step 6

advocating with empathy

When we support one another,
we are stronger.
When we talk about our
experience, we find meaning.
When we reflect on the meaning of our
shared experience, we form a movement.
When we realize that we are a
movement, we know we are
not alone and that we are powerful.
When we feel powerful,
we can carry on taking care.

DONNA THOMSON

Written by Farrah, Self Advocate

My Journey to Advocacy

I had a strong desire to become a self-advocate based on my personal journey. I realized that if I was facing these challenges, others with similar disabilities were likely experiencing them too, but without the courage or access to the resources needed to obtain the services available to them. This support could empower them to advocate for themselves and others in similar situations.

Organizations that assisted me in my Advocacy:

I was already connected to organizations that cater to people with disabilities so I looked on their websites such as Holland Bloorview, CAMH and University Health Network. I joined the youth advisory at Holland Bloorview until I was no longer in the age group. I then joined the patient partner group at University Health Network. I also saw a group at CAMH called the Self Advocacy group so I joined that as well. I share my lived experience plus I review documents to ensure they are written in plain language.

Next, my specialist from Surrey Place Center asked me if I would be interested in joining the Surrey Place Self Advocacy group so I gave it a shot and joined that group too.

In 2021 when I found out about Community Living Toronto (CLTO) from my peer buddy from the local Best Buddies chapter, I took it upon myself to research the organization. In June of that year I attended the CLTO Scarborough Regional Council meeting for the first time. A few weeks later I got a call from them, asking me if I wanted to be a part of a working project called influencers. Of course I said yes! Today the group has 10 influencers and we all advocate for different causes close to our hearts.

As part of my role at Community Living Toronto, I gave speeches for their 75-year anniversary launch breakfast, and I represent the influencers both internally and at various local events.

One day, I was surfing the Community Living Ontario website when I came across a group called the Self Advocate Council. I ran for council in 2022 and won a two-year seat. In the fall of 2024, I ran again and once more won a two-year seat.

Social media has helped me since I was in my twenties. I joined Facebook, and I'm still in many groups for both parents and people in the disability field. One day, I came across a group called Disability Collation, and I messaged the parent lead to get involved. I was invited to speak at rallies about my lived experience and gave several talks at Queen's Park to various politicians. This all began in 2018.

Participating in advocacy roles has given me great satisfaction and a sense of accomplishment, knowing that I am advocating for a better life for myself and other Ontarians with disabilities.

Steps in my Advocacy:

Networking

Social Media

Organizations in my community

Research causes that I am passionate about

step 6

Advocating with Empathy

It is true that most people with disabilities may require the services and supports of paid staff. Actually, it is true for all of us. We rely on the services of dentists, health care professionals, accountants, computer technicians or car mechanics. We may secure a cleaning service for our family or hire a home care service for ageing parents.

Depending on the situation, your family member who has a disability may be able to choose which services they receive, or they may have little choice. They may not have the power to change things if they are not satisfied. It's important to remember that our family members' life can be impacted by the services they receive, which can determine how they pursue dreams, be with friends or contribute to the world around them.

If services and programs are essential for people with disabilities, so is keeping them in perspective. Programs and services can be a way to get what your family member needs. And the need is unique to each person. Their lives should unfold according to their personalities and interests, rather than the priorities of service providers, support workers or programs.

This step discusses:

- Ensuring services support rather than displace a good life for people with disabilities
- Creating an effective working partnership with social, health, and education professionals
- Three types of relationship-based advocacy: self-advocacy, personal advocacy and public advocacy.

> Nothing happens
> until
> something moves.
>
> ALBERT EINSTEIN

Supporting not displacing a good life

We’ve seen it happen before. An innovation is launched that is intended to make life better. Then, before we know it, the innovation starts to control our lives. Some would say that’s true of smart phones. These seemingly harmless devices have worked themselves into every aspect of our lives—at dinner time, during conversations, even while driving. It requires discipline to lessen the impact of any technology whether it is a communication technology or a social technology.

After the Second World War, families in many parts of the world came to the same conclusion—that it was natural and preferable for their family members with disabilities to live in the community with them rather than in institutions. One of their big challenges was the lack of community services. All the funding was going to provide institutional care.

Families rolled up their sleeves and developed the needed supports themselves. They took over church basements, used discarded textbooks, raised funds to cover costs and started their own schools and other programs. Over time they were able to hire staff. From there, many programs and organizations evolved.

> Much of the current service structure for persons with developmental disabilities can be traced back to the efforts of parents in the 1950s and early 1960s. Associations for Community Living (ACLs) were among the primary advocacy groups to lobby for community-based services and to speak out about the welfare of people still living in institutions. In what came to be called the community living movement, these groups worked for the closure of institutions for people labelled as developmentally disabled.
> (Pedlar et al., 1999, p.15-16).
>
> In the 1970s and 1980s, many people who might once have been placed in institutions started to live in the community. Here the range of services that had previously been provided by a single institution was more dispersed. The potential existed for people and families to have more control over their services and to become actively involved in community life.

But here's the issue. While great programs have been developed, they might have gone too far in another direction. The presence of these services is so widespread that, unless families are careful, they will overshadow everything else about the person who has a disability. The people being supported must fight to be seen as human beings with unique and varied needs rather than as objects of service. Without the presence of families or family members with disabilities involved in the design of programs and services, this can make service delivery irrelevant to those who are meant to be supported.

> This is for
> the ones who
> will continue
> to push until
> every barrier falls…
> Equality sprouts
> from the
> branch of equity.
> Independence is
> the flower that
> grows from access.
> Freedom is rooted
> in the soil
> of advocacy
>
> LE DERICK HORNE

Despite their benefits and best of intentions, community services and programs, like our smartphones, have unintended consequences. Too often, disability may be equated with needing services and not much else. The average person might develop the impression that you must be trained to have a relationship with a person who has a disability. This becomes a barrier to developing friendships. As a result, people become isolated inside the service delivery system. And worst of all, people with disabilities and their families begin to think that services are 'all there is.'

These are some of the reasons why families should stop asking the question: 'What kind of program and service do we need?' This question always leads to more service and program solutions. Instead, start to ask: 'What's a good life?' This question can provide answers that have very little to do with services and programs.

The ingredients of a good life are the same elements of the Person-Directed Plan and Vision discussed in Step One (a network of caring friends and family, a place of one's own, support to make decisions, a life of meaning, and financial security.) Take a moment to revisit Step One and your answers to the Worksheets. That vision is your North Star. That vision illuminates the destination for you and your family member. That vision will help determine where services can help and where they can hinder.

Ted’s tips for Monitoring and Advocacy

By: Ted Kuntz, Former PLAN President and Parent with lived experience

TRUST IN THE CARE OF OTHERS

One of the greatest challenges of parents of a vulnerable individual is to trust that others can love and care for our relative as richly as we do. I’ve discovered over the years that many people have ‘fallen in love’ with my son, Josh I can see how their faces light up when they see him and the joy he brings. It’s best for us to allow others in when we are still around, so we can monitor and assist with the transition to the care being provided by others.

HOLDING ON IN A DIFFERENT WAY

Letting go of the care of our loved one is challenging. Many years ago, we offered a workshop called ‘Letting Go.’ It was intended for senior parents who need to transition the care of their child to others. No one attended. When we inquired as to why families didn’t attend, they responded that they couldn’t let go. When we re-titled the workshop to ‘Holding On in a Different Way,’ families came. The fact is, we never really let go while we are still alive, but we need to hold on in a different way, a way that allows others to care for our relative too.

INVITE OTHERS TO HELP WITH MONITORING

Extended family, friends, and network members can provide another perspective on whether our relatives are well cared for. What do they see? What clues or behaviours are they noticing? Sometimes our extended family and friends can see more clearly than we can. I’ve learned that collective wisdom is richer than individual wisdom.

HOW DOES JOSH RESPOND?

I’ve learned to trust Josh’s response to those I’ve entrusted to care for him. Is he glad to see them? Does he smile? Does he reach out and invite them to hold his hand or sit beside him? While his verbal skills are limited, his body language speaks volumes. Josh also has an uncontrolled seizure disorder. I’ve discovered that when he is well cared for, well nourished, sleeps well, and is relaxed, his seizures are less frequent. For Josh, the rate of seizing is a good indicator of whether he is happy and healthy.

WOULD I BE HAPPY?

One of the most basic questions I ask when I'm evaluating the quality of care being provided by others is to ask – 'Would I be happy here?' and 'Would I want to live here?' I've witnessed living arrangements that are essentially small institutions. There is nothing to indicate this is someone's home. And I've witnessed living arrangements that truly feel like a home—a sanctuary that is warm, personal and inviting. If we wouldn't be happy in a 'care facility,' then it's not likely our relative would be happy there either.

PEOPLE ARE DOING THE BEST THEY CAN WITH WHAT THEY KNOW:

I trust that caregivers are doing the best they can with what they know. Everyone wants to do a good job. And I've also learned that most of us have lived in communities that, until recently, segregated people with disabilities. Consequently, many people don't know how to be in relationship with our relatives who has a disability. I see that I have a role to play in inviting them into a relationship with my son and teaching them that his needs aren't 'special' at all. That he has the same needs as you and I—to be loved, cared for, have his choices honoured, security and safety, and dignity. I also learned that different resources have different strengths and limitations, and my job is to find those who are the best fit for my son.

Developing a partnership with the service delivery system (schools, service provider agencies and government funders)

We can recognize the role of service providers as one piece of the puzzle. Services are one tool in creating a good life. A Circle of Support is another. The key is to understand what each tool can do and what it can't do.

For example, Circles can tap into the hospitality and goodwill of the community.

- Services rely on a regulated system of trained staff.
- Circles take their cue from the passion and interests of the supported person.
- Services focus on needs.
- Circles are flexible. They can arrange hockey games one week, a birthday party or coffee outing the next.
- Services are based on standards and routines.
- Circles explore possibilities.
- Services strive for predictability.

Don't look back.
Don't say
you're sorry.
Let them hear
your noise.

NELLIE MCCLUNG
(PIONEER
CANADIAN
FEMINIST)

Circles of Support thrive and can be left to engage in the work they are best at, when services fill their role. Ideally, paid and unpaid support can be working together.

The best approach to maintain the quality of the programs and services our family members use, is to develop an authentic partnership with the providers. John O'Brien and Beth Mount, long-time advocates and thought leaders, tell us that partnerships are good when they can be individualized, are co-creative and deal openly with inequalities and competing values (2015). There is the possibility to imagine and work together on solutions that can move outside the usual boundaries of service provision and away from one-size fits all thinking.

People alongside their families and Circles of Support have been and can continue to be social innovators. Families and service providers can help imagine how their work can fit into a person's good life. Nurturing those positive relationships allows us to move towards more creative and thoughtfully designed supports. Advocacy, when necessary and done well, can help create these genuine partnerships and elevate the expectations of what's possible on all sides.

Relationship-based advocacy

Advocacy is part of life, for people with disabilities, their families, friends and networks. Social, educational and health services are human creations may not always be perfect for our family members There is often a gap between what people want and what service providers, funders and government and schools offer. Things can and do fall apart. Government funding is not always sufficient or allocated to the right priorities. A remedy must be sought. A solution must be advocated for.

Families are often called upon to support their family member in various ways. They might need to advocate for a change or improvement in a service, school setting, or for new funding for example. Relationship-based advocacy has two objectives:

1. Pursuing solutions while
2. Strengthening relationships with those who work inside various systems.

Where 'relationship-based' advocates differ most from traditional advocates is their focus on 'means' as well as 'ends.' This means they want results, but they also want to improve relationships with all the people involved along the way, to attract new allies, and to build the base that will help to resolve the next set of challenges. They create the conditions for joint problem-solving. They can approach a potential partner with a collaborative mindset. They practice civility and respect, addressing the problem and not the character of the supported person.

Mindset is everything! The way a family thinks can really shape a journey towards success. There is a danger that anger may undermine effectiveness. Using all your energy to explain why you are right leaves little room to pursue solutions. Instead of working together, families spend time defending a vision that might need adjusting or presented in a new way.

Absolute certainty can also limit our vision; by locking ourselves into one way of thinking, we might miss out on creative alternatives. It's essential to approach discussions with an open heart—questions from others can be opportunities for growth, not threats. Try to remember that it's important to avoid blaming those who challenge us or who can't help. Embracing differing viewpoints can lead to teamwork and innovation!

Most people support a relationship-based model of advocacy since relationships are essential for a good life. Relationships hold significant value. There is practical merit in this advocacy approach. The reality is that many people we encounter in the 'ecosystem' of our lives will be individuals we meet repeatedly.

Three Types of Advocacy

1. SELF-ADVOCACY

There is no substitute for speaking up or communicating for yourself. People with disabilities describe this as self-advocacy. In Step Four of this book, we discussed a variety of ways to support people with disabilities to make decisions. One of the key areas of decision-making is knowing what to do when something is wrong or doesn't feel right. In other words, finding your voice, learning to say 'no,' learning to complain and learning to ask for help.

First, we must make sure that people with disabilities are present when discussions and decisions affecting them take place.

A popular saying among self-advocates and their families is; 'Nothing About Us Without Us.' originated from the People First Movement.

This phrase has two important meanings: presence and participation. First, we must make sure that people with disabilities are present when discussions and decisions affecting them take place. Even in circumstances when the person doesn't communicate or interact in traditional ways, their very presence changes the conversation. It reminds people they are making decisions that will affect the lives of others and to be careful about making assumptions.

The second meaning of the phrase is more obvious. It is critical to ensure the active involvement of people with disabilities in decisions that affect them. None of us likes a professional who tells us what to do without considering us first and asking us questions. It may take more time and greater thought to authentically support people to make decisions, but it is crucial that we do what is needed to make space for people to participate in the conversations that affect their own lives. Remember there are various forms of accessible communication available, such as live captioning, sign language interpretation, communication boards, video recordings or audio recordings of discussions, to ensure everyone is heard and participating.

Self-advocacy can be a challenging concept for some families. Some family members may feel it is our 'job' to speak up for our family member who has a disability when they are young, or we may need to protect them. As our family member gets older, we may want to continue to advocate for them. At the same time, they need to develop the confidence to become their own advocate, in their own way. Otherwise, their vulnerability may only increase when we are no longer around.

Self-advocacy can be nurtured by:

- Believing in a supported person's capacity to speak or communicate for themselves
- Practicing opportunities to make daily decisions and learn from mistakes
- Joining a self-advocacy group if our family member wants to do this
- High self-esteem and confidence
- A network of family and friends.

We need to strike a balance between our natural instincts to speak on behalf of our family member and their right to express themself.

There are a number of self-advocacy groups and plain language resources in Ontario. People First of Canada (https://www.peoplefirstofcanada.ca) is a nation-wide organization that has chapters across Canada. People can learn about their rights and responsibilities and how to speak up for themselves.

Written by Naiomy Ekanayke, Parent

Their Biggest Cheerleader

My husband and I were blessed with twin sons 17 years ago. At birth, one twin, Jason, had a heart conditions and underwent three surgeries. At age two, we noticed they didn't make eye contact, lacked speech and exhibited many behaviours. We took them to preschool speech and language classes and they asked us to see a psychologist. Six months later, they were diagnosed with autism, and our lives turned upside down.

As a mother, I sought support by registering with relevant organizations and attending early learning workshops. We enrolled them in many behaviour and speech therapy classes, but something was missing. We felt isolated from society and alone. At that time, I encountered Extend-a-Family, an organization focused on inclusion, and attended several workshops that expressed a vision of hope. Our sons were attending special classes but didn't have friends and showed no academic improvements. We approached many schools to get our sons into regular classes and they refused. With an Extend-a-Family coordinator, we asked if one of our sons could try a regular class. A Toronto Catholic District School Board (TCDSB) school allowed this for only our son Daniel and Jason went to their Special class. After six months we could see great improvements in speech, social skills and academics with Daniel. We noticed Jason always had an educational assistant holding his hands, even playing outside. When asking for Jason to move to a regular class, they said no, and asked our other son to be taken to the special class. After attending an IPRC meeting without my Extend-a-family coordinator, I was called a bad mother and they even threatened to call Children's Aid.

Brokenhearted about the school system, my husband and I decided to remove them from this school, and we looked at our neighbourhood school, for both sons in the regular class. The Principal was initially uncertain and noted a lack of support. However, after we discussed inclusion and shared examples from church camps, they agreed to place both of our sons in a regular class with withdrawal assistance. A year went by, with their behaviour's reducing and our sons making friends and improving in academics. They had an IEP and were slowly improving. Teachers and staff saw our vision and elementary school was a success.

Extend-a-Family helped us create friendship circles at school to strengthen the boys' friendships. We invited them to our home for playdates and gatherings, and we built genuine friendships that still last today.

When it was time for middle school the transition went well with support from school and friends. Jason and Daniel were in many activities outside of school.

They had church friends, Air Cadet friends and an art community where they painted and learned new skills. The boys were well known in their circles and during the pandemic, they stayed close with social media. We were able to get the boys their own YouTube channel and started a small business to sell paintings, books and cards to build up their influence in their local community. We attended many fairs, markets and events and displayed their work.

Then it was time for high school and since it was during the pandemic, the transition was different but a year and half passed without many hurdles. During their second year, the Principal changed and the new Principal didn't recognize inclusion, and he gave us a hard time. But we didn't give up. We attended each meeting, introducing our sons positively and highlighting their community involvement and the importance of regular high school classes. We always built relationships with school teachers and they believed in our sons. To influence the Principal, we needed to go to the superintendent to ask for assistance. Thankfully it worked and our sons are blooming in high school, and are part of their school community. Every student and teacher, and even the new Principal cheers for them. We had a dream and a vision for our sons that they would graduate with their peers and it's happening.

We look forward to them working and volunteering in the community and we know they add value and contribute to society.

We have a long way to go, but we know we came thus far all because of our prayers and having so many people support us. Both boys have become independent and confident youth. As a mother, I am very proud of them and will continue to advocate for them and be their biggest cheerleader.

2. PERSONAL ADVOCACY

Advocacy can be a combination of art and science. It improves with practice and learning. There are key approaches families can learn and use to help their family member. Advocacy can look differently from one person to another - even if someone is nonverbal. Being able to choose ‘yes’ or ‘no’ is still advocacy for themselves. You may believe your family member might not be able to advocate for themselves because they are not verbal, but we need to challenge this thinking, because all forms of communication can be a form of advocacy. Aside from the other types of advocacy discussed earlier in this step, here are some basic tips.

a) Don’t do it alone: Try to have at least one person who you take to meetings, takes notes, compares impressions and with whom you can share ideas. People who know your family member well make for the best advocates. They may not know all the details of service, or situation or-funding, but they are grounded in what is best for our family and will fight on their behalf. One of the biggest gifts we can provide is to teach some members of their Circle of Support everything we know about advocacy and provide an opportunity to learn about advocacy first-hand. Please take one or two of them with you if this possible. After all, you won’t be around forever.

b) Take a bite-sized chunk: Don’t bring a huge list and seek remedies for all your concerns at once. It is more effective when you make your request clear and concise and focused on your immediate task. Bringing multiple issues forward can help you bring attention to the work needed to be done. However, at the same time, depending on the situation or people involved, it might not help you achieve the goal that is needed most urgently or quickly. So, it might be more strategic to stick to a single or a few grouped issues, depending on the context. Stick to your most urgent issue(s). As difficult as it seems, try to keep emotion out of the discussion and focus on facts. If you can refer to specific dates and issues or the people involved in a simple yet documented way, it will reinforce how organized and intentional you are.

   One of the ways to help you stay focused is to practice writing your ‘ask’ in 25 words or less. Try to frame your request in positive, non-judgmental language but with a clear expectation of the action you expect.

I learned a long time ago the wisest thing I can do is be on my own side, be an advocate for myself and others like me.

MAYA ANGELOU

c) Keep your momentum: By definition, you are advocating for something that government, schools, programs or service providers don't want to give, don't know how to give, or haven't thought about. Otherwise, you wouldn't need to advocate! You may not get a positive response the first time. That doesn't mean it is hopeless. Far from it. In fact, when it seems the most hopeless things might start to turn around. Systems, institutions and big organizations take longer to change course or change their minds than individuals or small groups do. Set yourself a goal of initiating one or two actions every week in support of your advocacy goal; for example, make a phone call, follow up on a meeting, send an interesting study you have just come across. If you remain thoughtful and helpful, you will eventually expand your team to include champions inside a system who will become your internal advocates. Typically, no one will care as much as you do, so keep track of your progress and note the details.

d) Organization and record keeping: Keep a journal or notebook or Word file – whatever works for you. If you can say "I previously called and spoke to Jane Doe on April 10" it will be better received than saying "I don't know... I called a while ago and spoke to someone." Notes will also help you with who to speak to next and when to follow up. Don't assume people will get back to you, or if they say they will, ask for a date. Ask if you can contact them if you don't hear back by that date. Part of being an effective advocate is being organized. Simply asking, "What's next?" at the end of a meeting or discussion can help manage expectations and ensure people are on the same page.

Effective Advocate

An effective advocate is someone who:

- Knows your family member well

- Has good problem-solving and negotiating skills

- Is self-confident and willing to be polite but assertive

- Neither seeks out conflict nor shies away from it

3. PUBLIC POLICY ADVOCACY

If you are advocating for your own interests or those of a family member, you can gain power by drawing more people into your advocacy network. This can include people from your own personal networks, co-workers and colleagues, people who are experiencing situations that are like yours, and political representatives.

While some people get nervous about the idea of political and policy advocacy, it can be very important in supporting a good quality of life. It can also help increase attention to problems that are being overlooked. We like this definition from the International Centre for Policy Advocacy:

> “Policy advocacy is the process of negotiating and mediating a dialogue through which influential networks, opinion leaders, and ultimately, decision makers take ownership of your ideas, evidence, and proposals, and subsequently act upon them” (Young & Quinn, 2012).

Building on the ideas in this quote, families can identify and discuss the influential networks, leaders and decision-makers that you can talk to and partner with to (1) build knowledge and understanding about developmental disability, (2) influence people to act on your behalf, and (3) inspire larger-scale changes that will benefit many people with developmental disabilities and their families. So where can people find out about existing groups that are already advocating? This might involve asking a Family Network if anyone is involved in a public advocacy campaign, following nonprofits or organizations on social media, or reaching out to specific advocacy-based groups about how you can help.

There is nothing more powerful than groups of families working together to secure the well being of their relatives with a disability.

a) Self-advocate Network

There is a growing number of regional networks of people who identify as having a developmental disability in Ontario. This includes groups like New Vision Advocates in London, The A Team in Durham region, and the Council of Community Living Ontario.

The growth of self-advocate networks is proof of increasing strength and political advocacy among people who have a developmental disability, something that is also shown by the popularity of the annual Speaking Out conference in Port Elgin. You can get more information about this and the above-mentioned groups on the internet.

People can influence policy by coming together to communicate with political representatives and community groups. This group effort strengthens personal support networks and can reduce reliance on assistance from people or organizations that may be biased or discriminatory.

You can find out more about self-advocate networks in your area by contacting your local Community Living organization. If there is no self-advocate network in your area, you can start one! It only takes two or three people to create this kind of group, and you can begin by simply talking about issues you may be facing in your life. If you need help, you can reach out to a family member, friend, or local Family Resource Centres, non-profit organizations, local community-based organizations as well, and tell them what you need.

b) Family Networks

Across Ontario, there are dozens of local and regional networks of family members of people who have a developmental disability. Some have come together around developmental disability in general, while others focus more specifically on Autism, Down syndrome, or other diagnoses.

You can find a list of many Family Networks on the Partners for Planning website.

Family networks can be a valuable source of support and advocacy for individual families, and people who have a developmental disability and families more broadly. You can see the influence of these networks:

- In the attention that some schools and school boards pay to the inclusion of students with disabilities within school communities.
- In the expertise that may or may not exist in the health care, social service, emergency service, and justice networks in your community.
- In the programs that local charities and non-profits have created to meet the needs of children and adults who have a developmental disability.

Family networks can also help engage with mayors and local councils, and Members of Parliament. If multiple families can work together and agree on solutions to important issues, it becomes easier to convince political representatives to act to make needed changes.

Written by Patricia Franks, Parent, Advocate, Executive Team member for Caledon Area Families for Inclusion (CAFFI)

Family Network Advocacy

Advocacy is something most people fall into because of an issue that arises in their lives that cannot be resolved through the usual channels.

This was the case for the parents of Caledon Area Families for Inclusion (CAFFI) in 2016 as we explored, questioned, and dug to find answers to our unresolved problem: How do beneficiaries with a Registered Disability Savings Plan (RDSP) get access to their money when the account holder dies?

CAFFI hosted a presentation for families on the RDSP. The parents and caregivers who attended asked good questions. The basics of how the program worked were explained, and setting one up was straightforward. However, it could not answer the question: What happens in the future? The money belongs to the beneficiary, so the holder cannot put any instructions in their Will. What happens if you are a single parent? What if the beneficiary has no living family left? Families were not interested in the cost and loss of decision-making that comes with guardianship.

Our local MP acquired a copy of the legislation from Ottawa, and a small committee read through the whole document. There it was—the problem that no one had worked out. This was a new program, and it would be years before any of the beneficiaries would access their funds. The Act did not address the eventuality that the beneficiary would outlive the holder and not be able to manage their own account.

CAFFI approached our local MPP as the regulations for the RDSP involved the province. Inquiries were made on our behalf without any clear answers. Over the next several years, we were bounced between the Federal and Provincial representatives, pointing at the other level of government as the place to get action. 2019.

Our new MP was willing to do some deeper legwork for us. Delayed by COVID, the conversations were restarted in 2021 with both the provincial and federal elected officials. Our MP made headway into the problem with the help of other MPs to find possible avenues for resolution. This eventually led to a meeting online with officials working for MPs in key departments in late 2022.

It is important when advocating that you bring in good partners to strengthen your cause. CAFFI invited Community Living Ontario and Pooran Law to join the meeting. Partners for Planning, Inclusion Canada, Family Alliance Ontario, and Autism Ontario also became involved. All these partners had been working on this issue for years as well.

The meeting in 2022 proposed that the groups submit a budget proposal to be added to the official Budget to be presented to the House in the Spring of 2023. Our submissions would be championed by the offices of the MP's we were engaged with. This whole process was a completely new tool for us. With much-appreciated help from our partners, we produced a proposal we could all use as a collective. CAFFI also went out into the community to collect signatures to support this submission, eight pages worth, from families and sympathetic community members.

Tenacity and frequent contact are other advocacy tools worth the investment. Keeping in touch with the people we spoke with and obtaining other contacts to pursue helped us keep our proposal front of mind and in the right hands.

The Spring Budget of 2023 included a half page of wording addressing the RDSP holder issue to add siblings as eligible holders and instruct the provinces to resolve the other outstanding problems by 2026. It was not all we asked for but it took a step forward that had not happened in many years.

The issue is now back in front of the province. CAFFI is a member of the RDSP Action Coalition of Ontario (RACO) committee, formed to push this issue to a positive conclusion for all beneficiaries in Ontario. More in-person and via Zoom meetings have helped this issue reach the right people. Promises to resolve this before the next election have been made. And the work continues.

As Families, we face many challenges unique to us, and unlike the larger public causes, our voices are easily lost. Advocating for change takes time, persistence, and allies. Take courage that change can happen. Reach out to partners and educate your community. We all want a good and fair life for our family members. The effort is worth it.

c) Provincial Disability Networks

There are several provincial networks that are led by and work with people with disabilities and/or family members, including the Disability Justice Network of Ontario, Citizens with Disabilities Ontario, Family Alliance Ontario, and the Accessible Housing Network. These networks can help bring more attention and focus to issues that might seem local but are actually provincial (and even national) in nature.

> Take your voice to where it'll be most effective.
>
> BUFFY SAINTE–MARIE

These networks are always looking for leaders and volunteers to contribute and offer direction – reaching out and getting involved can help to address the frustrations and barriers you may be facing in your own life, while also helping others who are in situations similar to yours.

d) Mayors and Local Councils

At the municipal level, your mayor (or reeve) and councillors can be an important source of information, support, and advocacy. They can influence the direction of local housing and social services and can make important changes that benefit people with developmental disabilities and their families. They are often in close contact with MPPs and MPs, who count on their municipal colleagues for accurate and up-to-date information about what is happening in their communities.

Be sure to invite your local representatives to attend gatherings, and speak at group, board and network meetings. Communicate with them regularly about provincial and federal policies that may be affecting people and families directly. The prioritization of health and quality of life among municipal representatives – and it doesn't matter if your municipality is small, medium, or large – can be a powerful tool in policy and political advocacy.

e) Members of Provincial Parliament (MPPs)

Members of Provincial Parliament can be very helpful at the local and provincial level. Many people and families often feel that they aren't important enough to talk to their MPP, or they don't want to impose on them – nothing could be further from the truth! You are definitely important enough, and it is an MPP's duty to be accountable to their constituents.

MPPs can be helpful in at least three ways:

1. They can help you to get access to provincial programs, and they can help when you have a problem with a provincial program (for example ODSP, Passport, or home care).
2. When they are at the legislature in Toronto, they can talk about the issues you are facing locally. Being in legislature means the MPP's, who are all elected representatives, sit in a legislative assembly. Members of the legislature review and discuss various issues. Bills passed by the Legislative Assembly are given royal assent by the lieutenant governor of Ontario to become law. They can also push for more resources to support people with developmental disabilities and their families.
3. They can support local groups to access provincial funds for events and programs that benefit people with developmental disabilities.

Getting to know your MPP doesn't have to be difficult – all you have to do is call or email to ask for a meeting. From the very start, remember that your MPP's staff will be your main point of contact – get to know them, and treat them well! Don't be afraid to send updates to your MPP and their staff, particularly if you are going through a difficult time with provincial programs – for example, if you're visiting the hospital a lot, having trouble accessing health care, or have a family member involved in the justice system.

Sometimes it can be difficult to keep stay calm and focused when talking to or writing your MPP. Very often, people contact their MPP when they're going through a tough time. If you reach out ahead of time and establish a relationship, things will go more smoothly when issues arise.

f) Members of Parliament (MPs)

While they have less influence over programs that affect people's everyday lives, federal Members of Parliament can also be helpful for people and families. Just like with provincial MPPs, it is a great idea to get to know your MP as soon as they come into office, especially if you are involved with a self-advocate network, family network, or provincial network. You can reach out for a meeting, or to invite them to attend an event or speak to a group. Connecting can be done in a variety of ways: email, social media, phone calls or in-person.

Federal MPs can be valuable assets if they work closely with provincial MPPs and local councillors, which many (perhaps most) do. For example, if you're having trouble engaging with your provincial MPP, you can ask your federal MP for assistance. In general, it is hugely important for our federal representatives to understand the current issues being faced by people with developmental disabilities and their families. The best source of information about those issues is people and families themselves.

There is a lot more to learn in order to successfully influence public policy. The original author of this book, Al Etmanski, is considered one of Canada's most effective advocates. See his blog series Tips for Solution-Based Advocacy and his book, Impact - Six Patterns to Spread and Share Your Social Innovations for more ideas.

Individualized funding

Most government funding for developmental services goes to agencies that provide various supports, like residential care and day programs. When there are open spots available, they match people to these services based on their needs and urgency. This is known as supply-side funding, where services are prepared by providers for people and families to use. On the other hand, some programs use demand-side funding, such as Special Services At Home and Passport. These programs give people a specific budget they can use to buy or create their own support. This way, services can be tailored to meet unique needs. Both can have positive outcomes, but as Catherine Frazee (1999) discusses, a "supply-side" approach is outdated because this model is based on the flawed perception that people with disabilities who consume services "cannot be relied upon to predict their own needs, manage their own affairs and/or recruit appropriate support." In contrast she notes, "demand-side" funding, can safeguard against the limiting effects of institutionalized values, create services that are more creative and responsive to the consumer's needs and provide an economic benefit as this type of funding is usually seen to be more cost-effective."

There is some hope that the Ontario government may move towards a funding model that gives people greater choice and control and includes an individualized funding option for those who want it. However, this is not yet available in Ontario. Right now, not everyone can access comprehensive budgets to manage their housing or day support needs. In the past, some people have benefited from individualized funding through pilot projects, special situations, and advocacy efforts. As we began thinking about in this chapter, traditional services can reduce the independence of people with disabilities. Individualized funding can help change this by giving people more choice and control. This can also change how supported people relate to the government and service providers, shifting the balance of power.

> Community is much more than belonging to something; it's about doing something together that makes belonging matter.
>
> BRIAN SOLIS

People interested in individualized funding should learn more about how it can help support self-determined lives. The Canadian Institute for Inclusion and Citizenship provides valuable academic information on the benefits and challenges of this funding across Canada. The Individualized Funding Coalition of Ontario also connects supported people and families to advocate for this issue. With the right support, individualized funding can help a person achieve their unique vision of a good life.

SAME FONT SIZE

Conclusion

This Step builds on all the previous steps. The Worksheets in those steps will help you become more specific about the quality of services, programs and support you expect for your family member who has a disability. The Worksheets provide the standards you; your family member and their Circle of Support will use as a monitoring guide. Those efforts may need to be supplemented from time to time by advocacy. The goal should always be to return to a healthy partnership and for your family member to enjoy their good life.

Written by Shannon's Parent

Whose Life am I Living?

Shannon and I were invited to a baby shower and I was excited to be going. When I heard Shannon coughing in bed this morning I wasn't sure we were going anywhere. Before I could make that decision, I needed to give Shannon a bath and get her sitting up, as once she was in her wheelchair it would be easier for me to tell how she was feeling.

With my husband out of town, I had two people to get ready, two people to shower, two sets of teeth to brush, and all the while I was still unsure whether Shannon would be well enough to attend today's anticipated event. We did manage to get ready on time and once she was sitting up in her wheelchair, Shannon's coughing slowed down. She appeared to be her happy self so off we went.

It's difficult sometimes to know whose life I'm living and today was no exception. It could have turned out differently, we could have succeeded at getting ready only to realize that Shannon wasn't well enough to go. Even as a young adult, Shannon still holds power over my life, often the deciding factor on whether we go ahead with our scheduled plans, or modify or cancel them. Today had a good ending.

Rob and I are also very aware that Shannon's life needs to be full of things for her to do and friends to meet up with, and the same applies to us. Shannon has a great group of friends, but activities need to be organized and schedules coordinated. At the same time, Rob and I have friends, and friendships take effort. Sometimes, these two worlds collide, and we're left with the decision as to who gets to visit with their friends, who gets dragged along or, as almost happened today, who needs to change their plans and stay home.

Shannon needs care. We are her parents-, so we either need to provide the care ourselves or effectively advocate on her behalf to have the resources to hire people who can give us our much needed breaks and give Shannon her independence.

The first time I really felt like Shannon's life was taking over my own was when she was leaving youth services and moving towards her adult life. Many of the discussions started by the specialists in the room were about my work. As a teacher, I worked three days a week with the summers off. I sat listening to the discussions about my availability and realized that our two lives were becoming even more entwined. The services Shannon may qualify for would be connected with my availability. We were looking to secure Individualized funding so Shannon had choices in how to live her life, but the hours she would qualify for couldn't be decided based on my schedule, could they?

I have always taken a leading role in Shannon's social life but as she grows older I need to be able to step back, let her go off to university without her Mom sitting at the back of the lecture hall. I too need some time on my own, time to read without guilt, go swimming or take a class. I wasn't just advocating for supports for Shannon, I was also advocating for the life I deserve.

Advocating for Shannon's services required us to sit back, listen to what was being offered, and decide how it would affect each of us, individually and as a family. It was a discussion that took time to work through and it was difficult for us to know what exactly we needed until the discussions began, until I could see my free time slipping away.

Shannon is currently enjoying her time attending school, hanging out with her friends and volunteering with children at both an elementary school and daycare. At the same time, Rob and I are working hard to ensure we are able to pursue our own careers and interests during the week.

You may also be interested in these additional resources:

Blog: PLAN Founder Al Etmanski has written extensively on advocating with empathy. Visit aletmanski.com/blog to check out Al's writings on this topic.

Book: Impact: Six Patterns to Spread Your Social Innovation, by Al Etmanski. Available to purchase at aletmanski.com.

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