
Introduction

Love is not enough

When thinking about the task of creating a new edition of *Safe and Secure*, language was one of the first things considered. Originally, the book was written by a parent for other parents. The language used was “you and your sons and daughters”. In this edition, we wanted to include everyone who supports someone who has a disability. After much discussion and consultation, we decided to use the word **Family**. In this book, Family means immediate family, including parents, siblings, grandparents, extended family members, chosen family, allies, friends, and members of someone’s Circle of Support. *Safe and Secure* is for anyone who supports someone who has a disability. As the title indicates, we want people to be safeguarded and have secure futures. This book is for anyone connected to a person with a disability who has a role in helping to make this happen and ensure a good life rooted in community.

Community is
where “we”
become “us.”

TIM BROADHEAD

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 many people supporting someone with a disability. You are definitely not alone.

Like everyone, you want to die with your affairs in order. You want to leave a clear blueprint of your wishes for your family member. 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 family member with a disability.

That’s the voice of love speaking.

Nevertheless, over 50 percent of Canadians die without a Will. Most of the other 50 percent haven’t had their Will reviewed and updated for at least five years.

That’s the voice of fear speaking.

Let's get right into 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 family member, help conquer fears and replace fear of the future with faith in the future.
2. We want to guide you through the process of creating a person-directed plan for your family member with a disability. We want to expand a vision of the possibilities and help put them into concrete terms. Having a plan, especially one that offers some flexibility, is better than no plan at all.
3. Finally, we want to shed light on the legal, financial, and specific solutions available to assist you in carrying out a family vision and to share practical tips on how to apply these solutions to your family's unique circumstances.

What we believe

We believe in families. We believe in the initiative, dedication, creativity, tenacity, and commitment families have. We believe that wishes, dreams, and desires for your family member who has a disability, can shape the future, but only if they are deeply involved and part of it. We believe in a world of possibilities. We believe that if you and your family member are willing to commit to the process of future planning outlined in this book, then that is the future your family member can have.

This book allows your family to look over the shoulders of other families who are on the same journey. In this book, 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 family member who has a disability. While the details of their plans may be different, the issues they are confronting are often similar to yours.

Another belief is that this book can help. It will provide your family with an overview of the entire future planning process. There are no single answers, no single solutions, and no miracles. In fact, some of the solutions

will never look perfect...it's a work in progress, with aspirations included alongside practicality. A person-directed plan is a mixture of common sense, commitment, hard work, a dash of bravado and lots of hope!

So, enjoy, create, laugh, and cry.

Developing a Person-Directed Plan – Seven steps to a safe and secure future

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

Many of us never really take the time to sit down and discuss what the future vision is for our family member who has a disability, with our family member and with other people. 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 so many confusing messages and countless pieces of advice, and so many complications. The need for resolution lurks just beneath the surface, emerging at the most unexpected times.

Sound familiar? Many families have encountered the seemingly overwhelming bits and pieces of advice and action required to prepare for the future. Families have said that the process is not as complicated as it first appears. There are only a few key elements your family needs to focus on. We have combined these elements to help you define a person-directed plan with your family member. This plan articulates their good life now and into the future. But for you, it is the road map that helps guide you in your support of them and ensures your peace of mind in doing all you can, while you can, to achieve that vision. That is what this book is about. It is what you should develop for and with your family member. But really, you will be developing it for yourself.

In this book is a seven-step process families can follow to create a safe and secure future for their family member who has a disability. It includes the best of your family experiences, dreams and wishes for the future, and your family knowledge and expertise. It combines all of these with the active

involvement of your family member with a disability, other members of your family, and selected knowledgeable professionals.

It is a plan that you will all create, control, and direct together. 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 – CLARIFYING YOUR VISION

Creating a Person-Directed Plan and looking at a vision for the future

STEP TWO – NURTURING FRIENDSHIP

Creating and maintaining a strong network of caring, committed relationships

STEP THREE – CREATING A PLACE TO CALL HOME

Home is where we can just be, and where we belong.

STEP FOUR – MAKING SOUND DECISIONS

Protecting vulnerabilities and honouring choices.

STEP FIVE – ACHIEVING FINANCIAL SECURITY

Wills, Trusts, and the RDSP: Using all the legal and financial tools at your disposal.

STEP SIX – ADVOCATING WITH EMPATHY

Ensuring services support rather than supplant a good life

STEP SEVEN – SECURING YOUR PLAN

The power of family to family connections and strength of family networks that can help guide your family's future.

How to use this book

We suggest you skim through this book until you come to a section that 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 many people don't—you can download the worksheets from the dedicated website: safeandsecurebook.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, the planning will be complete and there will be a record of your family's intentions—all contained in one place.

This book equips you with the knowledge and tools to make informed decisions about planning for the future and navigating the professional services available to you and your family member. By following the steps and advice presented here, you will be better prepared, use less professional time, and might save 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 family.

Think of Safe and Secure as a manuscript for the future.

Advice for families with younger children

As you will discover, there are some parts in this book specifically written for parents who have children under the age of 18.

Families with younger children are faced with enough challenges: being first-time parents, dealing with the news of a child's disability, and responding to

additional health challenges. This can be a tumultuous and intense period. Your family may not wish to focus on the future. Here are some tips to help along the way:

- Grandparents and other family and friends can help in a variety of ways, including making contributions to an RDSP or leaving money in their estate to contribute to a discretionary Trust.
- Enjoy your child. Don't let their childhood be remembered as a series of therapy and medical appointments. Make sure your family creates fun, happy memories too.
- Take some time for you and other family members. You'll be a better person if you aren't burnt out. Re-charge your battery from time to time. It won't be the end of the world if you decide to take a break, even for a month (if possible), then get back to medical and therapy appointments if you decide that's what you and your family needs.
- 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 every person who is a friend or shows interest in your child. You will be pleasantly surprised at how many of these people will become circle of support members when the time comes.
- Before high school is a good time to begin organizing a social support network for your future 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.

The single BEST support...

Connecting with other families who have children with disabilities is the single best support for any of the tough decisions you will have to make on behalf of your family member.