step 7

securing your plan

Before my stroke, I had the 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

step 7

Securing Your Plan

Achieving a good life and a secure future for your family member requires careful attention to a few key elements:

- A vision with as much detail as your family can manage, with the family member supported always at the center
- A network of caring, committed family, friends and community members
- A house that is a home
- Trusted Circle of Support, made up of both natural support and paid support, to assist with decision-making and advocacy
- A properly drawn and executed Will
- A solid financial strategy, which may include the Disability Tax Credit, an RDSP, and a Henson trust

This is a long list to add to an already busy life.

We would understand if, after first reading Safe and Secure, you thought it is too much. Let's be clear. First, it is too much for one person or one family to do on their own. Second, you don't have to do everything at once. Most families have put their plans together over a number of years. Thirdly, trust other families in similar circumstances. Initially, this may feel daunting, but the peace and security it offers once put together offers a tremendous amount of relief.

There is strength in families helping families. Families have acknowledged that one of the greatest sources for inspiration and guidance has been other families. Family leadership and collaboration has been a hallmark of the inclusion movement in Ontario and across Canada. The parent movement was a catalyst for change, advocating for de-institutionalization, and that movement elevated the dignity and choice of people who have a disability. There is an energy felt when families get together. Families can support one another and realize they are not alone. They gain not only knowledge and expertise but also recognize their contributions, which can support others.

The nature of the disability does not have to match since there seems to be a common bond among families, no matter the diagnosis. Sharing moments of excitement over victories, like a child saying their first word years later than typical peers or finally learning how to tie a shoe, is just one of the advantages of being connected to other families who really understand. Other families can see the value in these moments and share in them. These connections may also help with the relationship that exists between family members and the person being supported. Sometimes, when we learn about a behavior or struggle others are experiencing in their family, it helps us understand it better and be more patient. Siblings, grandparents and other supporting family members can become involved and gain connections to others who hold similar relationships, in ways they may not have experienced before. Relationships can grow in ways that were not expected. Connections can be surprising and often develop in ways we might not have expected during the planning process.

> There is no greater disability in society, than the inability to see a person as more.
>
> ROBERT M. HENSEL

My Community: Join Hands Lift hearts

My Communities are my life Song.

It's how I grow truly strong
Because In their presence, I connect and belong.

Through my mental and physical health
My Communities give me such wealth
No. It won't cost society a cent
Because my friends,
My many Communities take care of me in every sense.
They are my safety and support
My closest rapport
Everyone's different in my Community.
We work on common goals, together we navigate the loopholes
Society tries to control.

They influence me to stay accountable.
It's takes
A couple
To keep each other out of trouble.

My communities remind me I am part of a bigger picture.

That's the kicker,
Communities sharing Ideas together
and that bring hopes that flicker
A new spark
Hope always lingers.
Experiences of
Acceptance whispers,
You
Are a winner.
Awareness in learning
A longing, a yearning
Like sponge soaking knowledge
To Encourage such courage
To live on my own
I have surely grown.
Bring on the opportunities
That comes with having Communities.

JUDY NOONAN
Written December 2024

Written by Sherron Grant, Parent, Co-founder of Sawubona

I See You

When my son was first diagnosed with autism, at the age of 4, my world went spinning. Even prior to receiving the official diagnosis, I explored the World Wide Web, as I referred to it then, to learn more as my mommy senses told me that something just wasn't right. At the time, in 2000, the projected outcomes for my son were not good: Institutionalization, unemployment, no hope for any type of independence. This was the messaging coming at me like a speeding truck. My son was the first in our family to be living with a developmental disability.

As I continued to read, attend parent/caregiver groups, workshops and social events, I felt invisible, alone, an anomaly. You see, I identify as a Black woman. My son, now a Black man. Yet in all of the circles that I was in, the articles I read and the visuals that accompanied them, I saw no one that looked like me or my son. So what chance did my son have to be included and valued if the messaging seemed to communicate that people like him don't exist? And if you don't exist, do you matter?

As I slowly met other Black caregivers, we realized that it was time to create a group that would affirm our existence and value, and the hopes and dreams that we have for our loved-one living with a disability.

When my husband and I set out to connect with other Black parents/caregivers, we envisioned some small get-togethers in our homes over a meal, with the opportunity to learn from one another, laugh together, at times, commiserate, while coming up with solutions and ideas to follow up with. The goal? -- to no longer feel so alone, isolated and at a loss on this very bumpy ride.

In 2019 when my husband and I were considering starting a group, little did we know what the year 2020 would look like: the COVID-19 pandemic that saw us all restricted in our movement; the very public and traumatic murder of an African American man - George Floyd, whose name, before this moment, would mean nothing to anyone outside of his friends and family. Sadly, he became the face of a movement. The year 2020 would also mark the time when Canadians witnessed the uncovering of the remains of hundreds of children, victims of Canada's Residential Schools system. A racial awakening was born.

When we set out to establish this new group, little did we know how quickly the concept would be embraced for a safe space for Black families to discuss the issue of "race" and disability. At our first virtual meeting, we had over 40 families participate. Families from around the globe started reaching out to us expressing a range of emotions in being connected to such a space, one that was long overdue in their minds. This is how Sawubona Africentric Circle of Support was born.

Sawubona, pronounced sow:'bɔh:nah, not sah:woo:boh:na, is a Zulu or South African greeting that means “I see you.” It’s more than just a polite phrase – it’s about recognizing the worth and dignity of each person. Originally known as the Black Parent Support Group, as we grew, we wanted a name that represented our values and would grow with us as we continue to serve our 250+ community members. We chose the name Sawubona Africentric Circle of Support because we want our families and those we support to know that if they don’t feel “seen” in other spaces, WE see them. Everything we do is through an African/Afrocentric lens.

There has been harm and trauma experienced by Black families as a direct result of oppressive practices, whether intentional or not. We must work together to acknowledge these harmful practices and do better by these families and their disabled loved ones.

Families who have never been a part of a Family Support Network join us and express their joy in finding us. Those who are a part of other FSNs include us as another resource that meets a specific need along their journey. Wherever Sawubona fits, if it helps, then it’s all good.

Family Support Groups

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

MARILYN DOLMAGE

Family Support Groups, also known as Family Networks, can play a vital role in empowering families as they navigate the challenges of supporting a family member who has a disability. Research indicates that the effects of belonging to a parent-led parent support group are substantial. When you are a part of these parent-led groups, it fosters a strong sense of community. Members thrive by sharing experiences, building connections, and gaining valuable insights to tackle everyday challenges. The positive impact of these supportive networks cannot be overstated, as they not only reduce stress but also create resilience and optimism among families. They can create a welcoming space where everyone can flourish. Specifically, parents gain increased skills, an increased sense of power and a sense of belonging. Participants are able to connect with each other and provide support and skills to deal with day-to-day issues. Canchild (n.d.)

Family Networks provide a safe place for your family to ask questions, share information and gain knowledge and tools required to create a good life rooted in community. Here are some things to remember:

1. Know that it might take a while to find the right Family Network and build a connection or bond. You need to trust that the right group is out there for you. Don’t give up if the first group you try doesn’t feel right to you or your family.
2. Take time to reflect and see if what you need at this moment is what you are getting from being part of the group.
3. Be aware that as your family member matures and changes, your own needs may change too. Think about what age and stage your family member is at and what age and stage you are at. Families who are supporting someone over 21 years old and finished school have very different objectives than a newly diagnosed, younger family. If you outgrow a group, it’s okay to explore others.
4. Make sure the group resonates with you and your core values. Perhaps you may feel the need to belong to more than one network to meet your various needs.

Families share that they know they have found the right place when others in the room can finish their sentence–they “get it” in a way that others, while being supportive, just don’t.

The confidence and encouragement gained by involvement has led to enlightened changes in many families. These Networks, and the strength they provide to people, have enabled families to think about the future in a new way.

Reach out to a local Family Network

Finding a Family Network that is a good fit is well worth the effort. There are various ways to find the right one and we have provided some ideas to guide you.

- The Partners for Planning website has a Family Networks Directory that lists Family Networks that are accepting new families.
- Your family may also connect with local organizations associated with the specific disability that is impacting your family.
- Look for events you can attend where other families will be present.
- Sign up for various e-newsletters within the developmental sector. Not only will this help you stay current but will also inform you of events that might be happening.
- Is there a conference where you could meet others who might be further along the path and can offer advice or guidance? They might meet online or be held in-person, so you might try and locate one that is geographically close to home.
- Family Networks may be anchored by various cultures, linguistics or could be faith-based.
- Some groups might have a specific purpose, such as advocacy, or a focus on education for younger families or on housing for families who are supporting a family member who is older.

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

EMILY CARR

Written by Sharon Bak, President of Thunder Bay Family Network

The Story of Thunder Bay Family Network

Thunder Bay Family Network (TBFN) has collaborated with various groups over the years. Prior to TBFN's start, the City of Thunder Bay was already known nationally as a leader in moving toward individualized (or direct) funding. The Ministry of Community and Social Services (MCSS) created a pilot project in Thunder Bay called Choices. This pilot project was intended to show the benefits of individual or direct funding for individuals with a developmental disability. Essentially it was staff from various agencies who acted as facilitators for some families to help them with planning. It was TBFN's first foray into the whole piece of direct funding and facilitation at a family level.

Although the Choices pilot ended in 1999, it concluded with a Workshop. This event focused on an individualized funding approach and brought together people receiving support, families, service providers, and the Ministry of Community and Social Services. It was at this event that a gap in family networking was clearly identified.

Over the next several years, a select group of families met to determine their focus and direction. Between 1999 and 2006, partnerships and collaborations were pivotal to TBFN's work. We assisted with the Special Services at Home (SSAH) Family Network Project, which was a two-year pilot project funded by MCSS through a local respite service agency called Wesway.

As the small group of families continued to meet, they began to articulate what an organization with family values and ideals might look like. Lifetime Circles was another group in Thunder Bay that had many of the same members on it, and they were following the PLAN model out of BC, in that you would do a membership and then the group would support building a Circle of Support and sustaining it. Lifetime Circles Inc. had received their charitable status in 2002 and was developed by families to assure a safe and secure life for their loved ones. At around the same time, a parent group formed to raise awareness of the value of building Circles of Support.

TBFN and Lifetime Circles agreed to come together to form one organization and was successful in obtaining grant funding. This funding was used to conduct a project to establish support network systems for individuals with unique support needs and their families that is family focused, community-based and independent of agencies. On July 9, 2010, TBFN received their letter's patent and incorporated as a Board. That same year they also obtained charitable status.

Since that time, TBFN has been instrumental in presenting various workshops of interest to families, creating networking and peer-to-peer opportunities. They also engage in various advocacy efforts aimed at ensuring the voices of loved ones and families are at the forefront of decisions affecting them. Having evolved from a small group of concerned family members, its growth in the fibre of the community has been substantial and partnerships with local groups and agencies continue to remain strong. A focus on future planning, independent facilitation, peer-to-peer connections, supporting the building of Circles of Support, and retaining autonomy as a network is the focus of TBFN moving forward.

All throughout TBFN's history, the commitment to grassroots, family-driven support has remained. In 2022, the Board took on the task of a major restructuring, which included a new logo, an updated mission statement, and developing a core list of values that will guide them forward in all decisions and actions. Despite the challenges of the COVID-19 pandemic, which greatly impacted the important in-person connections that are so vital to building relationships, TBFN was able to pivot, be creative, and sustain the network through those difficult days. Since then, incredible work by the staff and Board of Directors has paved the way for ensuring a sustainable and strong Thunder Bay Family Network will continue well into the future!

Not every family is the same, and that's true with Family Networks. You need to find one where you fit, and your family is understood. Think about your family goals and what kind of support you are looking for. The phase of life your family member is at should also be a determining factor as to what Family Network best suits your needs. Take the time to reflect on what it is your family member needs, what you are looking for, and carefully consider the various options available to find the best fit.

Families as Social Innovators

Families are the original social innovators. Families don't quit—they keep moving forward. The commitment to their family member can reach beyond the boundaries of any job description, office hours, strategic plans, funding, and political priorities. Families like yours build creativity over time. Breakthroughs are sometimes the result of failures and continuous attempts to make things better. Resources may be limited, so families learn how make creative use of whatever they have.

> No amount of thought can ever reveal what comes unexpectedly.
>
> ARTHUR ERICKSON

Families are some of the best problem solvers around. In Al Etmansi's book on social innovation, Impact – *Six Patterns to Spread and Share Your Social innovation*, he refers to families as 'passionate amateurs.'

Passionate amateurs innovate for two reasons: Love and necessity. Love for their family member. Necessity because if they don't do something about the challenge that their family member faces, no one else will.

Fortunately, families are used to turning adversity around. You can become confident, and the natural creativity of families like yours can lead to new solutions for change that happen over time. Not a day goes by that people who support a family member who has a disability aren't figuring out a better way to do something. Families that are similar to yours are some of the best problem solvers around.

Written by Katie MacDonald, Sibling

The Sibling Perspective

It wasn't until my early 30s that I started to realize that I was a caregiver, even though I had been a sibling caregiver for my whole life. Growing up, he was always just my brother who we all loved, and that meant we supported him in certain ways. As I moved into adulthood, though, I became more aware of how much of my identity and decisions were influenced by the caregiving role I played for my brother. It felt very disorienting and a bit isolating, but it also motivated me to find other siblings to connect with. I feel very fortunate to have gotten connected with a non-profit sibling group that offered opportunities for group social connection, peer mentoring and therapy programs. Within this group, I found lots of space and acceptance to be myself, and to share my experiences, including my hopes and dreams. I learned much from hearing others' experiences and exchanging ideas and resources. Now, when I get a chance to connect with younger siblings, I encourage them to get involved with sibling or young caregiver groups. I am hopeful that early identification and support will help with managing some of the challenges that can come with caregiving from a young age.

Since connecting to the sibling group, I have become involved in running programs and supporting research initiatives that support siblings and/or young caregivers. It gives me a boost to see important caregiver issues affecting sibling caregivers being brought to light through the advocacy work done by provincial and national organizations. It makes me hopeful that although there is still much work to be done to support our siblings and their needs, plus our own caregiving needs, that there is a growing awareness and momentum building. I hope this means that within our lifetime, both my brother and I get to live in a society that values both of our roles and provides the right kind of support for us to both thrive as individuals and as a family.

Advocacy is a way to achieve a goal—a way to get us where we want to go. Families have been the driving force behind incredible progress in the field of advocacy and disability rights for many years, passionately addressing the needs of their family members. Their unwavering commitment and advocacy have transformed lives and fostered a more inclusive, compassionate society. It was families pushing governments and organizations to get invested and work together to close large government run institutions built for people with intellectual disabilities. Family Networks have been established across Ontario by families so they can exchange knowledge and support one another. Most hospitals and health care organizations have Patient and Family Advisory Committees to ensure health care puts people who need care first. Families have pushed for more integration in every aspect of life: employment, education, community involvement, housing and much more.

Conclusion

> Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.
>
> FRANCIS OF ASSISI

As you have worked your way through Safe and Secure, you may have noticed that each step builds on the last one. Each one on its own advances the opportunity for greater safety and a better life. The sections are thoughtfully connected and when taken together, they can offer a complete system of checks and balances. They may not be flawless, but they are thorough. They are what is needed to move ahead. It is crucial to redefine your family roles, to have effective planning and ensure continuity. This book becomes an invaluable resource that can be followed from one generation to the next. It can clearly hold detailed wishes, that focus on the best interests of the supported family member, focused on their input and contributions.

No one, not even those who have been involved in future planning work for decades, is ever satisfied with their final product. There will always be editing, adjusting and accommodations. That's natural. The difference is that your family will be amending a plan that is already in place. The hard work will already have been done, and the foundational pieces will have been covered; the heavy lifting completed.

We can assure your family that the results from planning, together, will lead to more peace of mind.

Safe and Secure is a book for families. We have supplied information, inspiration and stories. We are confident your family will find its own path. Your family will make decisions together and follow them, at times with doubts and at other times, fearlessly. You will go where your family member, heart and knowledge tell you to go. At the end you will have created your family plan, and know that this is a living, changing and ongoing blueprint. In your hands, it will flourish and grow and be adjusted when it needs to be. It will become a place of security and thoughtfulness.

Safe and Secure has supplied information and asked questions....
You supply the love and answers.

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, it's already written. There is nothing left to say. Now it's time for you and your family member to write the next chapter, together.

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