step 1

clarifying 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

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

Kirsteen is a Vancouver born and raised poet. In addition to being published by the Poetry Institute of Canada, her work is featured in the BC edition of this book, and several international editions. A complete collection of her work is published, entitled *Dear Butterfly: 50 Poems. Written by Kirsteen Main*

step 1

Clarifying Your Vision

Most people have plans for things they want to do in their life. They might have short-term plans like going on a trip or starting to volunteer. Other plans might be more long-term like finishing school and getting a job or buying a home. The same is true for someone who has a disability. Depending on the person, they might need more or less support in planning for their future. As someone who supports a person who has a disability, you can be instrumental in helping the person think about their future and what it might look like. As long as the person you are supporting contributes to that vision of the future and remains at the center of any plans, your family can begin the journey forward together.

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.

As you begin to make plans, everyone must be clear about what your family member wants. It can be a tricky balance for families as we consider what they desire with what they need to be safe and secure. This balance can be hard on families as they focus on what a supported family member wants their life to look like. This should always remain at the centre of any discussion.

- What is everyone trying to accomplish for your family member as they move into adulthood?
- What does everyone imagine for their future?
- What are their goals?
- What planning needs to be done to lessen any potential negative outcomes?
- What should be maintained?
- What do other people need to know when they gather to discuss your family member's future and your wishes, after you are gone?

Without specific answers to these questions, the rest of the planning might be difficult and incomplete. Knowing what your family wants to achieve is the first step in creating a Person-Directed Plan.

For many people, a good place to start is by completing a Will and establishing a Trust for the family member you support.

Will and estate planning

Most of the planning time in regard to a Will should be spent identifying what your family member is trying to achieve, thinking through their goals and objectives, and clarifying the vision. Once these steps become clear, everyone will be in a better position to evaluate the options available. Then technical solutions such as choosing a trustee for example, will follow. Once your family is comfortable and has made some decisions, you can then seek the advice of professionals. Part 5 of this book is dedicated to this process and will be helpful for families since it goes into the details of Will preparation.

> Vision without
> action is merely
> a dream.
>
> Action without
> vision just passes
> the time.
>
> Vision with action
> can change
> the world.
>
> JOEL BARKER

The family's Will and estate plan will be more relevant and useful because a vision has been clarified, and directions are clear. Even if you don't have all the answers, it's okay. You just need to take a deep breath and get started!

Think about the last time you planned a fancy meal. You didn't just walk into the kitchen and start cooking; you needed a plan. First, you decided what to make and found a recipe. You checked the ingredients, noted what to buy, and perhaps asked others for advice. After all this was done, you went into the kitchen and started. Maybe you double-checked everything again, but at some point, you took action and began! The prep work you did saved you time and money, and in the end, it helped with the execution.

What is a Person-Directed Plan?

A Person-Directed Plan is a summary of the plans for the social and financial well-being of your family member who has a disability. This document captures the work of a Person-Directed, planning process at a particular point in time. It may be a written document or include visuals or use some other means of communication. While it may include information that came out of a discussion process, most importantly it involves action steps tied to achieving a person's goals. This typically involves both short and long-term plans.

The most effective question to ask when making a Person-Directed Plan is: What is a good life? Families tell us that a good life for their family member should include the following:

- Authentic relationships
- A place to call home
- Financial security
- Contribution
- Real choice

The worksheets at the end of each chapter will assist with answering this question for your family. To download a copy of all Worksheets, visit safeandsecurebook.ca and click on Safe and Secure Worksheets.

What is a vision?

Visions are creations of the heart as well as of the mind. A vision is a description of the desired future for your family, with the family member who has a disability being at the heart of this vision. A vision should be directed by your family member's goals and desires, with a focus on their future financial and social well-being. Their needs for a good life must be prioritized. In addition, though, it is important to consider your fears for the future. Taking the time to understand what you and your family member want and don't want for the future helps provide a clear path forward.

> I would be truly blind if I did not have vision.
>
> HELEN KELLER

A clear written statement of a vision will help your family focus. Since a vision reflects values, traditions, and your family history, it creates a context for the other components of the Person-Directed Plan. It acts as a guide when making other choices - does it align with our vision or not? While we recognize that families are deeply connected and interdependent, consider this vision to be one that is centered and directed as much as possible around one person - your family member.

Clarifying and sharing a vision of a desired future for your family member:

- Enables you to see the world through your family member's eyes
- Invites the involvement of other members of the family and friends
- 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 the plan forward
- Changes the present

Sharing your ideas—particularly when you put them in writing—is important. Start to have these discussions now with everyone involved in supporting your family member. You don't want to wait until you are no longer available. Relying on others without telling them about the vision or plan could create problems for everyone.

You don't want to assume that other family members, such as siblings or other children, know and understand everything you know about your family member. They are busy with their own lives and even if they are around, they might not be taking notes or are engaged the way you think they are. Sometimes we need to be explicit and concrete.

Written by S.T., Parent

Overall Vision for LJ

Our child is 16 years old now. The plan for LJ started 13 years ago. It wasn't a plan really; just frantic Google searching, trying to figure out the "what now?"

What is Autism Spectrum Disorder?
What do we do with that?
Can our child still have a future?
How do you live in Holland when you've always planned for Italy?

We put every effort into surviving the present day, let alone envisioning the future. Every bit of information seemed so overwhelming back then. We felt time was against us. Everything had to be accomplished now. We knelt at the wall that our will could not scale. We were tired and spread thin on all sides. We needed grace. We called upon our Lord and Saviour for help and little by little, the help came. Agencies, special development workers, clinicians, family, other parents, random strangers and some dedicated teachers/staff blew a fresh wind of perspective into our lives. We could hope again. Their support and education impacted us greatly and we carry it with us at every phase we go through.

Over time, we learned how to distinguish our child from autism. He had a personality and an intriguing character that amazed and surprised everyone. We saw him as he is, not how society sees him. We learned to nurture his abilities while providing support to his disabilities. LJ's life was taking shape. He has such amazing interests that we, too, wanted to explore with him. We saw him as a remarkable child and knew we had to secure his future. That meant we had to speak up. We were presumptuous for the most part: life would just give LJ what he needed. A new wave of shock washed over us. We have to advocate?! The waters of advocacy were a culture shock.

We received the Safe and Secure (Ontario Edition 2020) book from Sawubona Africentric Circle of Support (a Family Network we are part of) as part of our previous book club series. It was even more empowering to have a road map to help us outline how to set LJ's future in motion. Our connection to Sawubona exposes us to helpful resources such as Partners for Planning. Networking breaks the isolation bubble and lends meaningful tools to expand our vision.

The years spent journeying through the stages of searching and surviving and networking and worrying and believing and advocating and planning have greatly contributed to our overall vision for LJ. These things have clarified what we want and don't want for him; what works and what does not. We are not experts, but we know the good and the bad we have to face. Visioning is a lifetime practice. We can now embrace change, knowing it's okay if our vision evolves. Time is no longer against us. We now know how to work with time, redeeming it almost. We are confident in the bright future that is secured for LJ.

So what is our hesitation to start?

Fear plays into this for sure but what keeps us as families up at night? Feeling completely overwhelmed – where do we even start? Who will do all the things we take care of?

Who will make sure our family member is not only safe but having a good life, that THEY want!

Who will ensure they are happy, healthy, part of a family – whatever that looks like, financially secure, and ensure they are contributing.

We want to know our family member has people who care, really care. We might go back and forth between the big picture of where will they live and with who, work or volunteer time, and the small things. If they say “my back feels a little itchy” you know that means “please come here and scratch my back but lightly and go slow, and for only 30 seconds because that is enough”. What about seeing them start to escalate and know what to try, or when it’s too late and it needs to play out. Will others know that when they ask you to stay with them at bedtime, they really want you to sit on their bed for a minute in the dark and not say or do anything, just have your hand on their arm. Who will look at the big picture PLUS get to know all the small things? If we feel overwhelmed at times, how can we ask others to take this on down the road?

What keeps so many of us from thinking about the future let alone formalizing a plan for our family member? What causes our paralysis? Why don’t we act? Maybe it’s fear.

Fear is an intriguing emotion. Fear 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. It’s more imposing in our minds than in reality.

In our personal struggles with future planning, we can identify common issues that everyone must deal with. We offer them here because we believe that where there is clarity, there is comfort. Where there is understanding, there is the ability to move forward.

The dream has in it
the seeds of the
person's gifts….
What are some ways
we can actually take
the seeds that are
in the dream
and plant them in
our community
right now?

JUDITH SNOW

FEAR OF OPENING UP Sharing your family's hopes and worries means discussing intensely personal matters with others—, 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 family member. Or we may not know who to turn to or who to trust. And we risk rejection.

We live in a culture that believes in self-sufficiency. We've taken our responsibilities as parents or caregivers seriously. We've tried 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, and our anxieties with others.

We need to ask others to:

- Help with planning
- Carry out wishes after we are gone
- Believe in our family member and the possibilities for their future

To do this, we need to reach out. We need to know who we can rely on. After all, what good are 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 your family member really wants? What if they have questions? Maybe they aren't interested? How can you be sure you will be understood?

FEAR OF DEATH 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 children without disabilities have fewer anxieties about death than others do. Not true. Perhaps what separates us from other families is our need to address the future of the family member we support, not just for our lifetime, but for their lifetime.

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 which we all must 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.

> 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 life we want to live in.
>
> NORTHROP FRYE

FEAR OF MAKING A MISTAKE, OR FEAR OF NOT BEING PERFECT

Some of us feel we need to create the "perfect" plan. We are afraid that we haven't covered all the bases. We may 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 an endless delay. Perfection could mean never getting started. Doing our best is as perfect as it will ever get.

Reasons why we might put planning 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 who 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.
- Our day-to-day life is busy and hard enough.
- The future is too hard to contemplate.
- I'm a procrastinator and I can't think about this right yet.

Written by Shay, Parent

Dare to Dream

Becoming a mother and having a daughter was very exciting despite the uncertainty of knowing what being a mother really was. For me, having been an only daughter and not knowing the feeling of a sister, I was delighted to have a daughter.

I had many expectations for my daughter. I wanted to provide her with everything I did not have, aiming to give her the very best of my ability. I saw how her dad doted on her and how she was always his delight. But then came the noticeable differences; she would cry, she would not play with other girls her age, she lost speech, was unable to fit into school and mocked in the community. Devastated is an understatement of what I felt. Her younger sister was taking all the attention and seeing them together, the differences became more evident.

I was still quite optimistic that I would get her all the help she would need to catch up, but five years later, when her younger brother started on the same trajectory, I knew I had more on my plate than I had bargained for. I did not see a positive future at the time. We were living in Nigeria, in a place where the children were regarded as outcasts or demons as a result of parental sin. Family and friends did not want me or the children anywhere nearby. They were considered an anomaly.

However, both children had a fighting spirit, and whenever I looked at them, I just couldn't let them suffer. We came to Canada, where they got support, they could go to school, they were seen as part of society, and I could dare to dream again. I also became connected to a family network called Sawubona and found a community of support. Within a year, my daughter had won two medals at the Special Olympics for elementary students. She was enjoying school and becoming more social. I did not have to hide any longer. My son got help and started walking. He also got hearing aids that helped us communicate with him.

Today, not only do I dare to dream, but I know both children have a bright future. It hasn't been all a bed of roses, but we conquer feats daily. I know there is still a lot of advocating to be done and obstacles to overcome, but I can dare to be optimistic. I am sure the best version of my daughter and son will make me so proud. This is particularly so, because I am aware of what efforts they continue to put into their everyday living experiences.

Plans evolve

Person-Directed Planning will change as circumstances change. It takes time for dreams to evolve. You can always update and revise a plan. In fact, you should expect to make changes along the way. Life and circumstances evolve and the unexpected can happen. As your family ages, the plan will need to change and that is okay. You may gain insight and pick up tips from your family member as they get older, and changes occur.

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

DOUGLAS COUPLAND

Planning is an ongoing process and can be supported by a facilitator or planner. Having someone in this role can assist a person who has a disability and their family to think about the future and listen to what a person wants for their life. The foundation of this process is rooted in a person's strengths and capacities and focuses on building relationships and accessing community resources that support a good life. Having an outside perspective gives them the opportunity to ask questions and start conversations you may not have thought of or knew how to bring up. Working with a Facilitator may or may not result in a formalized plan, depending on a person's preferences and needs. A person or family may not need a paid facilitator to get started with planning for the future, but if you are feeling stuck, unsure how to begin, or the next steps to take, this can be a helpful support.

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.

Reflections on having a Person-Directed Plan

- It's fair to other family members. They are aware of the plan and know their part in it.
- Worries about outside interference are less than before.
- Everyone is better prepared to face the unknown.
- The family has done the best we can for now.
- The family has left a legacy of love.

Believing in Me

It cannot be understated
how much I need you to believe in me.
My wiring can detect it
if you have doubts
and if you have reservations.

I know what it means to get bad vibes
and I get bad vibes
if you doubt my abilities,
if you doubt I am the author of my words.
I need you to believe in me,
or I might lose faith in myself.
I need you to send me
messages of encouragement
so I can keep up my mental state.

I will try not to disappoint you,
I will try to show you who I am.
But believe in me
and I have a better chance to do so.

ANDREW BLOOMFIELD

Written April 4, 2012

Quoted by permission

Written by Chris Beesley, Parent

How Life Changes

When our son, Mitchell was born, he was our first child. Like most new parents, we felt very excited, mixed with a little fear, a dash of uncertainty, and a whole lot of love and anticipation for a wonderful future.

When he was diagnosed with an intellectual disability two days after his second birthday, it felt like we lost the son we had. He was still the same amazing toddler, but we mourned the loss of hopes and dreams we had for him. Suddenly, the medical professionals and later, the education system told us everything he would never do or experience. Our vision for his life went from “the sky’s the limit” to what special education, day programs, and group homes he might eventually access. Like many families, we only knew what we were being told. Nobody offered us anything related to hope or a vision for a good life in the community.

Even though we didn’t have a clear vision for Mitchell, something didn’t seem right about what was being offered. We didn’t know what it was exactly, but we knew we hadn’t found it yet. That changed when our family had the opportunity to attend a Family Leadership series. There, we were given permission to dream again. We were taught the value of relationships and community and the importance of solid values. These became the rebuilding blocks of a vision for Mitchell’s life that he and those around him could hold and support.

Mitchell is very clear about what’s important in his life: family, a few good friends, music, trucks and tractors, horses, and a job. Oh, and pizza and meatball subs.

Sometimes, it’s challenging to hold this vision. Over the years, people have come and gone; some more supportive than others. It’s challenging to administer another adult’s life, managing his money and support. Luckily, Mitchell has a sibling and one of his support workers who have both taken on some of this responsibility. This will never end and will always need to be managed. We worry about who will step up to coordinate the plan and hold the vision when we can no longer do so, but we gain hope, knowing who the people in his life are.

Along this journey, we were fortunate to connect with some other like-minded families. Our small Family Network meets monthly to compare notes and support one another so that each of our adult kids’ plans remain appropriate and relevant. We have combined resources to contract with a Family Coordinator who knows our adult kids well, helps recruit supporters, facilitates values-based conversations, and helps each person connect to valued roles within our community based on that person's vision of what they want to do and who they want to be.

What does Mitchell's life look like day-to-day? He lives at home with us and his one sibling. He has different support workers with him on different days. They support him in doing things he is interested in and explore new experiences. He goes to a local gym several times a week, where there's a community of people who know him well and would miss him if he did not show up. He has a small business, going to local farms to collect free-range chicken eggs and sells them to his customers in our neighbourhood every 2 weeks. He makes a dollar a dozen and now understands he must work to earn money. One day soon, we will plan a new living arrangement everyone will be happy with – him most of all.

Thirty years later, we still feel many of the same feelings as when Mitchell was born: lots of excitement, a little fear and uncertainty, and a lot of love and anticipation for a great life. He's on a path of experience and exploration.

While Mitchell's future is bright, it's not guaranteed. He will always need support and supportive people in his life. He has a tight circle of family and friends who are there for him, but that will need nurturing his whole life.

It turns out we want the same things for Mitchell as we do for our other child: to love and be loved, to have supportive friends and family, and to take their place in society in a way that allows them to realize their potential and explore their passions. He'll need more, or at least different, support than our other child to achieve it. But that's okay; he's worth it.

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 family member with a disability. ____

____

List ten words to describe a typical day for your family member, in the best of all possible worlds.

____

____

Use some key words to describe your fears for your family member after you're gone. _______________

____

What is the most important message you want to leave your family member with a disability?_________

____

____

What do you want your other family members 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 know about your family member with a disability?

1. ____

2. ____

3. ____

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

____

____

____

How do you want to be remembered by your family members? ______________________________

____

____

____

Worksheet 2

A family portrait

Use this worksheet to develop a portrait of your family member with a disability as it will be an important record to pass to your remaining family members. It may be helpful to date this worksheet so you can re-visit and update on an annual basis or after any big life changes that impact your family member.

Health

List names and contact details of current doctors, specialists, and all health practitioners involved in the care of your family member with a disability (ie. dental, orthotics, physio, occupational, ABA therapy, vision/hearing related, massage, feeding tube, ostomy care, etc).

____

____

List all current health concerns: ____

____

List all current health treatments: ____

____

List all other health related concerns / treatments / annual checkups or appointments: ____________

____

List all current medication(s) and prescribing doctor(s) contact information: ____________________

____

Briefly describe key features of medical history: ____

Education, work and volunteering

List current educational and/or work and/or volunteer activity and details, and who else is involved:

____

____

What are your family member's future dreams in this area? ______________________________

____

Are there other possibilities in this area they would like to explore? ________________________

____

What are some highlights from your family member'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 family member had or still has a close connection with?

____

What are some highlights of your family member's work or volunteer experience?

What did they like about it? What didn't they like about it?______________________________

____

____

Housing

Describe your family members' current living arrangements: ______________________________________

____

What are some future housing options/possibilities for your family member? _______________________

____

Are there currently plans in place for future housing options, and if so, who is involved and aware of these plans? ____

____

Summarize any previous living arrangements, if they existed: _____________________________________

____

What did your family member like about their previous experience or dislike? _______________________

____

Who are the people who had a significant relationship with your family member in these previous living arrangements and could they be helpful with future planning? ____________________________________

____

Leisure and recreation

List current social, recreational, cultural, artistic, and athletic activities: ____________________________

____

____

What are your family member’s interests and preferred activities in these areas? ______________

____

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

____

List important people who are involved with your family member at any activities you have listed:

____

Personal

Describe the day-to-day life of your family member with a disability. What does their week look like?

____

____

How would you describe your family member’s beliefs and values? _________________________

____

What cultural customs and traditions are important in your family? __________________________

____

How does your family member with a disability participate in these? ________________________

____

Is spiritual and religious worship important for your family member? Is this an area that could be explored? ____

____

What are the significant events, markers or milestones in your family member’s life? ________________

____

____

What brings comfort and peace to your family member?______________________________________

____

____

Who has been your family member’s greatest source of emotional support? ______________________

____

____

Who are the most significant people in their life? ____

____

____

Who do they see on a regular and on-going basis? ____

____

____

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 family member 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,

____