

ONTARIO EDITION

safe and secure

**SIX STEPS TO CREATING
A GOOD LIFE FOR PEOPLE
WITH DISABILITIES**

Al Etmanski

with Jack Collins and Vickie Cammack

RDSP contribution by Jack Styan

ONTARIO EDITION

safe and
secure

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Ontario edition, 2010

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 advisor or consultant when planning to implement any strategies. This will ensure the latest available information is taken into consideration and matched with individual circumstances.

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This book uses the term “disability” to refer to those challenges, conditions, circumstances, handicaps, and impairments that limit the functional ability of people. In all of PLAN and PLAN Institute’s work, the person is the primary focus, the disability is secondary.

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Acknowledgements

The persistence, passion, and creativity of a remarkable group of individuals and families in British Columbia gave rise to the creation of this book. My thanks to the founding board of PLAN and to the many family leaders in BC whose efforts have inspired individuals and families across Canada and around the world.

Family
is who
loves you.
WAYSON CHOY

This Ontario edition is made possible by The Law Foundation of Ontario who has a long standing tradition of supporting initiatives that promote and enhance justice for all Ontarians. By helping us spread the word about the Registered Disability Savings Plan, and informing individuals and families about the importance of future planning, The Law Foundation of Ontario has made—and will continue to make—a real difference in the lives of many across the province.

Our thanks to the following individuals for offering up their skills, expertise, and thoughtful review: Susan Beayni, Lorna Aberdein, Julie and Kalman Fejes, and Debra Johnsen.

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And finally, a special thanks to Jack Collins, Vickie Cammack, and Al Etmanski, the authors of *Safe and Secure*. This book is evidence of your leadership and inspiration.

Jeff Dobbin
Executive Director
PLAN Toronto



Preface to the Ontario Edition

A tough question perches on a shoulder of every parent I have met: What will happen to my son/daughter with a disability when I die? For 20 years, Planned Lifetime Advocacy Network (PLAN) families and supporters have embraced tough questions: Who will be there after we are gone? Who will love our relatives? Whom will they love? Who will protect and keep them safe? Who will appreciate and nurture their gifts?

The collective creativity and problem solving ability of these parents is the inspiration behind this edition of *Safe and Secure*. Although difficult questions will always prevail, we are united in the belief that together, we can create a good life for our relatives with disabilities.

PLAN specializes in families helping families. We are led by families and our agenda is dictated by family concerns. We believe in self-sufficiency. In order to preserve our family voice, we thrive independent of government funding.

PLAN focuses on what is loveable about our relatives rather than on what is “wrong” with them. That’s because we are surrounded by people who are deeply in love. This includes moms and dads, naturally. Equally, it includes sisters, brothers, aunts, uncles, grandparents, cousins, friends, neighbours, and—in many cases—service providers, professionals, and government workers. We are united by the bonds of caring, affection, and a common desire to ensure security and well-being for our relatives.

This book is our major vehicle for passing on our knowledge, for sharing our stories, for inspiring you to act, and for enhancing the life of your relative. Plunge in. Start anywhere. We are confident the straightforward principles of *Safe and Secure* will provide you with peace of mind and the realization that you are not alone.

First written in 1996, this edition has been revised and updated for families in Ontario. The immediate catalyst for this was the

availability of the Registered Disability Savings Plan (RDSP), the first of its kind in the world.

PLAN led the initiative to create the RDSP: researching its benefits; convening and mobilizing families; engaging with the Federal Government of Canada to have it made into law; and working with the Ontario Government to extend asset limits and eliminate RDSP claw backs from Ontario's Disability Support Program. Particularly when combined with a caring network of support, the RDSP is an important resource for ensuring that people with disabilities do not have to live in poverty.

We invite you to join a growing worldwide movement of families that are embracing innovation and creating the lives their sons and daughters deserve. We share the certainty that our sons and daughters make unique and valuable contributions and that we all benefit when these contributions are given.

As we take charge of the future—and as we nurture caring networks for people with disabilities—we are awakening the world to the importance of belonging, the importance of trust, and of reciprocity. When this happens, lives are transformed, communities are changed, and our capacity to care for one another is enhanced.

Al Etmanski
President and Co-founder of PLAN

Hope means to
keep living amid
desperation and
to keep humming
in the darkness.
In the midst of a
gale at sea, is to
discover land in
the eyes of
another. It is to
see that they
understand you .

HENRI NOUWEN

Introduction

We are in a period of transition unlike any other in recent history. For individuals living with a disability and their families, the Ontario Edition of *Safe and Secure* could not have been published at a more critical time. In the past two years alone, we have witnessed considerable change that will have a long-term impact on our families. Some of these changes are highlighted below.

The Ministry of Community and Social Services passed a new act. *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, changes the model in which individuals with disabilities will receive provincial support. This legislation recognizes the importance of individual planning for people living with disabilities. It moves towards a new approach where individuals and families have a stronger voice and greater control over the supports they receive.

Our free market and financial systems have proven to be vulnerable and the Ontario economy is in a state of transformation. For many of us, the future is much less certain.

The Federal Government announced the development of the Registered Disability Savings Plan (RDSP). This is a made-in-Canada program that encourages families to look to the future and to begin long-term planning. The RDSP changes the future for our relatives. It signifies a new government perspective towards people living with disabilities, one that is based on offering a hand up rather than a handout.

As new initiatives are developed, new challenges surface. The RDSP alone is a catalyst to change for many provincial and federal policies. It will, for example, entice governments to address long standing issues in areas like guardianship, supported decision-making, and person centred planning.

We believe that change is good and long overdue in Ontario.

Safe and Secure will encourage individuals and families to ask a new question: “What is a good life?” Instead of looking to service

agencies for the answer, individuals and families will begin the process to answer the question themselves. They will determine what they need in order to work towards a good life.

But our greatest hope for *Safe and Secure* is that it will help emphasize what we understand to be the foundation to a good life: loving, caring relationships with family and friends. In isolation, our sons and daughters—and our families as a whole—are more vulnerable. Yet with supportive relationships, safety, security, and opportunities abound. *Safe and Secure* will also be a cause for change in our schools, organizations, and communities. As affiliates of PLAN, we believe the future holds unlimited possibilities.

JEFF DOBBIN, PLAN Toronto

LORNA ABERDEIN, Planned Lifetime Networks
(Waterloo Wellington Oxford)

JULIE FEJES, Lifetime Networks Ottawa

DEBRA JOHNSEN, Thunder Bay Family Network



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I Can Dance !!!

Me dance?

Me?

Who, me?

Yes...

Freely, whirling, with grace

And a teacher too

Teacher of life

Teacher of joy

Spreading laughter in the midst of

Bombs clashing and words which strike us.

Advocate of strong will and continued hope.

I am a voice

Sometimes fun, silly

Sometimes certain, firm

Working for justice

Working for peace

A strong spirit, a woman of faith.

I live my faith

I dance it.

And I dance...

I dance for joy in life's gifts

I dance in sorrow for friends lost

I am a friend

The bonds I make are rooted

Deep within.

These bonds weaving a web,

A network

A heart network.

I am a connector

Bringing people together

Bringing people to encounter

A way of just being

People transforming

Ideas

Bodies

Hearts

When I dance

Yes

I dance

BY: REBECCA BEAYNI

(AS RECORDED BY ANNA BRUNO)

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by Rebecca Beayni...

My friend, Anna Bruno, listened to my story as told by friends and family over the years. She learned that I lived in Lebanon when I was young and that I am, among other things, a connector and a peacemaker. She is also my dance partner and knows how much I love to dance. She and I wrote the poem as she confirmed along the way that she understood my ideas correctly. I do not use a device but make confirmations of yes and no by raising my right or left hand and by facial expressions. For more information go to my website: www.rebeccabeayni.com.

Introduction

Love is not enough

I don't think
intelligence exists
without love.
Love is intelligence.
What kind of
intelligence would
you have
without love?

ROBIN BLASER

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 in North America 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

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

share practical tips on how to apply these solutions to your unique circumstances.

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

Another belief of ours is that this book can help. It 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.

Developing a Personal Future Plan – Six 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.

Community is
where “we”
become “us.”

TIM BROADHEAD

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? 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 convinced 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 six-step process 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 six steps are as follows:

- Step one Clarifying your vision
- Step two Nurturing friendship
- Step three Creating a home
- Step four Making sound decisions
- Step five Achieving financial security
- Step six Securing your plan

Advice for parents of younger children

As you will discover, there are a number of sections in this book specifically written for parents who have children under the age of 18. These include pages 102, 141, and 150.

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 every person 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.
- Before 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.
- Connecting with other parents 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 child.

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 most don't—you can download the worksheets from www.plantoronto.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.

