two, PLAN is a social enterprise. We do not rely on government grants for our operations. Instead we earn our income by selling our 'intellectual and social capital.' We charge fees for some of our

products and services to those who can afford it. We seek partnerships with financial institutions, law firms, trust companies and estate planning specialists. We also have a successful publishing arm and started a private business, Tyze.

Earning our own revenue gives us flexible funding and independence. We are able to champion issues that benefit the financial and social well-being of people with disabilities and their families without fear of ‘biting the hand that feeds us.’

Three, PLAN operates from a citizenship paradigm. We know that people with disabilities have an important contribution to make to society and that they are an underestimated and underutilized resource. We want to replace notions of pity and charity with the expectation that people with disabilities, like all citizens, have the responsibility to contribute to the world around them.

Planned Lifetime Advocacy Network (PLAN)

PLAN's core values

Our founding parents lived through decades of changes affecting their relatives. Many of them created the original parent-led community living and disability organizations. They had experienced the ups and downs of government funding. They knew the quality of programs and services could vary. They knew what to avoid and what to emphasize. They wanted to create a positive organization based on a spirit of abundance. They built our organization around four core values:

1. relationships keep people safe and are the foundation of a good

life

2. financial self-sufficiency—**i**ndependence from government funding
3. family direction—our constitution calls for a majority of **board** to be family members
4. **contribution**—meaning comes through **contribution**, and so does recognition as full citizens.

Because **Bill** is so open about his needs and feelings I found I could talk about my own, something I feel society has discouraged men to do.

DOUG, A PERSONAL NETWORK MEMBER

PLAN's four basic functions

1. FUTURE PLANNING ADVISORY SERVICE

PLAN offers up-to-date information on all the elements of future planning (and deal with the present for that matter). This includes information on:

- the RDSP
- Wills and estates
- discretionary trusts
- government benefits
- home ownership

- disability tax benefits
- Representation Agreements.

2. CREATING AND MAINTAINING A PERSONAL NETWORK

PLAN believes the best time to consolidate friends and family into a Personal Network of support is NOW. PLAN's future involvement in the life of a person with a disability is conditional upon the existence of a Personal Network and PLAN's active involvement with the individual, the Personal Network, and the family. Without this personal and intimate contact with people and their families, PLAN would not be in a position to understand—let alone advocate for—the best interests of the person with a disability.

3. FAMILY SUPPORT AND ADVOCACY

A common response from families associated with PLAN is the degree of support and comfort they derive from working together. Families with Personal Networks meet regularly to share concerns and to seek advice from each other. Families accompany each other to critical meetings as advocates.

On a broader scale, PLAN works closely with provincial and federal governments to advocate for legal and financial improvements that will benefit people with disabilities.

4. LIFETIME COMMITMENT

This is the ultimate and most fundamental function of PLAN. Families can take advantage of all the services offered by PLAN. However, if families want PLAN to watch over all the plans they have put in place for their relative after they die, then they should become lifetime members.

PLAN: A SOCIAL ENTERPRISE

Since our founding parents did not want us to rely on government funding, we had to figure out a way to earn our own revenue. We didn't know it at the time but we were becoming a social enterprise. A social enterprise is a type of not-for-profit organization that fulfills its social mission by earning income. It doesn't just rely on grants and charitable donations.

A social enterprise fulfills its mission by earning its income and mobilizing untapped resources.

In order to become successful as a social enterprise we had to learn how money works. We invited business people and investors to advise us. We discovered we were sitting on an untapped disability market. For example, the combined disposable income of people with disabilities in Canada is approximately \$47 billion. Further, the total disposable income of the disability sector is in excess of \$300 billion. This includes the total purchasing power and financial assets (mortgages, savings, investments, business accounts) of their families, friends, service providers and professional supporters. PLAN's simple math for understanding its economic power is as follows: One in 10 Canadians has a disability. Each has at least two others, (a relative, friend or professional) who care about their well-being. Therefore, at a minimum, at least three in 10 Canadians are part of an untapped disability market. That gives us an estimate of the number of Wills to be written or revised, discretionary trusts to be established, or life insurance policies to be taken out. Quantifying the special need market is very useful when negotiating partnerships with law firms, insurance companies and financial institutions.

PLAN's social enterprise revenue sources include:

- partnership with credit unions, banks, life insurance companies, law firms, and financial and estate planning advisors who are interested in catering to this emerging disability market
- charging a fee for our products and services
- establishing businesses such as book publishing and TYZE.

Our emergence as a social enterprise has not been without struggle. It was a difficult decision to charge for our services. But we knew without financial independence our effectiveness as advocates was limited. We now have a Network Endowment Fund to assist those who cannot afford to pay our fees.

If you are interested in learning more about social enterprise and social finance, please visit [www. planinstitute.ca](http://www.planinstitute.ca) and click on Innovate with Us.

There are many benefits to being a social enterprise. It has enabled us to stay faithful to our core values and to further our social objectives. Our diverse funding base has made us more stable financially. The money we earn doesn't come with strings attached. This flexibility enables us to respond to emerging needs such as, for example, financing the campaign to create the RDSP.

Perhaps more importantly, being a social enterprise allows us to earn our own way. We are confident this independent economic base prepares us for whatever the future holds and is a model for other organizations to follow.

We were struck recently by a comment from one of our founding members, Joan Lawrence. She pioneered the development of services and programs for many people with disabilities and has been a long-time advocate for families. “I’m having so much fun,” she said. “It reminds me of the early days of the parent movement. Everything is so positive. Rather than tearing down, we are constructing something new. It so much easier to get things done. So much more satisfying.”

PLAN Institute for Caring Citizenship

To respond to the growing interest in PLAN from across Canada and around the world, we created the PLAN Institute.

The PLAN Institute:

- provides on-line courses, workshops, training, and consultation on caring citizenship; social network facilitation; social enterprise; family leadership; organizational development; and social innovation
- mentors groups of families who are adapting the PLAN model
- distributes books, CD ROM’s, and DVD’s
- researches and publishes on citizenship, social networks, natural caregiving and belonging.

The Institute currently supports more than **40** groups of families around the world. The only other one in BC is PLAN Okanagan.

The PLAN Institute offers an annual Leadership Training course for families interested in learning how to adapt our approach to their local area. For those interested in learning more about social change, the Institute offers a four day retreat called *Thinking Like a Movement*. For

more information about the PLAN Institute visit: www.planinstitute.ca.

PLAN Okanagan

The purpose of PLAN Okanagan is to create safe and secure futures, in community, for people with disabilities and their families. Its dream is that no one be alone.

The core values of PLAN Okanagan are similar to PLAN's: relationships, contribution, self-sufficiency and family direction.

PLAN Okanagan believes that the greatest collective of knowledge in the community is held within families. It is the families who have advocated for their family member with a disability. It is the power of families coming together which started PLAN Okanagan and other organizations dedicated to providing a better life for their loved one with a disability.

PLAN Okanagan hosts monthly Families to Families Group gatherings that take place the last Thursday of each month (excluding December and August). These are informal gatherings, in a relaxed setting.

The Families to Families Group gatherings are an opportunity for families to discuss their burning questions and to benefit from the experience and knowledge of other families who have walked and are walking this path. Topics include: school years, transition to/from school or work, moving out, financial planning, Vela Microboards, and many more.

For more information, contact PLAN Okanagan through their website at: www.planok.ca.

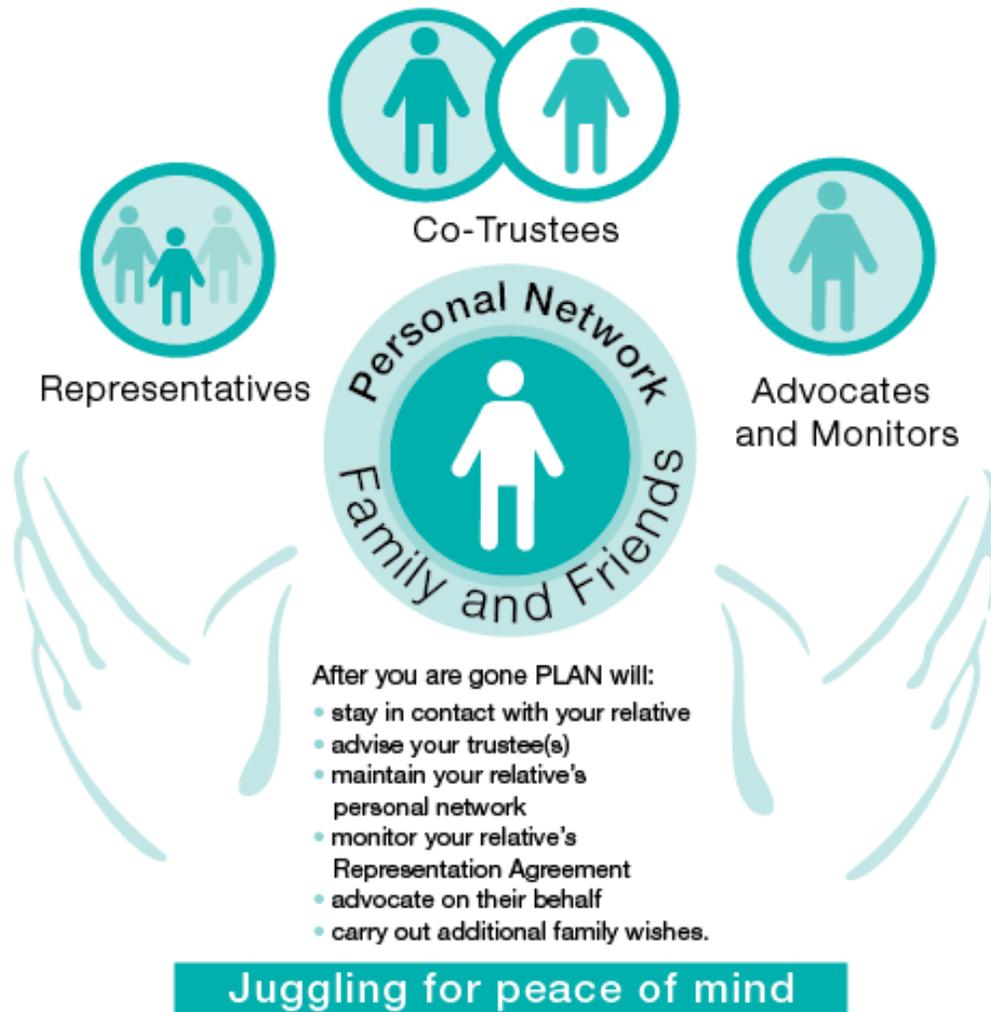
Lots of helping hands—a juggler's delight

Let's face it, multi-tasking is a survival skill for families. We must juggle various roles - that of parent, spouse or partner, employer or employee, friend, shopper or consumer, student, citizen and creator. And if we have a family member with a disability, we have to keep a number of additional considerations in mind. Since you can't grow additional hands, the trick is to rely on the helping hands of others. Have a look at the "Juggling for peace of mind" illustration that follows. It represents the number of balls that ultimately have to be juggled, not just by you but also by other family members, your friends and supporters and, if you wish, by PLAN.

The first and most fundamental ball is the Personal Network of family and friends you develop and maintain for your family member. Their Personal Network is also the source of their trustees, Representatives, advocates and monitors.

The second set of balls is the co-trustees. As we advised in Step Five, it is better to have two trustees. One trustee can take responsibility for managing and overseeing the financial aspects of the trust. It is very important that at least one of the trustees is in a close relationship with your family member, preferably as a Personal Network member. To ensure financial decisions are made in the best interest of your family member, you can also include directions in your Will for your trustees to consult with them and their Personal Network. Lifetime members of PLAN may also direct their trustee(s) to seek advice from PLAN

regarding trust expenditures.



The third ball contains the Representatives chosen by your family member to support them make decisions. Members of the Personal Network make good Representatives. There is also provision in Representation Agreements for the appointment of a monitor to prevent exploitation. This is a role that a staff member of PLAN can be asked to perform.

The fourth ball relates to the advocates and monitors who will keep

their eyes on the programs and services your family member receives. It goes without saying that people who are in a close relationship with your family members make the best advocates.

Adopting the right attitude can convert a negative stress into a positive one .

HANS SELYE

At this point you have a majestic set of checks and balances to oversee the well-being of your family member. You can go one step further and rely on an organization like PLAN to back up these arrangements. Lifetime members of PLAN rely on us to:

- stay in regular contact with their family member
- maintain the health of their Personal Network
- advise trustees on expenditures
- monitor Representation Agreements
- advocate on their family member's behalf.

In addition, families have special wishes and concerns that they ask PLAN to keep an eye on. For example, one parent wanted PLAN to make sure a particular family tradition continued to be honoured. Another wanted PLAN to make sure a special item of furniture that had been in their family for a long time was not lost or discarded.

You are not alone. You can rely on other families especially if they have created an independently financed organization devoted to the future well-being of your family member. When you do, a juggler's terror

becomes a juggler's delight. And a juggler's delight becomes peace of mind.

Achieving the complete Personal Future Plan

This book presents seven steps for preparing for the future—and indeed changing the present—for your relative:

STEP ONE – CLARIFY YOUR VISION Rallying people around your hopes for the future.

STEP TWO – NURTURE FRIENDSHIP Creating and maintaining a strong network of caring, committed friends and supporters.

STEP THREE – CREATE A HOME Making a house a home.

STEP FOUR – MAKE SOUND DECISIONS Protecting vulnerabilities and honouring choices.

STEP FIVE – ACHIEVE FINANCIAL SECURITY Wills, trusts, and the RDSP: Using all the legal and financial tools at your disposal.

STEP SIX – ADVOCATE WITH EMPATHY Ensuring services support rather than supplant a good life.

STEP SEVEN – SECURE YOUR PLAN Appointing and mentoring your replacements whether they are individuals or organizations like PLAN.

As you have seen, each step builds on the last one. Each one on its own advances the opportunity for greater safety and a better life. The steps are also interrelated and, taken together, they offer a complete system of checks and balances. They may not be foolproof but they are thorough. And that's what is needed to replace what families do now and to provide continuity from one generation to the next.

No one, not even those who have been involved in the future planning business for decades, is ever satisfied with their final product. There

will always be tinkering and adjusting. That's natural. The difference is you will be amending a plan that is already in place. The hard work will already have been done and the basics will have been covered.

We can assure you the results will lead to peace of mind.

Conclusion

Safe and Secure is a book for gardeners. We have supplied you with the seeds of inspiration and information. But it is up to you to supply the rest—the planting, the weeding, the watering, and the nurturing. We are confident your shovel and hoe will dig a path into new territory. You will make the rows boldly and follow them fearfully. You will go where the rows lead. At the end you will have created your garden. In your hands your garden will have flourished. It will have become a place of security and repose.

We have supplied the seeds. You supply the love.

To download a copy of all Worksheets, visit www.plan.ca and click on Safe and Secure Worksheets.

Worksheet 11

Your summary checklist

I have completed all the following documents:

- A family portrait of my relative.
- My letter to the future, clarifying my wishes.
- A list of my relative's documents: birth certificate, social insurance card, health care card, etc.
- An up-to-date Will that reflects my current wishes.
- A description of the purpose of the trust.
- An up-to-date list of my major assets and where they are kept (insurance policies, bank accounts, stocks, mutual funds, and so on).
- and
- I have stored all these documents in a safe place.
- My executor knows where these documents are kept.

RESOURCES

Reading List

A Good Life

Al Etmanski

Vancouver: Orwell Cove and Planned Lifetime Advocacy Network,
2004

Al Etmanski's inspirational guide rethinks disability and the value of people with disability in a caring society.

Abundant Community—Awakening the Power of Families and Neighbourhoods

John McKnight and Peter Block

Berrett-Koehler Publishers; 1st edition, 2010

Each neighborhood has people with the gifts and talents needed to provide for our prosperity and peace of mind—this book offers practical ways to discover them.

www.abundantcommunity.com/home/book.html

Becoming Human

Jean Vanier

House of Anansi Press Limited, 1998

We could have chosen any number of Jean Vanier's books because they are all worth reading. This book is illustrative of the power of Jean's insight which is inspired by people with disabilities.

The Body Silent

Robert F. Murphy

New York: W. W. Norton, 1990

Without a doubt this is one of the best books written about and by people with disabilities. An anthropologist writes about his own gradual experience of becoming a person with a disability and what keeps him safe and maintains his quality of life.

Breaking Bread and Nourishing Connections: People With and Without Disabilities Together at Mealtime

Karin Melberg Schwier and Erin Schwier Stewart

Paul H. Brookes Publishing Co. Baltimore, 2005

A feast of insight into the art of dining and hospitality.

Building Communities from the Inside Out: a Path Towards Finding and Mobilizing a Community's Assets

John McKnight and John Kretzmann

We continue to model our work at PLAN on John McKnight's analysis and insights. You can download a pdf copy by searching Google for this title.

The Careless Society

John McKnight

New York: Basic Books, 1995

This represents the best of John's writing. Inspired by the CBC radio series, "Community and Its Counterparts." John and his writings are a major inspiration to Al Etmanski.

The Church of **80%** Sincerity

David Roche

A Perigee Book, New York, 2008

This is a funny, honest, and irresistible glimpse into everyone's inner beauty and worth.

Community: The Structure of **Belonging**

Peter Block

Berret-Koehler Publishers, Inc.; San Francisco, 2008

Peter eloquently and elegantly explains how belonging is the path by which communities can emerge out of fragmentation.

Co-Production and Personalisation in Social Care: Changing Relationships in the Provision of Social Care

By Contributors Eddie Bartnik et al.

Research Highlights 49, 2007

This book explores the theory and practice of the developing innovative practice of co-production – a model of service in which users of a service will play an active and participatory

role in the service provided for them, adopting a working partnership.

Dear *B*utterfly

Kirsteen Main

50 Poems. Kirsteen takes in the world around her through her visual and auditory senses but because her communication must be facilitated, she must rely on the help of others. When asked how she can write at someone else's convenience, she says the words are just waiting to be unlocked from the poetry file. This is the first complete collection of Kirsteen's work to date. To purchase a copy visit PLAN's online store or email: c_newlife@shaw.ca.

Deepening Community—Finding *J*oy in Chaotic Times

Paul **B**orn

San Francisco: Berrett-Koehler Publishers, Inc., 2014

Using stories from his experience growing up among people displaced by war, insights from his career as a community activist, writer, and speaker, and the results of interviews with 500 people, Born shows how we can deepen community.

In the Company of Others

Claude Whitmyer, editor

Revised by Cathy Ludlum and the Communitas Team

New York: Jeremy Tarcher, 1993

This is a compilation of writings on the art of community development and building community connections.

The Company of Others: Stories of *B*elonging

Sandra Shields and David Campion

Vancouver, The PLAN Institute, 2005

This creative collaboration by author Sandra Shields and photographer David Campion uniquely captures the spirit and significance of personal networks. Compelling stories and photographs lead the reader on an intimate journey into the lives of five individuals—with no connection to one other and little in common, except in one respect: each person is at the centre of an active social “circle”—a network of caring friends and family whose lives are enriched by the relationship they share. An extraordinary and moving book about the transformative power of family and community.

Crossing The River: Creating a Conceptual Revolution in Community and Disability

David Schwartz

Cambridge, Mass.: **Brookline Books, 1992**

The best description from an American point of view on the new way of thinking—or the paradigm shift—in social services for people with disabilities.

The Diving **B**ell and the **B**utterfly

Jean-Dominique Bauby

London, Fourth Estate, **1997**

Recently made into a compelling and thoughtful movie.

Down Stairs That Are Never Your Own: Supporting People with Developmental Disabilities in Their Own Homes

John O'Brien and **Connie Lyle O'Brien**

Visit <http://thechp.syr.edu/rsa.htm>

This is a good overview of alternatives to group homes and the conceptual shift that will be required in order to achieve widespread home ownership or rental accommodation for people with disabilities.

Facilitating an Everyday Life

John Lord, Barbara Leavitt and **Charlotte Dingwall**

Inclusion Press, **2012**

This book is for people who want to make a difference, who want to feel free to be dedicated to citizens who experience vulnerability, and who want to use an effective process that is a change maker.

Facing Death, Embracing Life

David Kuhl, M.D.

Doubleday Canada, **2006**

A sensitive and all encompassing guide for those living with a terminal illness and for those who care about them.

Four Walls of My Freedom

Donna Thomson

London UK: **McArthur & Co.**

Donna Thompson reflects on issues of inclusion through the lens of her personal family experience.

From *Behind The Piano*—The *Building of Judith Snow's Unique Circle of Friends*

Jack Pearpoint

Toronto: Inclusion Press, 1990

This is the book to read if you want to learn more about Judith Snow, an amazing human being.

Getting to *Maybe*: How the World is Changed

Frances Westley, Brenda Zimmerman, and Michael Patton

Toronto, Random House, 2006

PLAN's story is one of many used to illustrate a new approach to changing the world.

The Healing *Web*—Social Networks and Human Survival

Marc Pilisak and Susan Hillier Parks

University Press of New England, 1986

This book will give you all the theory behind the importance of social networks. In our opinion, it is a classic and a must read for anyone who wants to dig a bit deeper.

How to Change the World—Social Entrepreneurs and Power of New Ideas

David Bornstein

New York, Oxford University Press, 2004

This book tells the stories of people who have both changed lives and found ways to change the world.

How to Create a Trust

Visit www.vcpgv.org

This best seller is published by the Voice of the Cerebral Palsied. Already in its third edition, this popular resource guide contains updated information and a brand new section on Disability Tax Credits.

The Goode Life: Memoirs of Disability Rights Activist *Barb Goode*

Barb Goode with Jim Reynolds

Spectrum Press, 2011

The inspiring story of one of Canada's most remarkable and humble citizens who, in her mission of supporting equality and giving voice to those who had no voice, traveled much of the globe and met some of the greatest leaders of our age and some of the most vulnerable of citizens. Barb Goode is a self-advocate leader who has done amazing things in her life and this is her story.

Liberation Welfare

Edited **by** Paul Gregg and Graeme Cooke

Contributors: Eddie **B**artnik et al.

http://www.demos.co.uk/files/Liberation_welfare_-_web_final.pdf?1271779162

Mind/**B**ody Health: The Effects of Attitudes, Emotions and Relationships (3rd Edition)

Keith **J.** Karren Ph.D., Lee Smith, Kathryn **J.** Frandsen

Benjamin Cummings, 2013

This is a very good book for introducing body/mind health issues.

Moving Toward Citizenship: A Study of Individualized Funding in Ontario

John Lord

Toronto, Individualized Funding Coalition of Ontario, 2006

The Myth of **A**bility The End of Ignorance

John Mighton

Vintage Canada, Toronto

John's writings honour and apply to every child. He pays attention to how kids pay attention, captures their imagination, and enlarges their self-confidence.

Now available in e-book format.

On **E**quilibrium

John Ralston Saul

Toronto, Penguin Books, 2001

John is PLAN's Patron, collaborator, and intellectual inspiration. The sections on Imagination and Intuition are thoughtful; they validate what formal systems ignore or discard.

One Candle Power—Seven Principles that Enhance the Lives

of People with Disabilities and their Communities

Pat **B**eeman, George Ducharme, and **B**eth Mount's original work on Circles **b**rought together, **r**evised, and updated.

Toronto: Inclusion Press, www.inclusion.com.

A classic!

PATH: Planning Possible Positive Futures

Marsha Forest, **J**ack Pearpoint, and **J**ohn O'**B**rien

Toronto: Inclusion Press

We like this one a lot. It's a practical planning process that provides a good way of stepping out of the day-to-day and allowing your heart and mind to soar. It also provides an excellent structure for strategic and future planning. Visit www.inclusion.com.

Pathways to Inclusion: **B**uilding a New Story with People and Community

John Lord and Peggie Hutchison

Concord Ontario, Captus Press, **2007**

This is an examination of various perspectives on disability. John and Peggie provide insightful discussion on the current need for social innovation to move vulnerable citizens from areas of exclusion to social inclusion.

Peace **B**egins With Me

Ted Kuntz

Coquitlam, **2005**

Ted is a Past President of PLAN. This best selling book inspires people from all around the world. Visit www.peacebeginswithme.ca.

Roots of Empathy—Changing the World Child **b**y Child

Mary Gordon

Thomas Allen Publishers, Toronto, **2005**

Mary is a spirited colleague whose work brings **b**abies into classrooms to foster empathy, reduce aggression, and increase tolerance.

Slow Dance: A Story of Stroke, Love and Disability

Bonnie Sherr Klein

Toronto, Knopf Canada 1998

What's Really Worth Doing and How To Do It—A **B**ook for
People Who Love Someone **L**abelled **D**isabled

Judith Snow

Toronto: Inclusion Press, 1994

Words of wisdom and inspiration from one of the wisest.

The World We Want—**V**irtue, **V**ice and The Good Citizen

Mark Kingwell

Toronto, Viking, 2000

Mark's writing on justice provides a thoughtful framework for a new theory of citizenship that includes people with disabilities and others whose contributions have been ignored.

Films and Videos

Best Boy

Ira Wohl

This film won an academy award several years back. It's a true story in which the director filmed the process of his cousin, a middle-aged man with a disability, leaving home. There is a companion follow-up documentary as well. You can find it at specialty video stores or libraries.

Peace of Mind (CD)

The Peace of Mind CD-ROM is a practical and loving guide to help you plan for the future of your relative with a disability. It combines personal stories, testimonials, tips, and step-by-step worksheets to get you started on your path to peace of mind.

Shameless: the Art of Disability

A film by **Bonnie Sherr Klein**

Art, activism, and disability are the starting point for what unfolds as a funny and intimate portrait of five surprising individuals.

Temple Grandin

Biopic of an autistic woman who has become one of the top scientists in the humane livestock handling industry.

The Ties That **Bind**

Force Four Entertainment Inc.

National Film **Board of Canada, 2006**

A documentary film about Chris Jordan, his family, and PLAN. There is a companion resource guide in both English and French. This DVD is for all families worried about the future well-being of their relatives with disabilities.

And Then Came **John**—The Story of **John McGough**

A **video by** Telesis Productions, Mendocino, California

This remains one of our favorites. It's a true story of an artist, who happens to have Down syndrome, and the love that emanates from his connections in the community.

PLAN collaborators

www.abcdinstitute.org This is the home of John McKnight's Asset Based Community Development Institute.

www.abilities.ca This is the website for the talented Ray Cohen's many important initiatives including Access Guide Canada and the award winning Abilities magazine.

<http://www.advocacyschool.org/> Sean Moore's Advocacy School.

www.ashoka.ca This is a global fellowship of social entrepreneurs. Al Etmanski was one of the first two Canadians selected to be part of this prestigious network.

<http://www.hubcapbc.ca> BC Partners for Social Impact – A provincial network of social innovators and social entrepreneurs from business, government and community. Co-Chaired by Al Etmanski.

www.cdss.ca The positive communications and strong ethical stances make the Canadian Down Syndrome Society a leading advocacy organization.

<http://chance.unh.edu/> The Center for Housing and New Community Economics. Chance is dedicated to increasing access to integrated, affordable and accessible housing.

www.communityworks.info This is the website of David and Faye Wetherow, social inventors, trainers, and consultants.

www.fieldnotes.ca This is the website of Sandra Shields and David Campion. This talented couple have dedicated their writing, photographic and artistic talent to economic and social justice issues.

www.ilcanada.ca This is the umbrella organization for the Independent Living movement in Canada and a network of Independent Living Centres.

<http://ildspinitiative.com/docs/ToolkitforPeoplewithDisabilites.pdf> Find, Choose and Keep Great Disability Service Providers.

www.in-control.org.uk This website is testimony to the power of families and individuals with disabilities. In Control led the campaign for direct funding or self-directed support for the elderly and people with disabilities.

www.inclusion.com This is the website of Inclusion Press International and the great work of Jack Pearpoint, Lynda Kahn, Cathy Hollands, and the late, esteemed Marsha Forest.

www.judithnow.org Everything in this website is based on Judith Snow's insight that the personal and social differences that challenge us are storehouses of contributions and opportunities.

www.laidlawfdn.org This website is dedicated to encouraging young people to become

healthy, creative and fully engaged citizens. Nathan Gilbert and his team are major supporters of our **B**elonging Initiative.

www.larche.ca L'Arche is PLAN's closest collaborator, embodying and exemplifying the work of their founder **J**ean **V**anier. It is worth **s**ubscribing to **A** Human Future, a **q**uarterly electronic **p**ublication featuring thought provoking interviews with outstanding Canadians.

www.mcconnellfoundation.ca This **w**eb site is the home of the progressive **J**W **M**cConnell Family Foundation and long-time supporter of PLAN and the PLAN Institute.

www.normemma.com This **w**eb site links to the talented, inspirational and humorous team of Norman Kunc and Emma **V**an der Klift who provide keynote addresses, workshops, and training in the areas of inclusive education and disability rights.

[www.q](http://www.qualitymall.org)ualitymall.org This is a **w**eb site where you can find free information **a**bout person-centered supports for people with developmental disabilities. Each of the "Mall Stores" has departments you can look through to learn **a**bout positive practices that help people with developmental disabilities **l**ive, work and participate in our communities and improve the **q**uality of their supports.

<http://www.sigeneration.ca/home/labs/> For an **o**verview on social innovation 'labs' and links to leading **e**xamples see Social innovation Generation.

www.tamarackcommunity.ca This **w**eb site is full of resources and practical advice for community engagement, community organizing, and convening.

Relevant organizations for PLAN families

Ability Tax and Trust

www.abilitytax.ca

The group assists persons with disabilities and their family members in navigating through the Income Tax Act to maximize all disability tax credits and benefits.

Autism Society of **British Columbia**

www.autismbc.ca

The ASBC is a parent-based society providing support to individuals with autism and their families.

BC Association for Child Development and Intervention

www.bcacdi.org

The BC Association for Child Development and Intervention is a provincial association of agencies that provide child development and therapy services to children with special needs and their families in British Columbia.

BC Brain Injury Association

www.bcbraininjuryassociation.com

The British Columbia Brain Injury Association is a Provincial organization serving the interests of all British Columbians affected by Acquired Brain Injury.

BC Centre for **Ability**

www.centreforability.bc.ca

Its mission is to provide community based services that enhance the quality of life of children, youth, and adults with disabilities and their families, in ways that facilitate and build competencies and foster inclusion in all aspects of life.

BC Coalition for People with Disabilities

www.bccpd.bc.ca

The premier advocacy organization representing people throughout the disability community.

BC Paraplegic Association

www.bcpara.org

This association assists people with spinal cord injuries and other physical disabilities in achieving independence, self-reliance and full community participation.

British Columbia Mobility Opportunities Society

www.disabilityfoundation.org

This society provides opportunities for people with physical disabilities to explore the outdoors, centred around the TrailRider, a specially designed, single-wheel remote access wheelchair that enables the user, propelled by able-bodied helpers, to take part in wilderness and recreational activities.

Canadian Mental Health Association— BC Division

www.cmha.bc.ca

The Canadian Mental Health Association (CMHA), BC Division exists to promote the mental health of British Columbians and support the resilience and recovery of people experiencing mental illness.

Canadian Red Cross—Aids to Independent Living Program

www.redcross.ca—click on AIDS TO INDEPENDENT LIVING PROGRAM

This program provides free loans of medical equipment to adults coping with long-term illness and disabilities, who do not have the financial resources to purchase or rent the necessary equipment.

Cerebral Palsy Association of BC

www.bccerebralpalsy.com

This organization works to raise awareness of Cerebral Palsy in the community; to assist those living with cerebral palsy in reaching their maximum potential; to see those living with cerebral palsy realize their place as equals within a diverse society.

Choice in Supports for Independent Living (CSIL)

www.health.gov.bc.ca/hcc/csil.html

Provides direct funding for purchase of in-home personal assistance. Contact Community Care Services or the Ministry of Health office in your community.

Coast Mental Health

www.coastmentalhealth.com

Coast operates the Coast Financial Trust program for mental health consumers who have Person with Disability status with the Ministry of Social Development and Social Innovation.

Community Legal Assistance Society

www.clasbc.net

Provides free legal advice and representation on issues affecting people with disabilities.

Community Living *BC* (CLBC)

www.communitylivingbc.ca

This organization delivers support and services to people with developmental disabilities and to children with special needs and their families in British Columbia.

Down Syndrome Research Foundation

www.dsrf.org

This Foundation was formed in response to the need expressed by parents and professionals for detailed and research-based information for themselves and for the community at large.

Family Support Institute

www.familysupportbc.com

Canada's first family support organization for families who have sons and daughters with disabilities. Vickie Cammack was their founding Executive Director.

Inclusion *BC* (formerly *BC* Association for Community Living)

www.inclusionbc.org

Inclusion *BC* enhances the lives of children, youth and adults with developmental disabilities and their families by supporting abilities, promoting action and advancing rights, responsibilities and social justice.

Inclusion *BC* Self advocacy resources:

http://www.inclusionbc.org/resources/weblinks#Self_advocacy

INCOMMON.TV

INCOMMON.TV is a web-based story-sharing channel which captures and share stories of community living and living with disability.

Infant Development Program of *BC*

www.idpofbc.ca

Serving children from birth to three years old who are at risk for, or who already have, a delay in development.

Ministry of Social Development and Social innovation

www.gov.bc.ca/hsd

This Ministry is responsible for **BC Benefits**, CLBC, employment, housing, and other programs impacting the lives of people with disabilities.

Nidus Personal Planning Resource Centre and Registry

www.nidus.ca

This website contains information about Representation Agreements.

Opportunities for the Disabled Foundation

www.oftdw.org

The mandate of this organization is to help people with physical disabilities to live more fulfilling and independent lives.

The Public Guardian and Trustee of *British Columbia*

www.trustee.bc.ca

The Public Guardian and Trustee of **British Columbia** operates under provincial law to protect the legal rights and financial interests of children, to provide assistance to adults who need support for financial and personal decision making, and to administer the estates of deceased and missing persons where there is no one else able to do so.

Saferhome Standards Society

www.saferhomesociety.com

This is a resource for universal and safer design and building homes adaptable to the ever changing needs of people regardless of physical needs and age.

Self Advocate.Net

www.selfadvocate.net

Made by self advocates with disabilities built for self advocates with disabilities. This site has contacts with people all over Canada and the rest of the world. It is developed by and for self advocates with world wide links.

SET-*BC* (Special Education Technology)

www.setbc.org

Ministry of Education provincial resource program lending assistive technologies (reading, writing and communication tools) to ensure students' access to educational programs.

Society for Disability Arts and Culture

www.s4DAC.org

Based in Vancouver, the Society for Disability Arts and Culture (S4DAC) presents and produces works by artists with disabilities and promotes artistic excellence among artists with disabilities working in a variety of disciplines.

Society of Special Needs Adoptive Parents (SNAP)

www.snap.bc.ca

SNAP is a provincially registered not-for-profit and federally registered charity that helps families with challenges through mutual support, information, sharing, and advocacy.

Vela Microboard Association

www.microboard.org

This organization concentrates exclusively on developing micro boards for people with disabilities.

PLAN quick links

Al Etmanski's *blog*

www.aletmanski.com

Al Etmanski's *blog* series: Tips for Solution-**B**ased Advocacy

www.aletmanski.com/al-etmanski/tips-for-solution-based-advocacy

PLAN Institute for Citizenship and Disability

www.planinstitute.ca

PLAN Okanagan

www.planok.ca

Planned Lifetime Advocacy Network (PLAN Vancouver)

www.plan.ca

RDSP Resource Centre

www.rdsp.com

Tyze Personal Networks

www.tyze.ca

PLAN's Toll-Free Hotline:

1-844-311-PLAN (1-844-311-7526)

PLAN books and products

PLAN and PLAN Institute for Caring Citizenship offer products for sale. Please see below for a list of items and a brief description. To order, please visit www.plan.ca or www.planinstitute.ca.



The Company of Others, a creative collaboration by author Sandra Shields and photographer David Campion, uniquely captures the spirit

and significance of personal networks. Compelling stories and photographs lead the reader on an intimate journey into the lives of five individuals— with no connection to one other and little in common, except in one respect: each person is at the centre of an active social “circle”—a network of caring friends and family whose lives are enriched by the relationship they share. An extraordinary and moving book about the transformative power of family and community.



Impact – Six Patterns to Spread and Share Your Social Innovation

Stay tuned for Al's latest book on social innovation. Visit www.plan.ca or Al's blog www.aletmanski.com for publication news.



A Good Life

Al Etmanski

A Good Life for You and Your

Relative With a Disability is an inspirational guide to rethinking

disability and the value of people with disability in a caring society. It provides families, caregivers and

those worried about the well-being of people with disabilities with insights, stories of inspiration, and practical advice.

It offers a step by step guide to creating a plan for the future which provides for the safety, security, and well-being of people with disabilities.

Peace of Mind (CD)



The *Peace of Mind* CD-ROM is a practical and loving guide to help you plan for the future of your relative with a disability. It combines personal stories, testimonials, tips, and step-by-step worksheets to get you started on your path to peace of mind.

The Ties That Bind (DVD)



a National Film Board of Canada production

In *The Ties That Bind* award winning documentary, filmmaker John Ritchie takes a first hand look at a family's struggle to let go, when every instinct compels them to hang on. Ritchie

follows the Jordan family—Kathleen, Bill, Chris and his two siblings—for almost three years. The result is an extraordinarily intimate film that reveals, with raw emotion and surprising humour, the complexity around one young man's transition toward a more independent life.



Peace Begins With Me

In *Peace Begins With Me*, Ted Kuntz shares the story of his journey of making peace with his son's disabilities. It is a journey through darkness to a life that is now filled with peace, joy, and happiness. At the core of Ted's message are simple yet powerful strategies that enable all of us to experience more peace and joy and create a life more of our choosing. A must read!

What readers say about *Safe and Secure*

“PARENTING CHILDREN with disabilities is to land in Oz and to search for the way home. As a parent, foster parent, advocate, friend, teacher and service provider, I know what it is like to be carried along by the tornado of systems. Every page in *Safe and Secure* is like a map of our heart. It leads us home.”

AARON JOHANNES, M.A.
Parent and Facilitator,
Spectrum Consulting

“YOU MUST READ THIS BOOK. There is no better resource for a family struggling to ensure a safe future for a loved one with a disability. As the saying goes, “When someone dies, a library burns.” Don’t lose what you know. Let this book be your library about your loved one.”

GEOFFREY W. WHITE
Principal, Geoffrey W. White Law Corp.

“SAFE AND SECURE IS UNIQUE, comprehensive, and written from experience. The personal stories breathe life into the content. Not only that, but for those of us who think we have addressed all the issues involved in providing for our loved ones, we are challenged to go a little farther, to consider a variety of aspects of the subject being contemplated. *Safe and Secure* leads me to review past decisions in light of newly presented possibilities.”

BERYL SAWYER
Parent

“SAFE AND SECURE IS A WONDERFUL — and wonderfully useful—guide to solving problems that many people will never have to face. Our family has found it enormously helpful.”

WILLIAM GIBSON
Parent and Author



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