



GATEWAY TO BUILDING COMMUNITY



A guide *for* families *by* families that are beginning their journey of supporting a loved one with a developmental disability.



Introduction



"Gateway to Building Community"

is dedicated to providing support and reassurance to parents, caregivers, and families who have just learned their loved one has a disability. This initial experience can be daunting and is accompanied by various different emotions, but one thing that is important to remember is that *you are not alone.*

The **intention of this guide** is to foster a safe space for parents, caregivers, and families to process and embrace their feelings, provide a sense of community, and assist them in developing an understanding of where to start in terms of support for themselves and their loved one.

Understanding Disability and Diagnosis



The environments and age groups in which parents and caregivers find out about their loved one having a disability varies. Some learn this after the loved one is born, and others find out years down the road. Some parents and caregivers receive a conclusive diagnosis for their loved one, some receive multiple, and others don't "fit" into a diagnostic category. Every family has their own unique story and circumstances to initially navigating and understanding their loved one's disability.

Conclusive Diagnosis

A conclusive diagnosis is when the health condition(s) of your loved one is/are named and identified as fitting into an established disability category (i.e. down syndrome, autism, spina bifida) which can be determined by the results and conclusions made from tests and assessments. Sometimes it can be a lengthy process in coming to such a diagnosis. This can be very frustrating for parents and caregivers because typically they want some answers as soon as possible. If you discovered that your loved one has a disability in utero or shortly after giving birth, a diagnosis may have been identified. **If you find out that a loved one has a disability later in life and/or are currently awaiting a diagnosis, there are a few reasons why it may take some time:**

- 1 Large waitlists when accessing the necessary appointments and assessments with the right practitioners
- 2 Some disabilities (autism, learning disabilities, muscular atrophy, etc.) can only be officially diagnosed as the child develops. This is to ensure that there is an appropriate amount of evidence needed to reach a conclusive diagnosis

In some instances, a conclusive diagnosis can be helpful and elicit a sense of relief for parents, caregivers and families. It could be seen as a way to explain their loved one's behaviours and a gateway to understanding their world. It can also be upsetting to others as it confirms a new and initially daunting reality.

Inconclusive Diagnosis

An inconclusive diagnosis is when the health condition(s) of your loved one do not meet some or all of the criteria within an established disability category. This means that your loved one's disability may not be officially named or identified, which can be quite confusing. You might want some answers or an explanation around your loved one's newly found disability so you can begin to understand their situation and start figuring out what the next steps are.

It can be difficult to begin navigating the "next steps" when there is still so much uncertainty. Another thing that makes having an inconclusive diagnosis challenging is sharing the news with your family and friends. *"How am I suppose to tell others when I don't even really have a concrete answer myself?"* This can add additional stress to the already anxiety-provoking process of telling others.

It can feel even more isolating for parents, caregivers and families when their loved one does not have an officially identified disability. You may feel as if your loved one is excluded from both the disability world and the neurotypical world. *"Is there a place where my loved one will fit in?" "Who can I relate to?"*



Here is an audio clip of a mother in the UK sharing her experiences of her daughter's inconclusive diagnosis:
<https://www.cysticfibrosis.org.uk/news/inconclusive-diagnosis-life-on-the-edge>

Next Steps



Whether you have a conclusive diagnosis or not it, is important to remind yourself that your loved one's disability does not define who they are.



Allow yourself to feel and process all of your emotions. This is a very difficult time for all parents, caregivers, and families no matter their circumstances. **Go to: "What to Expect - Grief and Other Emotions"**



Actively seek the support of other members of this community but also place your efforts in helping to *create* and *sustain* such connections that are inclusive to all.

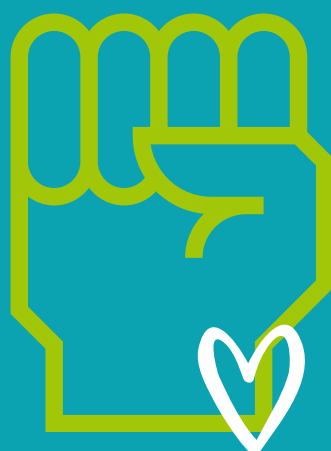
The ability to relate in these instances can be very therapeutic, but linking with other parents, caregivers, and families who bring different experiences and knowledge to the table is an extremely rich learning opportunity and practices the very inclusion that you want for your loved one.



Through this process of beginning to understand your loved one's disability and diagnosis, practitioners, friends, or family members might have this mentality where your loved one will be a burden and that you should lower your expectations for them. It is crucial that you do not let these types of comments influence how you understand your loved one and their future. Believe in and encourage their strengths across the lifespan. You will be amazed at what they can do when you focus on and uplift their individual abilities!

There are inevitable challenges that come with raising any individual; the hurdles that are to be jumped over just may not be as frequent or as high as with raising someone with a disability.

While these hurdles can be difficult to manage, the experiences and learning opportunities that arise give diverse and wonderful perspectives to not only your life as a parent/caregiver, but to all of the individuals' lives who are a part of you and your loved one's support circles.



Milestones

Milestones will be something that come up in conversation quite frequently as your loved one grows, especially within the younger stages of development. *Will my loved one start walking around the same time as other typical children? What about when their first word will be?* It is important that you throw out this idea of developmental milestones, because they can be exclusive of the growth processes for children with disabilities and they can set parents, caregivers, and families up to think a certain way about their loved one that does not meet them where they are at in terms of ability. **Here are some ways in which you can tell developmental milestones to hit the road:**



Avoid comparing your loved one's development to where other children their age are at.



Focus on ability, not disability.



Centre and celebrate the achievement of an activity rather than the performance. This shifts you away from solely focusing on *how* things are done developmentally and brings you more towards uplifting the overall accomplishments of behaviours and skills in whichever technique and time frame fits your loved one's unique abilities.

As your loved one ages there will be other social milestones expected to be achieved, such as obtaining employment, graduating college or university, and moving out of the family home. These types of milestones are important to consider as they can set your loved one up for becoming the best independent version of themselves. The key to this is inquiring about and listening to the needs, desires, and interests of your loved one in order to understand how they want to live their life and respecting and supporting them through whichever path they choose to take.

"EVERY INDIVIDUAL IS A DIFFERENT KIND OF FLOWER WITH DIFFERENT CARE NEEDS. SOME NEED A LITTLE MORE WATERING THAN OTHERS AND SOME TAKE A LITTLE BIT LONGER TO GROW, BUT THE ENVIRONMENT IN WHICH THEY LIVE PLAYS AN IMPORTANT PART IN HOW THEY BLOSSOM AND CONTINUE TO THRIVE."



What to Expect - Grief and Other Emotions



There are a few things that you may expect to experience when learning your loved one has a disability. The first and most universal experience is grief.

Grief can manifest in different ways depending on the individual and the situation, but a typical grief experience for parents and caregivers who have just found out their loved one has a disability is mourning the life they thought they would have. Specifically for parents, it is quite common to begin dreaming about the life and opportunities they want their children to have before they are even born. The confirmation that they have a disability can feel as if those dreams are not attainable anymore.

Along with grief, parents and caregivers may experience other strong feelings after learning their loved one has a disability.



It is okay to grieve, and it is okay to have conflicting emotions around your loved one's newly found disability. It is very important to allow yourself to process this news in a way and time frame that makes sense to you. It is also important to point out that the grief and conflicting emotions you feel can be lifelong. There may come a time where you feel as if you have finally accepted and embraced your circumstances until something occurs that resets you all the way back to how you felt in the beginning. This is normal, and this is part of the journey.

It can be extremely helpful to establish early on and actively engage in a self-care routine that fits your individual needs and interests in order to support you in being the best advocate you can be for and with your loved one. To find out more around the importance of self-care and how to start your own self-care regime, explore the **Personal Check-In** section located within the **Caregiver Roadmap**.

Another way that may assist you in working through your grief and emotions is leaning on the members of your support network. We will discuss this in more detail later on.

What to Expect - Family Tension



Another thing that you may expect to experience is issues or tension between family members after learning that your loved one has a disability. As discussed previously, this can be a stressful time for parents, caregivers, and families. This anxiety can be further exacerbated when the time comes to tell others about your loved one having a disability.

Sharing the News

There are various reactions that people can have when you tell them that your loved one has a disability. Some people react positively or remain neutral about the situation. Others aren't sure what to say which can cause them to either react awkwardly, negatively, or in a pitiful manner. Either way, how an individual reacts or responds can have a huge impact on the parents/caregivers and their relationship between the individual. This is especially apparent when it comes to family members. We may expect our family to be there by our sides when the going gets tough, but unfortunately this isn't always what happens. If they don't react in the positive and supportive way that we might have expected it can inflict anger and despair towards them, which then causes tension in the relationship.

There are a few things one can be mindful about when trying to understand why a family member may have reacted in a negative way to your news:

- They could have been in shock and their response was a reflex
- They could have been in denial and the negativity was a way to put up a shield to such a reality
- They may have not had the communication skills quite yet to truly express how they feel
- Family members go through their own process of grief that can be very different from how a parent or caregiver grieves. They may not know how to process this grief, so they project their emotions on the source of such grief

These are all just examples of what could be, but the only way to tell what is really going on inside their heads is to communicate with them. When you feel the time is right, explain to them how important your loved one is to you and share what you need and expect from them in terms of support going forward. If you initiate a positive mentality towards your loved one, it is most likely that others will follow.

You cannot control other people's reactions, but you can control how to share your story with others. **Here are a few suggestions for how to let others know that you have just learned your loved one has a disability:**



It can be a good idea to tell family as soon as possible after it has been determined your loved one has a disability, but don't feel rushed to do so and share on your own time.



Always remember to share information about who your loved one is first, and that the disability is only a fraction of who they are as a person.



If you have other children, be honest and open about their sibling's circumstances and create a comfortable and safe space for them to ask questions.

Spouse/Partner Tensions

If you have a spouse or partner, much like any other duo raising an individual you will have to work as a team. As mentioned before, raising an individual with a disability can come with its unique challenges and stressors which can place a strain on parental relationships. Communication and transparency are key values to uphold to manifest and sustain a healthy relationship between you and your spouse/partner. It is also important to allocate time and space to spend quality moments together as a couple. A strong connection and bond between parents/caregivers support them in facing adversities together, advocating for and with their loved one, and it sets a great example of healthy relationships.

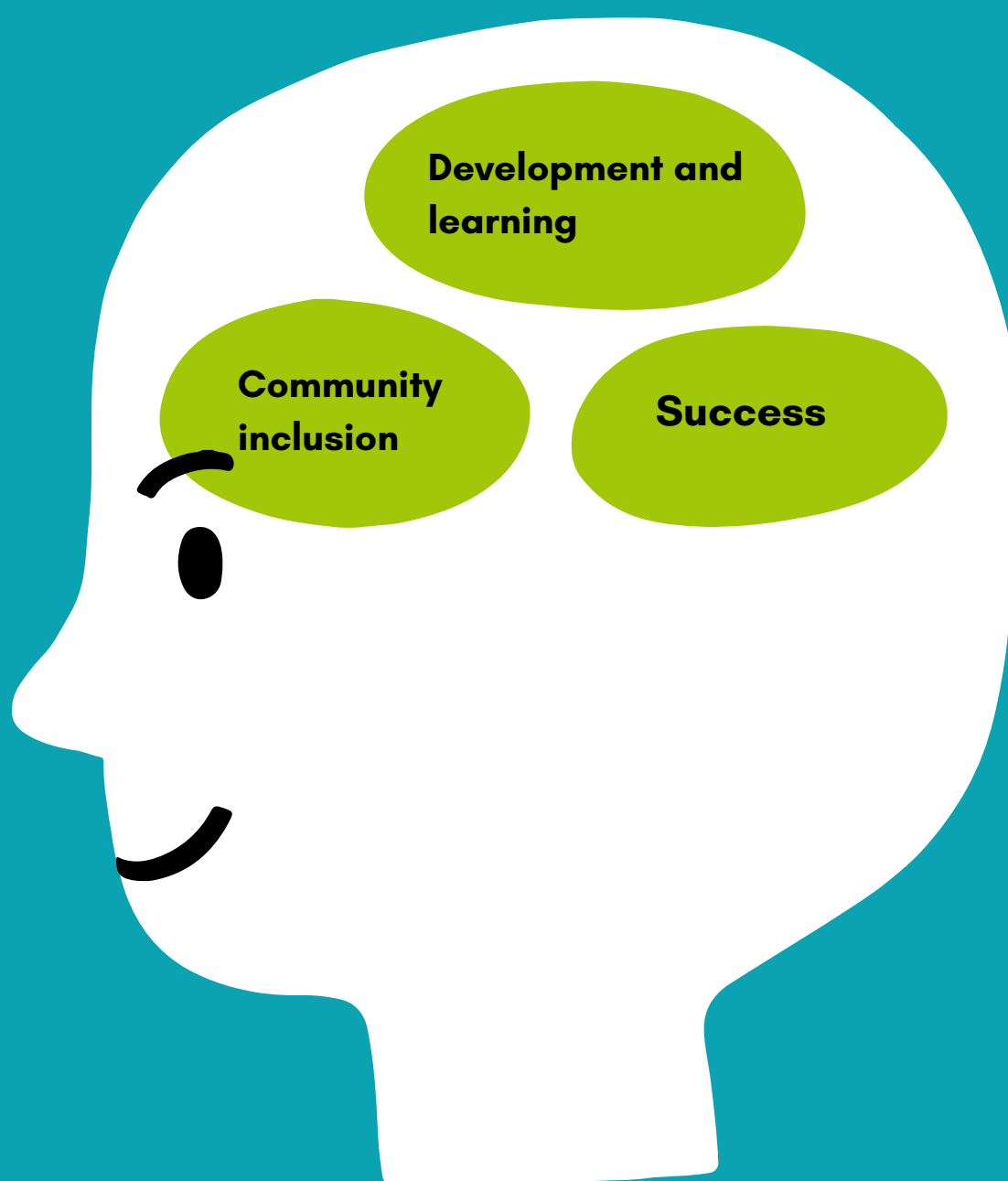
What to Expect - Navigating Supports



Information

As a parent/caregiver to a child with a disability, you will need to become the gatekeeper of knowledge and resources for your loved one. This means that you will have to gather information on various topics, issues, and services. Keep in mind that there isn't a single resource out there that offers all the knowledge needed to raise and support an individual with a disability and there is no "one-size-fits-all" solution. This is because information about disabilities and disability services are always changing. With that being said, it is important that you position yourself as an active learner and information gatherer in order to ensure that you are receiving the knowledge and supports that fit and honour the individual needs of your loved one.

Knowledge is power and having an array of information to pull from can help you become the best possible advocate for and with your loved one. Because there is so much knowledge and resources out there for you to access, it can get very overwhelming. To avoid an information overload, start seeking out knowledge in the areas that feel most applicable to you in the moment and assess it based on how it will contribute to creating the life and opportunities you want for your loved one. You can ask yourself questions such as: *how will this information support my loved one's development and learning? How will this information foster community inclusion? How will this information set my loved one up for success on their own terms?* Trust your gut and listen to your instincts!



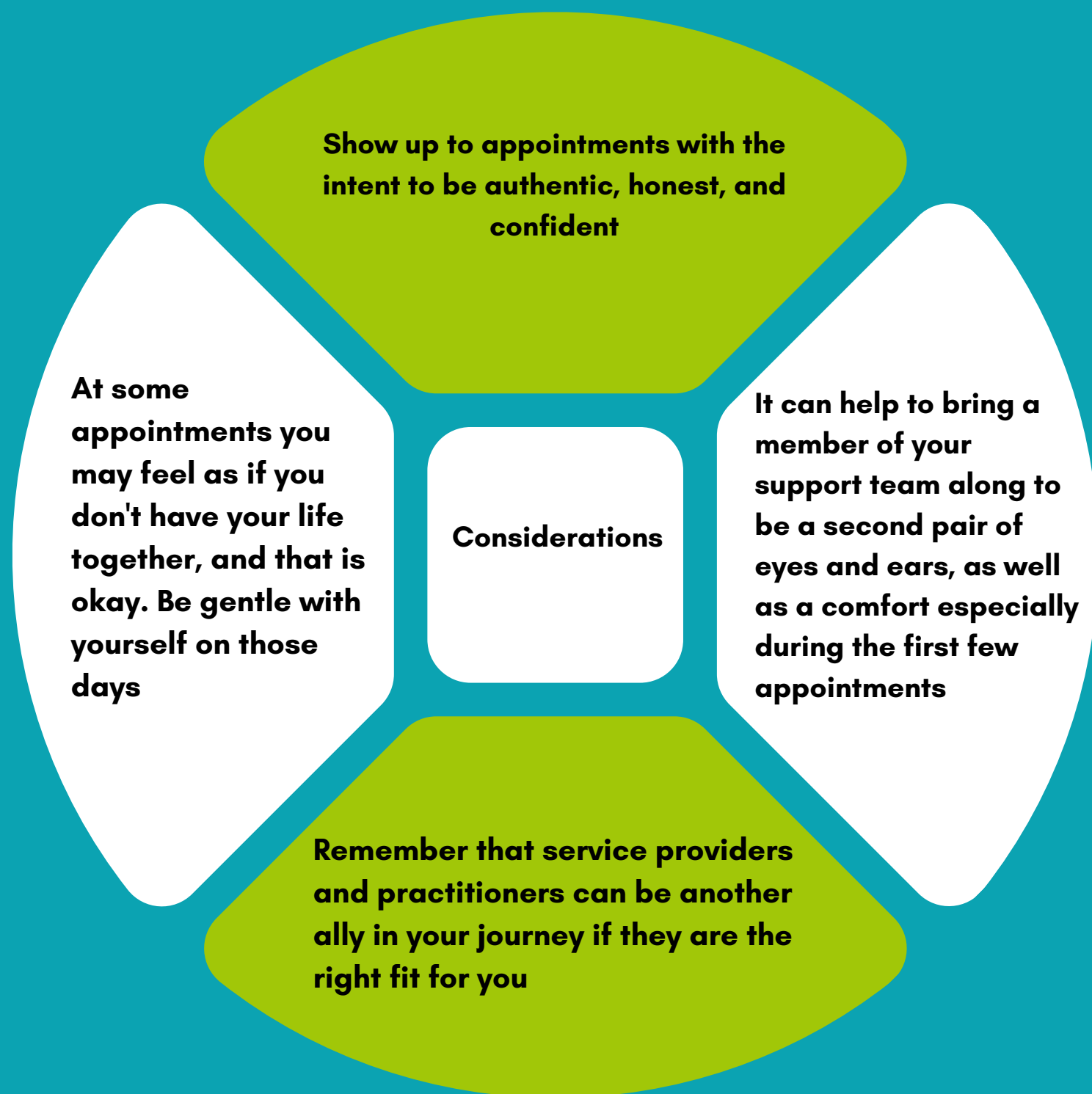
TIP: It can be helpful to establish an information binder or journal to keep things organized and easily accessible for when you need to look back on the resources and knowledge you have already collected. It also supports you in being able to constantly reflect on the gaps in the information you have in order to understand the knowledge areas that you may need to add to going forward.

Service Providers and Practitioners

Throughout your loved one's life, there might be quite a few different service providers and practitioners that play a huge part in supporting their overall health and well-being. Working as a team with such professionals can help things run smoother and foster a much needed space for effective collaboration. One thing to remember as you begin to navigate support is that YOU are the expert of your loved one. You know their needs better than anyone else. The practitioners and service providers that are part of your loved one's care network should be dedicated to providing insight on and supporting you through creating a full and wonderful life for your loved one, whatever that may mean for you and your family. You don't have to settle for anything less than that and you have a right to speak up. Don't be afraid to share that you feel as if your loved one's needs are not being met and appreciated. If they are unable to further provide that support, you can ask to be connected or even take the initiative to find someone else who can.

Think about your family values. *What are some qualities that you want to foster and maintain within your family unit and your loved one's overall support team?* Such values can further guide you in effectively identifying the right individuals and their accompanying supports that you want in your loved one's life. Examples of these values can include transparency, authenticity, openness, flexibility, and patience. Establishing a set of values can take time and shift as you become more familiar with navigating support, but you can start by thinking about what is important to you and your family right now.

Below is a diagram that outlines some helpful considerations to take when interacting with service-providers and practitioners:



The Importance of Support Systems



Not only is it crucial for your loved one to have a strong support system, but it is also important for you as the parent/caregiver to have a tribe of individuals supporting you as you begin and continue on this journey. This could be a mix of friends, family members, neighbours, and colleagues. Whoever it is, you want to make sure that these individuals are willing to hold space for you at your darkest and most vulnerable times and are genuinely interested in growing with you in the process. They are the people who share both your joy and your pain.

Who comes to mind as you read this?

It can be helpful to identify the people who you just know will be in your corner when you need someone to lean on by creating a list. Writing down your support network allows you to physically see how many people are there for you which can help you feel less alone.

If you feel as if maybe there is room for some additions to your support team, a great way to get connected with others is through disability support organizations or online groups. It can be very therapeutic and reassuring to speak to individuals who share similar experiences as your own.



Gateway Association offers various ways to meet and connect with other parents, caregivers, and families of individuals with disabilities such as Families Forward meetings four times a month and educational workshops. Also, the Gateway App in which you are viewing this guide has a **live chat** option where you can engage in digital conversation with anyone from staff, self-advocates, other parents, families, and caregivers.

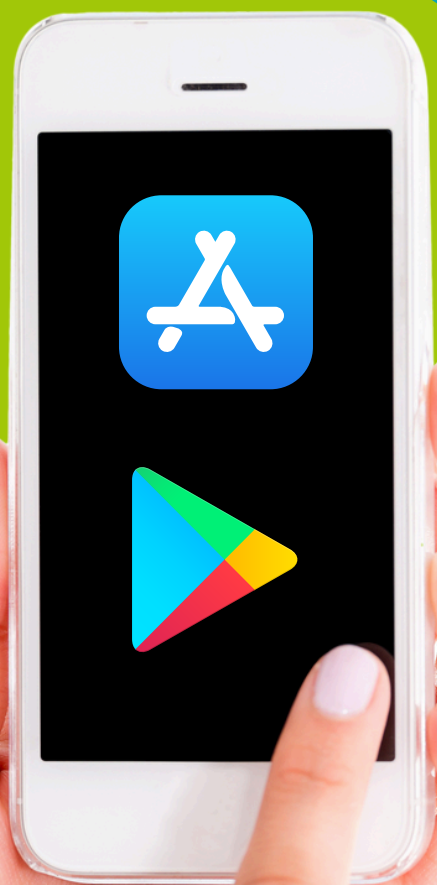


Regarding online groups, there are multiple parent and caregiver Facebook support groups that tailor to the different communities/areas in Alberta. You will need a Facebook account to access them and typically they are private. This means you must put in a request and be accepted into the group for confidentiality purposes. If this is something that interests you, use the "Search Facebook" bar on the left-hand corner of your Facebook page (if you are on a mobile device the magnifying glass search icon is on the right) and search and explore the different support groups in your area.

Whether it be online or in-person, there is lots of opportunity out there to build or add to your own personal support system!

**ARE YOU A
CAREGIVER?**

THIS APP IS FOR YOU!



1

Connect with other caregivers and have a safe place to chat.

2

Access the Caregiver Roadmap 24-7!

3

Attend Gateway Association Family Support meetings monthly.

4

Find & explore new resources weekly. Learn new digital skills.

5

Download Gateway Association's App today, and learn to explore the digital world.

GATEWAY



Resources



Leave a Message



Community
Feedback



The Learning
Centre



Upload Content



Spotlight



Top 5 Spotlight
Responses



Gateway YouTube
Channel



Meeting Room



Live Chat



Survey re
Gateway App



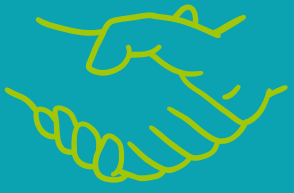
CHANNELS



CHAT



Meet Members of the Gateway Community



Here you will find the stories from some of the various parents and caregivers who are at the heart of Gateway Association and the work that we do. These individuals were once in your shoes, figuring out where to start and how to begin their journeys. Take the time to get to know these individuals and their families, engage with each of their contributions, and reflect on the areas that speak to you and your circumstances. *How can you relate to these individuals? How do you feel after reading their stories?*

Meet Hali



We have been raising our oldest grandson, Dominick, since he was three days old. He has multiple diagnosis including: ASD, OCD, SPD, Complete Speech Apraxia and Pica. Dominick is a teenager now and the happiest most loving child I know. There have been rough times, but we don't let them keep us down. We try to take the good days and the bad days in stride and never give up.

The best advice I ever received was "you are the expert on your child." What I took that to mean was that you will encounter numerous specialists and experts in their field but no one knows your child better than you. Listen to your loved one and never stop advocating for their needs.

Meet Kristie



My name is Kristie. I'm the mother of 4 children, 2 of which are special needs. March 7th 2014 we had an appointment telling us that our son has a genetic deletion which is the reason for his delays and low muscle tone. I felt like the rug was ripped out from under my feet. I felt like someone died. In a sense he did. The life we visioned for our son was turned from a he's just delayed to what will this now mean for him, for his life. It was a hard pill to swallow. There was very little information about the deletion, we still didn't know what it means for him. I went through a grieving period. It was so hard but you need to go through it, you need to process it. It's ok to feel like you have lost your child. In a sense you have. This doesn't make you weak, this doesn't make you a bad mom or dad, this is something you need to do in order to be the best parent you can be.

After we got the genetic diagnosis, we became very busy with Preschool and at home services. This time was so very lonely. My life revolved around therapy and our new baby, born March 25th. My 'friends' never reached out and I was all alone. I no longer had the time to reach out and no friends reached in. This was the begging of the dark tunnel I entered. I felt like I was in this tunnel for a couple years before I started to move towards the end.

They tested my husband and I for the deletion and in December we learnt that I also have the 15q11.2 BP1-BP2 deletion meaning that there is a 50% chance my other children may have the same deletion. I was due in June with our 4th child. In 2018 our son spent 6 weeks at the Glenrose doing an assessment. The diagnosis from that was that he has an intellectual disability. The form with the info about it in brackets said "formerly called mentally retarded." My heart broke. I couldn't get those words out of my head.

Just after this our 3rd daughter was tested for the deletion and it came back that she also has the deletion. This time I was ok, we already knew in our gut that she had it so now we could get her the supports she needed. In Grade 1 she also received her Intellectual Disability diagnoses, we knew that was coming too. This time I felt like we had already processed her diagnosis before we even got it.

So far our other 2 children have no indication of having the deletion, we are 50/50. I had to learn how to take care of me as a mom but this was a really hard thing for me to do. I'm a stay-at-home mom and my life is my family and children, there was no me. I am so blessed to have an amazing husband who has been my support and I his through this whole time. He was my rock, he's the one who would tell me to take a break to take care of me. I felt so guilty though so very very very guilty taking care of myself. Over time I have learnt that in order to be the best mom I can be I need to take care of me, I don't need to feel guilty for that. I have had some 'real' friends come into my life since my dark tunnel and I am so thankful for these friends. I have learnt to invest my time where others invest it back. I have learnt that you can't make other people understand what your life is like and that is ok. My husband and I both have families we are close with and they have been great support and this we are also thankful for. My husband is my rock and he doesn't blame me he embraces our chaos and I'm so blessed.

We made the choice to not limit our children, to work hard with them so they can be everything they can be. They work so hard just to accomplish simple tasks most people take for granted. We still have no idea what life will look like for our 2 kiddos but I have found peace. It has taken a long time to get here but I made it.

It's hard finding resources for our kids and for us as parents. The biggest resource for me has been my local special needs community. I have learnt so much through them. Facebook groups and local associations have helped me learn so much. Reach out to these communities and breath, it will be ok and you will be ok. Your feelings are ok, your thoughts are ok. Remember you aren't alone.

Meet Kim



In my 40th year, I found myself unexpectedly pregnant. We (my husband, Ken, and I) were a blended family with four teenage daughters ranging from 15 to 18 years of age. When Kyra was born in the spring of 2002, I was already an experienced mother, so I knew something wasn't right with my daughter. However, I quickly learned that doctors are apt to brush off this gut sense. I was treated as an over-anxious parent, we were thrown on excessively long waitlists to see specialists, and we were told to simply "wait and see."

I continued to push the doctors and finally Kyra was assessed and followed by some of the best specialists in the world located at Toronto's Sick Kids Hospital and the Holland Bloorview Rehabilitation Hospital for Children. After hours of missed work and specialist observations, we were told that Kyra was on the Autism Spectrum, her brain did not develop properly (she had "Dysgenesis of the Corpus Callosum"), and really we should "not expect too much"; she would "never walk or talk." The level of devastation upon hearing this cannot be understated. However, we were not ready to give up on our girl.

We endlessly researched her new "labels." Despite all we had read, we knew that Kyra had the ability to learn. She was just much slower on the uptake. And with that, we were committed to providing her every opportunity she needed to have the best chance in life. And in many ways, this is where our journey truly began.

By the time Kyra was two-and-a-half, we were forced to make some significant changes to ensure our own health, our family, and Kyra's care didn't fall apart. I made a career change, moving from my Development Management position at a prestigious private school to a fundraising and development position at a specialized learning centre for children with special needs. This allowed me to apply my innate skills to build a flourishing charity for kids like Kyra, all with differing needs.

This new job certainly didn't pay as much, but the shift provided access to the specialized therapists Kyra needed all under one roof. Kyra was now part of a daily early intervention program, receiving coordinated behavioural therapy, speech therapy, occupational therapy, and physiotherapy. We started to see some gains in her behaviour and language development, and I was working just down the hall while it was unfolding.

It was at this centre that I started to finally connect with many families that had stories that paralleled ours. Many of these families were completely lost, unsupported, and unable to afford the early intervention their children needed. Together, with these families and the existing staff at the centre, we established a charity with the goal of inspiring possibilities. We raised funds that allowed families to receive bursaries toward their intervention expenses, but more importantly, we created a place to connect with families on this same lonely journey.

Eventually, Kyra started to age-out of the centre and we started to consider pre-school options for our now four-year-old. Understanding the pain of exclusion from the outset, I was adamant that Kyra be integrated with other children. I did not want her to always be an “other.” As Kyra was settling into preschool, we were unexpectedly on the move again.

Ken was offered an exceptional opportunity in Red Deer and after visiting the city for the first time, we knew it was meant to be our home. Red Deer quickly felt like home. The community was supportive and welcoming. The care, education, and family support we received from CSC (Aspire) were exceptional. I was quickly welcomed to CSC’s Board of Directors and soon thereafter connected with the Central Alberta Autism Society. We were finding our way and this world that was feeling much less foreign than it was on that fateful day in the doctor’s office in Toronto.

Before the end of our first year in Red Deer, I started working as the Fundraising and Marketing Director at CSC. Over the next three years, I met families and heard their all-too-familiar stories. I became very involved provincially, as both the President of the Autism Society in Central Alberta, and a Director on the Board for the Autism Society of Alberta. As well, I served as the co-chair on the Housing Advisory committee with the Sineave Foundation. This is where I really started to see the void in long-term planning for children like Kyra, and my interest in real estate crossed-over and I decided to become a Realtor.

While working as a Realtor throughout the last 10 years, I continued to stay active on the aforementioned provincial Boards and I grew my involvement in a housing committee in Calgary focused on finding options for families just like mine. I started to see all the pieces of our long and sometimes arduous journey with our girl finally come together. Through our experiences with Kyra, we were faced head-on with startling gaps in our society, yet, during my time as Kyra’s mother, I simultaneously came to possess the marketing, development, community, health, care, familial, and logistical knowledge needed to begin to fill these holes. However, Ken and I couldn’t do it alone and I knew that us parents with special needs children needed to grow together and learn from one another in order to solve the crisis that faces us all. Thus, in an effort to formalize this need for unity, I established a parent group called Connecting CommUNITY.

As its name suggests, Connecting CommUNITY was founded for the purpose of connecting families. Over the years, advocates and supportive parents grow apart from one another simply because of time and limited options for socialization that naturally comes with having dependent children. We spend our time navigating the system and looking for opportunities for our loved ones to be involved and included in society. Connecting CommUNITY was established to join parents and other key stakeholders together to find financially sustainable housing solutions and help guide the journey toward independent living.

While still very much in its infancy, Connect CommUNITY has been the birthplace of many novel ideas and a place to commiserate on many expected and unexpected challenges on this journey. We now know, for example, that our priority need not be the “structure” of a building, but rather assisting families as their special needs children make the transition from childhood to adulthood. We need to help parents become emotionally and financially ready to live apart from their children and we need to assist families in developing a long-term housing and support plan that is sustainable for all involved. We need to think about safety, inclusion, and meaning for these vulnerable and valuable members of our society. We need to ensure that parents can plan for their own end of life without simply relying on “hope” that their children will be taken care of after they are gone. And we are getting there, one small step at a time. The fun is really just beginning and the possibilities are endless.

When I was suddenly thrown into being an expectant mother again at age 40, I never could have imagined that it would have landed me here 19 years later. Kyra’s challenges have created many awakenings. It is because of her challenges that I have had the privilege of meeting many amazing and dedicated parents. Her challenges have helped me to understand the limitations our system places on families, educators, and service providers. And most of all, her challenges have left me exactly where I was meant to be.

Meet Yonique



I remember the day my aunt called my mother in 2006 about my new cousin who was about to be born, the doctor said more testing needed to be done as soon as possible. We didn't know what that meant because no one in our family had gone through this. My mother and aunt are like sisters so naturally, we were all worried about my aunt and the new baby, my mother waited by the phone the next day to find out the news. The doctor said there was a high chance that the baby would be born with Down Syndrome and a heart defect. We had knowledge of this diagnosis but had no idea what day to day life would look like, I began googling articles and sending them to my aunt and we would talk about what to expect when we finally got to meet this beautiful little girl. On November 15th, 2006, Keturah was born but she was quickly taken away and hooked up machines as they prepared to operate on the two holes in her heart. The surgery lasted 3 hours and my aunt finally had a chance to hold her baby girl for more than a few minutes. We were finally able to visit mom and the newborn in the hospital which was exciting but calmed our whole typically loud and enthusiastic family down as we carefully held her one by one.

Keturah has had numerous minor health procedures including cataracts removed at 3 months and tubes placed in her ears at 4 years old. Our family have always banded together to help as much as we could from driving to medical appointments to spending the evening with her when mom needed a break. When she turned 10, my aunt felt comfortable enough to start exploring community options as her personality started shining through. Her love for music and dance was apparent, we wanted to find a class where she could express herself. I called a dance studio in the city to see if she would be supported to stay on task and was abruptly told that the class is too fast paced, and she would need someone there with her to avoid distracting the whole class. We were extremely upset that there was nothing available where she could feel like she belonged. We were persistent and found a lovely class, but it was soon shut down due to low attendance. We still haven't found the perfect fit for Keturah to dance but will never stop looking. We are grateful that she has had the opportunity to be apart of her community camps and activities where she can meet new people.

Keturah is headed to high school next year and this is one of the biggest transitions of her life. We are creating a vision and planning for the future to help make the transition simple for everyone involved. We want her to have a say in the decision being made about her and will support her along the way. Even though I am not living with Keturah, we are extremely close, and in the future our family would Keturah to live close by or even continuing to live with a family member. We have learned that anything is possible especially if you advocate and have a clear goal for what you would like to see. We take the saying "it takes a village to raise a child" to heart because having a support network is essential for others who are experiencing a similar journey.

Moving Forward

We hope that this guide has given you the confidence and knowledge to move forward in your journey as a parent or caregiver of an individual with a disability. Taking the time to engage with "**Gateway to Building Community**" was a major first step in the right direction.

Take pride in yourself for being here.

So, what's next?

Explore the rest of the Gateway App! There is a copious number of resources and learning opportunities at your fingertips. The rest of the **Caregiver Roadmap** is a module-based learning experience with content that is relevant to supporting your loved one across the lifespan. Some of the topics include:

- Life Transitions
- Visioning and Valued Roles
- Community Inclusion
- and many more!

SPREAD THE WORD!

If you cross paths with other parents, caregivers, and families who have also just begun navigating the world of disability, share this guide with them. We are all in this together and it is important that we practice compassion towards others to keep this strong sense of community alive and thriving.



Remember to take your time and choose the areas to start with that speak to your heart in the moment. Be patient with yourself, practice self-care in a way that meets your needs and reach out to your support networks.

References

- "Welcome to the Family" Guide
<https://open.alberta.ca/publications/9780778559320>
- Support Services
<https://gatewayassociation.ca/support-services/>
- "The 'F-Words' in Childhood Disability"
<https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2214.2011.01338.x>