

step six

securing your plan

Before my stroke, I had a mistaken notion that feminism meant independence; the unspoken corollary was that disability (and aging) meant shameful dependence on others.

What I have learned finally is that in asking for help I offer other people an opportunity for intimacy and collaboration. Whether I am asking for me personally or for disabled people generally, I give them the opportunity to be their most human.

In Judaism, we call this gift a mitzvah.

BONNIE SHERR KLEIN

george's story

Back seat driver

GEORGE HALL has seen the future and he likes what he sees. Sure he still has worries, but he is satisfied he has done everything he can think of to ensure Rick's future. What's more, he has seen Rick thrive in his new life. George has a real sense of what will happen when he's not around.

He has already started to take a back seat in his son's life. "I'm seventy-three next month," he exclaims. "I'm slowing down a bit. I guess I've earned the right to be a back-seat driver."

Besides, George has a backup. The chauffeur for all his plans is, no surprise, PLAN. He has become a Lifetime member of PLAN. PLAN is prepared to make a lifetime commitment to monitor the quality of Rick's life, to maintain the health of Rick's circle, to provide advice to his trustee, to visit Rick on a regular basis, and to stay on top of all the other plans George has made. In other words, all the things that parents do for their children now, PLAN is prepared to do after they're gone.

In this regard PLAN spells continuity as well as peace of mind to George. "It's better to make your arrangements with a group that you expect to be around for a while," he concludes.

But there's more. You see, while it's true that George's plans for Rick are focused on Rick's future, they are really about George's future as well.

George has sold the family home, leaving Rick behind while he makes a move to Sechelt on the Sunshine Coast. That's a move he never would have considered in the past.

George's wisdom is astute. "Part of the enrichment in life is learning. If you're feeling at all uncomfortable about your plans, a few simple steps will enhance the future for both you and your relative. You can't depend on anybody else, the government, the local association, your friends or family, on a loose arrangement."

As a former salmon fisheries biologist, George knows a lot about swimming upstream, about enhancement, about courage, and about destiny. It's time, he thinks, to complete the life cycle.

Besides you can't really qualify as a back-seat driver without having been in the driver's seat first. ■

step six

Securing your plan

Even small steps
away from
segregation lead
to a better
life, when taken
with conviction
and respect.

MARILYN DOLMAGE

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

- the ongoing involvement of caring, committed friends and family
- control over the home environment
- trusted friends and family to assist with decision-making
- a properly drawn and executed Will
- a financial strategy including an RDSP and a discretionary trust
- sensitive and caring trustees who know your family member.

We trust you've also thought about:

- how you want to divide your property and financial assets
- which relative, friend, Personal Network member or company might be a trustee or co-trustee of the discretionary trust
- what services you may want from a lawyer, accountant, trust officer, and financial planner
- consolidating all this valuable information in the worksheets provided throughout this book!

We trust you now have a clear idea about what your relative's life will look like after you are gone. Your picture includes:

- who their friends will be
- where they might live
- how they will make their contribution to society
- what might be put in place to keep them safe
- who might serve as an advocate and monitor
- what role your other family members might play.

Worksheet 10—Your Summary Checklist—can be found at the end of this step, on page 183.

Ode to David

A FEW WINTERS BACK David tripped and fell. Uncharacteristically, he seemed to be losing his balance regularly. Members of his Network accompanied him to a series of medical appointments only to hear the unimaginable: David had an inoperable brain tumor.

David's Network was told there wasn't much that could be done except to keep him comfortable and out of pain. In fact, a lot was done. His time in hospital precipitated an outpouring of love. The walls of his hospital room were papered with cards and banners. Amnesty International sent a poster listing all the campaigns David had participated in. The Vancouver Symphony made him a DVD. The Vancouver Bach Choir sent a video full of personal greetings. Political candidates for Mayor visited. At the hospital's request, David's Personal Network created a visitor's roster. It was becoming overwhelming for the nurses but not for David. More! I want more! was David's response.

David was aware of his condition while talking through all his options with his facilitator Karl and his closest friends. Routine mattered most. As Christmas was coming, friends arranged a larger than usual party. Sandwiches were cut to his specifications: crusts off, triangular shaped, with orange cake and sherbet for dessert. The conductor of the Bach Choir led the carols,

accompanied by the principal pianist of the Vancouver Symphony. Worried he might miss the chance to celebrate Mozart's birthday, David suggested the evening end with "Happy Birthday Dear Wolfgang!" "Yo Mo," was the refrain from a tattooed and pierced younger activist in attendance.

In time David moved into a hospice made more welcoming by the presence of a piano and a good sound system. Bramwell Tovey, the conductor of the Vancouver Symphony Orchestra, along with his wife Laura, visited just after David slipped into a coma. Speaking softly, Mr. Tovey thanked David for being the Symphony's number one fan:

You have visited me backstage after so many performances, always gracious, never gratuitous with your comments. Thank you for understanding what we were trying to do. Thank you for speaking the language of music. David, it's my turn to thank you. We love you.

Kissing David on the cheek, he left the room only to spot the piano. Soon Mozart's Masonic Funeral Music filled the room where David lay sleeping.

David rallied just two days before dying and insisted that his Network take him to the polling station to vote in the federal election—an engaged citizen to the end. David's death, when

continued on page 170

I knew I loved
him, and he knew
I knew it. I held
that sweetness
in my arms,
and waited for
whatever was
going to happen
next. We did
that together.

IAN BROWN

Families helping families

Your challenge is to make the necessary arrangements for your relative to have a safe, secure, and comfortable life beyond your lifetime. This is an immense challenge. Who knows what the future will be like? They haven't yet invented a cell phone that works from the grave but if they do the inventor will be a parent of a child with a disability! In the meantime, who can you count on?

If you are like us, you may still have one nagging concern: Who does what I do, keeping an eye on everything? Who will be my eyes and ears, my arms and legs? Who will monitor the plans I have made? What is my plan "B"?

Our answer is simple: trust other families in similar circumstances. PLAN was created so we could share our strength, expertise, and know-how. PLAN was created by a small group of families who wanted a new type of organization: one controlled by families, one that would remain financially independent, and one that would focus exclusively on the social and financial well-being of our relatives with disabilities.

PLAN offers four basic functions which correspond to the four letters in our name:

PLANNING FOR THE FUTURE PLAN offers current information on everything you will need to plan for the future (and deal with the present for that matter). This includes information on:

- the Registered Disability Savings Plan (RDSP)
- wills and estates
- trusts
- government benefits
- home ownership
- disability tax benefits
- creating a social network.

LIFETIME MEMBERSHIP We offer this for families who want PLAN as a back up to monitor all the plans they have put in place and to intervene and advocate where necessary.

david's story

continued from page 168

it came, couldn't get any better: he died peacefully on the 250th anniversary of Mozart's birth.

Those who accompanied David on his final days couldn't help feeling that David's mother would have been pleased. David did not die alone as she feared. And his life, her life, was not in vain.

A memorial celebration was held at Fairview Baptist—a celebration which ended with more than 200 attendees singing ODE to JOY.

An Ode to a Good Life

An Ode to a Good Death

An Ode to Friendship

An Ode to David.

A Canadian Broadcasting Corporation TV documentary on David Cohen's remarkable life and death can be obtained through the PLAN Institute. Please visit www.planinstitute.ca. ■

ADVOCACY We offer both personal advocacy for individuals and families and public policy advocacy to improve the lives of all people with disabilities.

NETWORK We help you create and maintain a Personal Network for your family member.

Flowers and compost

When you think of it, our 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 enjoy all stages of growth, to savour the beauty of the moment, and to appreciate the sweat of preparation. 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 good, 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?

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. It is also true for us as a movement of families.

The parent-based disability movement arose at the end of the Second World War in the wake of the eugenics movement and the atrocities committed against people with disabilities. It also arose in reaction to professional advice to send our children away to institutions. Those early seeds of change—planted in dank soil—have blossomed into the most wondrous of plants.

The parent-based disability movement was the first internationally-based consumer movement. It led to the creation of the UN Charter of Human Rights for Persons with Disabilities. Before Ralph Nader, before consumerism, we existed!

Looking into the future

We see some disturbing trends and new challenges on the horizon which we are paying close attention to. Think of these challenges as the weather conditions that any sensible gardener needs to prepare for. So let's descend underground into the compost and poke around for a while. Perhaps we'll see the seeds of a solution, the beginning of another beautiful plant!

CHANGING DEMOGRAPHICS Within 15 years, population aging will be a key challenge facing our national and provincial economies. In 2005, there were 44 children and seniors for every 100 Canadians of working age. By 2030, there will be 61 children and seniors. By 2025 there will be more people over 65 than under 15 in Ontario.

The potential impact is threefold. One, there will be fewer taxpayers and therefore smaller operating budgets at every level of government.

Two, increased health care expenditures (one source suggests if current trends continue, health care costs in Ontario will account for more than 70% of the provincial budget by 2017).

Three, with a smaller fiscal pie and a greater share of the smaller pie going to health costs, there will be fewer resources to respond to social, educational, and environmental challenges.

Not everyone agrees on the size of the fiscal challenge we face. Every expert has a different set of assumptions. Maybe health care costs won't rise as dramatically as predicted. Maybe a new wave of immigration will fuel our economy. Maybe our birth rate will stop declining. We can't predict how governments will respond and how successful they will be in reining in health costs, and creating more efficiencies.

We do think it is prudent, however, to recognize there may be less financial resources to spend on disability supports in the future.

There is something
bigger than fact:
the underlying spirit,
all it stands for,
the mood,
the vastness,
the wildness.

EMILY CARR

No amount
of thought
can ever reveal
what comes
unexpectedly.

ARTHUR ERICKSON

NEW 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 mercy killing, right to die legislation, and a reverence for technology and genetic engineering reflect a quest for perfection and implicitly a belief that some lives are not worth living. With every new tragedy or scientific discovery, fears surface that ambiguous terms like "quality of life" will be used within an emerging "new" eugenics movement. In the past, funding shortfalls have been linked to cutbacks in support for people deemed not as worthy; that is, because they are not contributors or productive and, therefore, are a drain on society's limited resources. Our challenge is to ensure our relatives with disabilities will have fair access to future medical treatment and other government funded supports.

New solutions for changing times

Fortunately families are used to turning adversity around. Reduced tax bases and the increasing size of health care budgets are just the latest in a series of challenges we have faced before. We are confident the natural ingenuity and creativity of families will lead to new solutions for our changing times. PLAN is one of them.

PLAN Affiliates - part of an international movement

Lifetime Networks Ottawa

Lifetime Networks Ottawa grew out of the desire of a few families to ensure that their family member with a disability is lovingly cared for in the future. Out of that simple desire, Lifetime Networks Ottawa was established and has flourished. In addition to developing a substantial member base, a trained team of quality facilitators currently facilitates personal support networks.

Lifetime Networks Ottawa assists families in planning a good life for their relative with a disability, both now and in the future, by:

- building and monitoring Personal Support Networks

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

- providing future planning education and information
- providing family networking and social opportunities.

PLAN Toronto

As an organization made up of families with a relative who is vulnerable, PLAN Toronto believes that relationships form the foundation to a good life.

PLAN Toronto supports individuals with disabilities and their families in planning for a safe and secure future by:

- building personal support networks comprised of caring friends and family.
- providing consultation and workshops on an array of future planning issues
- creating a space for families to connect, to dream, and to inspire together

With the Centre for Social Innovation as its new home, PLAN Toronto is part of a network of over 170 organizations committed to social change.

Thunder Bay Family Network

The Thunder Bay Family Network is a growing and evolving network of families that seeks to implement innovative strategies to support and strengthen families. It is a not-for-profit corporation led by families to ensure a safe and secure life for all.

TBFN will nurture the strengths, dreams, and the interests of families, with a view to creating inclusive caring lives for all members. Its vision includes:

- an inclusive community that supports diversity for all citizens
- meaningful lifestyles for loved ones that offer choices, relationships, and opportunities, in a safe, supportive, and inclusive environment
- supporting strong family voices within the community to build community capacity
- creating support networks for individuals and families
- achieving peace of mind through shared experiences, financial planning, and supportive networks.

A social enterprise fulfills its mission by earning its income. It also sits on untapped resources which can be mobilized for social good.

Planned Lifetime Networks (Waterloo Wellington Oxford)

Planned Lifetime Networks is a non-profit charity established by and for families living in the Region of Waterloo and area who have family members with disabilities. It helps families plan a safe, secure, and quality future for their family member living with a disability. It believes the best guarantee of a good life is the presence of caring, actively involved friends and assists in the development of a network of committed friends in relationship with the person with a disability and each other.

Planned Lifetime Advocacy Network (PLAN)

The families who created PLAN had a clear list of do's and don'ts. Do create an organization that can withstand the winds of change. Don't rely on government funding. Do become financially self-sufficient. Don't do anything to weaken your effectiveness as advocates and monitors.

These families wanted an organization that would:

- survive them
- not drift from its mission in a search for funding
- keep an independent eye on all the plans they had made for

their individual relatives as well as for all persons with disabilities.

While each Ontario affiliate organization operates independently, together they share the core values, concepts, and approaches that embody the PLAN model.

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—no reliance on government funding for organizational operating costs
3. Family leadership—our constitution calls for a majority of board members to be family members
4. Contributing Citizenship—the contributions of our relatives leads to their recognition as full citizens and brings meaning to their lives.

PLAN's four basic functions

FUTURE PLANNING ADVISORY SERVICE

PLAN offers up-to-date information on all the elements of future planning.

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.

If you are interested in learning more about social enterprise and social finance, please visit www.planinstitute.ca and click on Innovate with Us.

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.

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 you want PLAN to watch over and protect the best interests of your relatives after they die, then you must become a lifetime member.

PLAN: a social enterprise

Since our founding parents did not want us to rely on government funding, we became a social enterprise. A social enterprise is a new type of not-for-profit organization that fulfills its social mission by earning its income. Social enterprises realize they sit on untapped resources which can be mobilized for social good.

Our expertise was detailed knowledge about what parents and families needed in order to create a safe and secure future for their relatives. This brought us in touch with credit unions, banks, life

PLAN's social audit: staying faithful to our values

Our social audit measures member satisfaction and our effectiveness at achieving our goals. It gathers input from our individual and family members, Personal Networks, staff, business partners, and community supporters.

If you would like to read what families have to say about PLAN check out www.plan.ca or www.socialaudit.ca.

insurance companies, law firms, and financial and estate planning advisors who were interested in catering to this emerging segment of the disability market.

Our social enterprise revenue sources include:

- partnering with law firms, financial institutions, and companies who are in the future planning business
- charging a fee for our products and services.

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 an Endowment Fund to assist those who cannot afford to pay our nominal fees.

There are many benefits to being a social enterprise. It has enabled us to stay faithful to our core values. We are able to use our new found economic muscle 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, launching 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.

The emerging disability market

Most of us have heard about the green economy—businesses dedicated to reducing pollution and lightening our ecological footprint. Perhaps you have heard of the grey dollar, that is, products and services purchased by seniors. Or pink tourism—businesses catering to travel by gays and lesbians. These are all markets that have grabbed the attention of businesses and companies.

As we developed and matured as a social enterprise we discovered there was also a disability market. One of the most promising areas for the future of the disability sector is to mobilize

Adopting the
right attitude
can convert
a negative
stress into a
positive one.

HANS SELYE

this market to assist with our financial sustainability. For example, the estimated RDSP market in Canada is at least \$80 billion. The discretionary trust market size is another \$80 billion. \$160 billion is a lot of money! Can you think of ways we can mobilize our collective economic wealth to protect the future of people with disabilities? We can.

Some of our ideas include pooling the capital in our RDSPs and discretionary trusts to create a Disability Investment Fund. Another idea is to establish a No One Alone Fund to finance the costs of social networks. We are convinced that harnessing our collective economic power is a critical component in securing the future for all people with disabilities. Contact PLAN if you are interested in pursuing any of these initiatives.

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, and belonging.

The Institute currently supports over 40 replications around the world. It offers an annual Leadership Training course for people interested in learning about the PLAN model. For those interested in learning about social movements, the Institute offers a four day retreat called *Thinking Like a Movement*. For more information about the PLAN Institute visit: www.planinstitute.ca.

Philia dialogue on caring citizenship

When we think of citizenship, we usually think of rights and responsibilities. There is an expectation that everyone in society has a responsibility to contribute. Our friends and family members want to contribute. They are an under-utilized resource in society. We believe the next advance for people with disabilities will be made from this theoretical foundation. To promote these ideas, we created an international web dialogue on caring citizenship. Please visit www.philia.ca.

PLAN: A model for creative problem-solving by families

PLAN is an organization providing hands on, practical support to families and people with disabilities. It is also a movement of families.

In the broadest sense, PLAN is about:

- strengthening the family arm of the disability movement
- working together on behalf of all our family members with disabilities
- welcoming supporters from all sectors of society
- focusing on the abilities of ourselves, our relatives, and our neighbours
- seeing the possibilities by creating a climate of continuous innovation
- meeting government as an equal
- putting all our eggs in one basket and treating them gently
- finding roses in the compost.

We were struck recently by a comment from one of our founding members, Joan. 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.”

Achieving the complete Personal Future Plan

This book presents six steps for preparing for the future—and indeed changing the present—for your relative:

STEP ONE – CLARIFYING YOUR VISION

Rallying people around your hopes for the future.

STEP TWO – NURTURING FRIENDSHIP

Creating and maintaining a strong network of caring, committed friends and supporters.

STEP THREE – CREATING A HOME

Making a house a home.

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 – SECURING 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.

In concluding this book we wanted to end with a final story that would motivate or inspire you to march right out and do everything that needs to be done. The truth is, we've already written everything we know. We've nothing left to say. No final flourish. We're still in the field ourselves, you see. Look around you. There we are, your companion gardeners.

Worksheet 10

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 discretionary 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.

