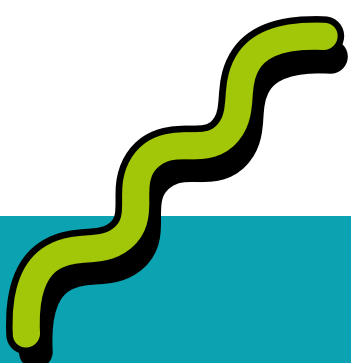
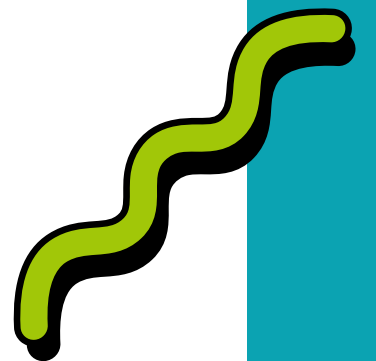
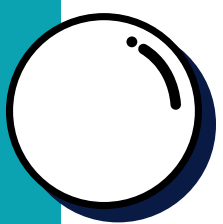


# **BIRTH-2 LEARNING MODULE**



# Introduction

This learning module will centre the knowledge and actionable steps that families have deemed essential to engage with during the birth-2 year stage of your loved one's life.

The module has 5 topic areas of focus:

- Life Transitions
- Visioning and Valued Roles
- Navigating Supports
- Advocacy
- Community Inclusion

Remember to go slow, filter through the information by what is relevant to you and your loved one at this time, and take breaks when you feel necessary. You want to avoid becoming overwhelmed and experiencing an information overload, so make sure to take care of yourself in a way that makes sense to you.

Happy learning!



# **LIFE TRANSITIONS**

# Understanding Life Transitions

Life transitions are a common experience among all human beings. They can be understood as periods across the lifespan that involve internally and externally adapting to change(s) or a new reality. Some transitions are universal, and some are different depending on the individual and their circumstances. Transitions can be messy and both predictable and unpredictable, but they are a necessary and major contributor towards our growth and the shaping of our individual identities.

## What Do Life Transitions Look Like From Birth-2?

During this stage of your loved one's life, you don't necessarily have to start planning for their transition into adulthood just yet. It can be quite overwhelming to think that far ahead into the future, especially when you are still trying to figure out how to process and navigate your new reality as a parent/caregiver of an individual with a disability. It is important that within this stage you try your best to be in the present and meet your loved one where they are at. Our little one's grow up fast. We don't want to miss those precious moments near the beginning of their lives because we are too caught up in the 'what-ifs' of the future.

There are two common life transitions that you may expect your loved one to encounter from Birth-2:

### 1 Developmental Milestones

This particular area of the lifespan places a major focus on development and hitting particular milestones. You will find that most physicians use your loved one's development as an indicator of their progress, and compare such progress to that of other 'typical' children their age. It is important that you shift away from comparing your loved one to others and focus on and uplift their individual victories and abilities. If you want to learn more about how to do this, check out the **"Milestones"** section in the **Welcome Package/"Gateway to Building Community" Guide**

### 2 Outside Care

If you are a parent or caregiver that took leave from employment when your loved one was first born, you may be looking into who will provide care for them once you return to work. If you are a stay-at-home parent or caregiver, you might be looking for outside care to give yourself a break to have some uninterrupted time to run errands and/or fulfill your own self-care needs. This care could be in the form of a daycare centre, Pre-Kindergarten program, respite, or in the hands of a family member/friend. Whatever the reason might be as to why you are searching for outside care, this can be a major life transition for both you and your loved one.

You might experience some anxiety around not having as much control over your loved one's daily care. You could also be worried about your loved one feeling as if you have abandoned them, and fear that the individual(s) you trust to take care of your loved one will not be able to meet and sustain their unique needs. Passing the torch to someone else can be scary and stressful, but it is key to supporting your loved one's independence and inclusion early on. It's important that you work through your emotions in ways that align with your individual needs in order to make this transition easier for both yourself and your loved one.

Your loved one may also experience a mix of emotions as they transition from you solely being their primary care source. Some children initially react in a positive manner which makes the transition process much easier. A fairly common response for children who are being introduced to new avenues of care is the development of separation anxiety. Your loved one might be so accustomed to having you by their side that it is very upsetting when you are not, especially when they are placed in an unfamiliar environment. This can trigger an emotional response each time there is even an inclination that you are leaving them.

Your loved one might not understand at first that when you leave you *are* coming back. To help them understand this and support them through their transition to outside care, **here are some tips to consider:**



- Practice separation for brief periods at first. As your loved one gets used to the distance, begin gradually increasing the time that you are away from them
- Create a quick but meaningful goodbye ritual. This could be in the form of a special handshake, phrase, kiss, hug, or a wave through the window as you go
- Communicate with or show your loved one that you are leaving, then go. Try not to stall!
- Try to show up around the same time each day for pick-up, and acknowledge your loved one as soon as they see you
- Have a mixture of both familiar surroundings and unfamiliar surroundings. If you have hired a support worker or family member/friend, have them come over to your house to provide care at first. Once your loved one has adjusted to the individual, start alternating from your house to the care provider's house every week and adjust as needed. If your loved one attends a centre have them bring something familiar from home like a favourite blanket or toy
- Try to keep your care source as consistent as possible for your loved one
- Try not to give in. It can be difficult seeing your loved one have such an emotional response to your departure and you might start questioning your decision to put them in outside care. Acknowledge and work through your emotions and remember that it takes time and patience to adjust to change

### **Inappropriate Attachments**

Another thing that can make this transition to outside care challenging is an inappropriate attachment. Especially within this age group, a healthy level of attachment to parents or primary caregivers is needed in order for a child to feel safe, secure, and learn about/engage with the world around them. As they age, their attachment should begin to disperse to other individuals they meet and the relationships they form. If this shift in attachment does not occur or the opportunity to do so is not offered, the child can become overly dependant on their parent/primary caregiver. Your loved one may still need to rely on your supports as they continue to experience transitions, but every individual deserves a life and relationships outside of their parents/caregivers and family. When this inappropriate attachment is not addressed early on, it hampers the child's ability to be independent and successfully transition throughout the lifespan.

Introducing new avenues of care for your loved one is a great way to start moving away from developing or beginning to break an inappropriate attachment early on. **Here are some questions to keep in mind that reflect on the relationship you have with loved one as you continue to raise and provide support to them:**



Are you your loved one's only friend?



Do you do everything for your loved one, even though they may be able to do some of it independently?



If your loved one did not have a disability, would you expect that you would have the same relationship?

# Pointers for an Effective Transition Process

It is important to note that there might be other transitions that you and your loved one experience throughout this particular area of their life. As mentioned previously, life transitions can be commonly experienced or unique to the individual. Whatever the transition may be, **here are some key points to consider when aiming for an effective transition process:**

**Be aware of where your loved one is in the transition process**

What emotions or behaviours are observable?

How are they reacting to the change?

**Provide support**

Physically show them that you are there to provide love and support

Create a safe space for them to express their feelings around the transition

Family/Friends

**Lean on others around you for support**

You - you know your loved one better than anyone!

Gateway Association

Medical professionals, counsellors, and other practitioners

# Wrapping it Up



Remember to take things one step at a time and be patient with both yourself and your loved one. Life transitions are inevitable and will be present throughout your loved one's entire life. Developing your own understanding of the life transitions your loved one will experience and a healthy skillset towards managing change is crucial to not only supporting you through your own transitions, but positively contributing to the part that you play in your loved one's. It also sets the tone for how your loved one will work through their life transitions as they age. Children are like sponges who absorb everything that their parents or primary caregivers say and do. You want to make sure you are setting good examples for them in all areas of life as early on as possible!

# References

- "Separation Anxiety and Separation Anxiety Disorder"  
<https://www.helpguide.org/articles/anxiety/separation-anxiety-and-separation-anxiety-disorder.htm#>
- "Gateway to Transitioning" Booklet





# **VISIONING AND VALUED ROLES**

# Understanding Visioning

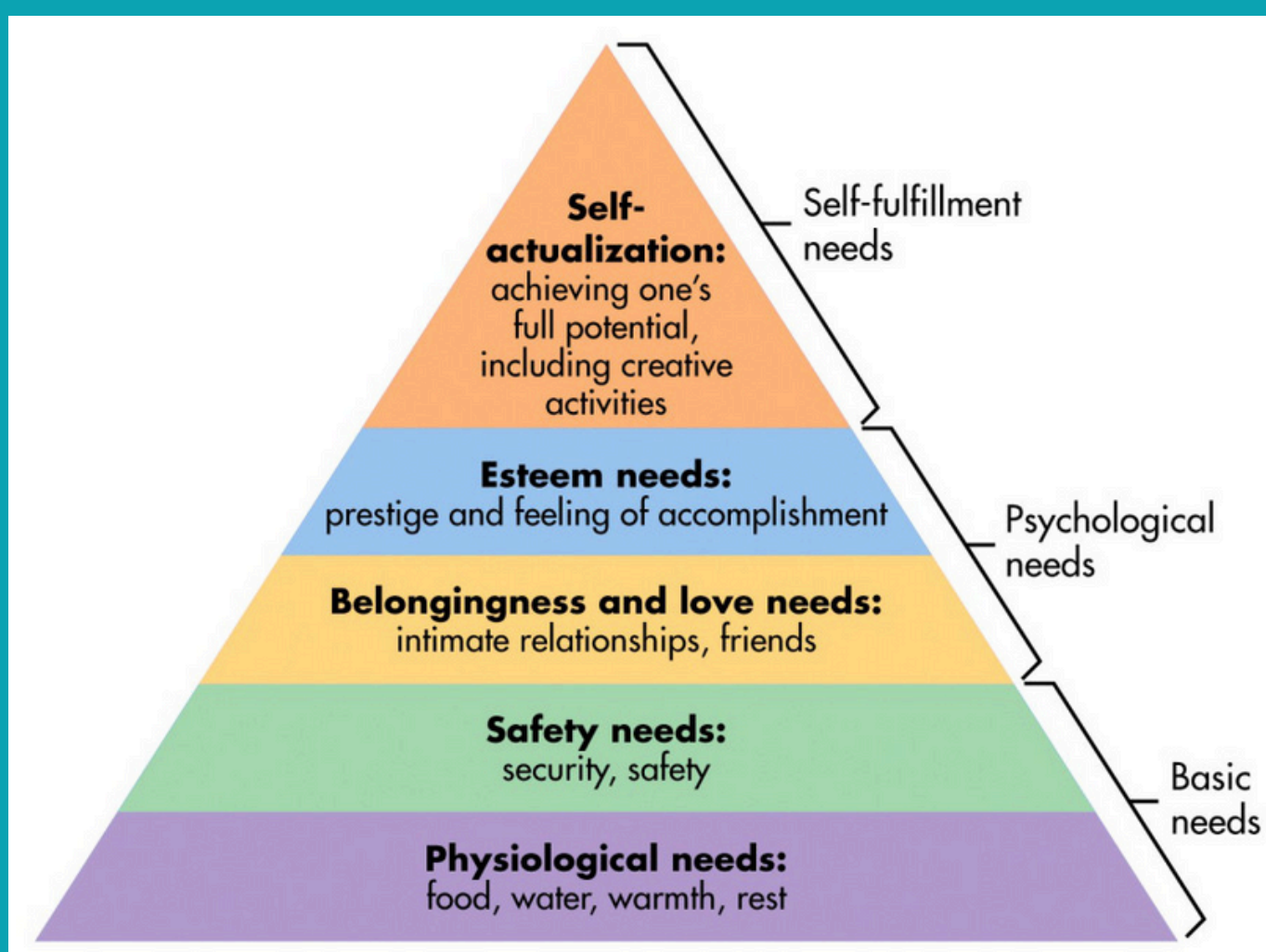
## What is Visioning?

A vision can be understood as a dream that we have for our future, our ultimate end goal in life. It is derived from our individual hopes, interests and aspirations. It can be big or small, and sometimes not make sense to anybody but ourselves. That is okay! It is our own vision or dream after all. Visioning is the process in which we bring forward the intentions of our vision or dream to better understand ways we can make it a reality.

## What Does Visioning Look Like From Birth-2?

It can be helpful to take smaller visioning steps within this age group as you are just beginning to understand your new world as a parent/caregiver of an individual with a disability. **There are a few ways in which you can start to engage in visioning for your birth-2 loved one:**

- Whether your loved one has received an inconclusive or conclusive diagnosis, you can start by developing a vision around how you want to navigate their health condition(s) going forward. What will I need in order to support them to the best of my ability? What do I think they will need from me? What will assist me in fully understanding their situation?
- Think about what is important to you right now, and how you want to see that further. What are the next steps?
- How do you understand a "good life", and how will you incorporate this as you raise your loved one?
- Your vision could start off by being for the whole family. For example, if you are wanting to foster and teach community inclusion as early on as possible you can set your first vision as your family unit all being active members in your local community. This could mean keeping up with your social networks, engaging in communal activities, and being a friendly and reliable neighbour to those around you.
- Focusing your vision on the five areas of Maslow's Hierarchy of Needs. How will you support your loved ones basic needs going forward? Psychological needs?



These are just a few examples on where to start, but the possibilities are endless and don't let anyone limit them for you and your loved one. As you go along, remember to always plan for the person and not the disability. There is no disability in a vision!

# Tips for Planning and Implementing Visions



Create a *vision board* that uses imagery to capture your vision and what it entails as a reminder to what you are working towards. **\*Go to: Birth-2 Activities and Resources - "How to Create Vision Boards" & "The Big Picture"**



If you are less of a visual learner and enjoy putting your written thoughts on paper, practice writing a *vision statement*. **\*Go to: Birth-2 Activities and Resources - "Writing a Vision Statement Activity"**



Start to plan goals that will be the stepping stones to achieving your vision or dream. Goals should be *SMART*; Specific, Measurable, Attainable, Reasonable, and Time oriented. Some prompts to support you in thinking about your goals are:

- *I can do (blank) this year/in the future to start moving toward my vision*
- *I can try (blank) to achieve my goals*



Once you have established your goals for your vision, brainstorm strategies or tangible actions that you can engage in to meet those goals and ultimately your vision. Don't be afraid to move on if a strategy isn't working for you. This is all part of the process, so try to remain open-minded and patient! Questions you can ask yourself to support you in thinking about strategies are:

- *What do I need to complete my goals?*
- *Who needs to be involved for me to achieve my goals?*



Get more people involved in planning and implementing your vision and share your vision with all individual's who are involved in your loved one's life. Connecting with others in this process not only takes some of the pressure off of you in getting the vision to come to fruition, but it can also multiply the perspectives and influence you to think of visions for your loved one that you may have never thought of before.



Evaluate the process as you go. Check-in with yourself by asking questions like:

- *What have been my strengths or successes?*
- *What needs more work or support?*
- *Is what I am doing today getting me closer to my vision?*



"YOUR VISION IS NOT LIMITED BY WHAT YOUR EYE CAN SEE, BUT BY WHAT YOUR MIND CAN IMAGINE."

# Understanding Valued Roles

## What Are Valued Roles?

Valued roles are behaviours, relationships, responsibilities, and duties we carry out in life that are widely recognized and acknowledged within society. The roles we engage in tell others that we interact with about who we are, enhance our self-image, and encourage us to further develop our skills.

## What Do Valued Roles Look Like From Birth-2?

Valued roles are an important component towards connection, inclusion, and independence. It is ideal that you begin to think about the roles you want your loved one to have as they age early on. A good role to start fostering in this area of life is within your family unit. Supporting your loved one in identifying that they are a son/daughter, sibling, or grandchild and how important that is places an emphasis on how they are valued and connected within your family.

Below are some questions to prompt you to start thinking about the valued roles you want your loved one to have as they age. You can also check out **Birth-2 Activities and Resources - "Valued Roles Parent/Caregiver Activity"** for more support in this area.

**What position in your life do you take pride in the most?**

**How have you established your own valued roles?**

**What are your values?**

**How do you plan to pass down these values to your loved one?**

## Valued Roles for More Dependent Individuals

If your loved one is more dependent because of their health condition, valued roles will look a little different for them. This does not mean it's not possible though! The roles that they engage in might need to be ones where they can have someone fully supporting them, or perhaps they are just centred around relationships that they have with others. No matter the circumstances, all individuals deserve the chance to establish and carry some type of valued position in their life.

# Wrapping it Up



Visions and valued roles are not static and are ever-changing as your loved one continues to grow. Their individual visions and valued roles will become more apparent as they develop their own preferences and interests, and will change through new life experiences. As a parent or caregiver, developing an understanding of visioning and valued roles as early on as possible creates emotional readiness that supports you in taking the next steps necessary to help your loved one create and live their own independent and wonderful life.

# References

- "Gateway to Transitioning" Booklet
- Resourcing Families - "Harness the Possibilities"
- Maslow's Hierarchy of Needs  
<https://www.simplypsychology.org/maslow.html>
- Vision Quote  
<http://www.picturequotes.com/limited-vision-quotes>



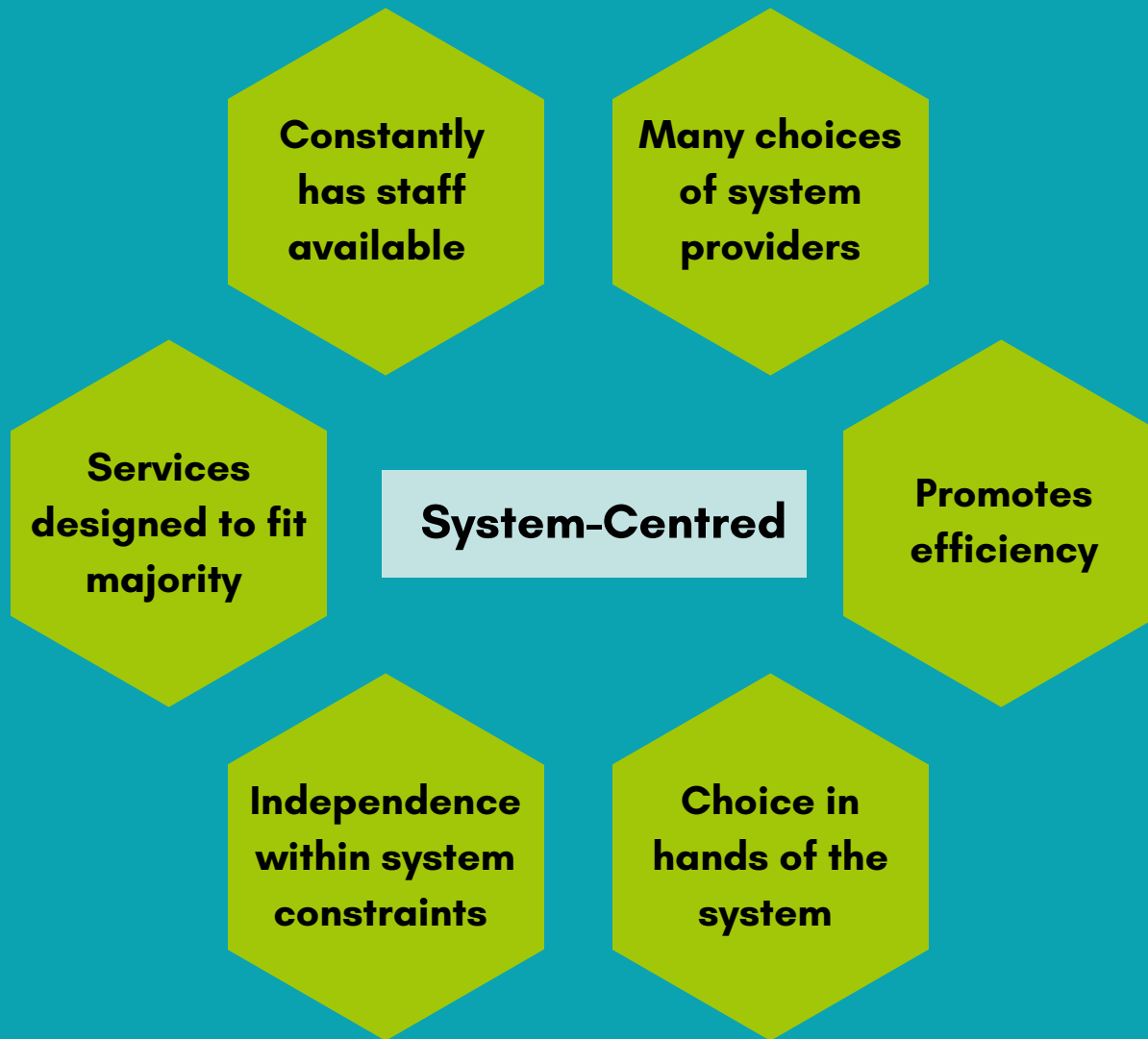
# **NAVIGATING SUPPORTS**

# Understanding Approaches to Supports and Resources

## Person-Centred vs System-Centred Approaches

As you begin to navigate support for your loved one you will notice that there are two prominent approaches used; person-centred and system-centred. Gateway strongly believes that focusing on a person-centred approach guarantees individuality of supports that are tailored to the unique needs of your loved one, but the choice is ultimately yours to choose and it depends on how you envision support.

System-centred approaches have a focus of supporting individuals in program service settings based on an assumption of universal need. Typically this approach is seen in agencies and large public policy settings (hospitals, group homes, schools, etc.)



Person-centred approaches have a focus of designing supports to fit the needs of each individual within their community. Person-centred also refers to Family Manage Supports where families are in charge of hiring staff for their loved one.





It is possible to have a person-centred approach to system service settings. For example, FSCD contracts are system based but the ways in which families implement them and the hours they receive for respite/care are person-centred.

## Identifying Resources

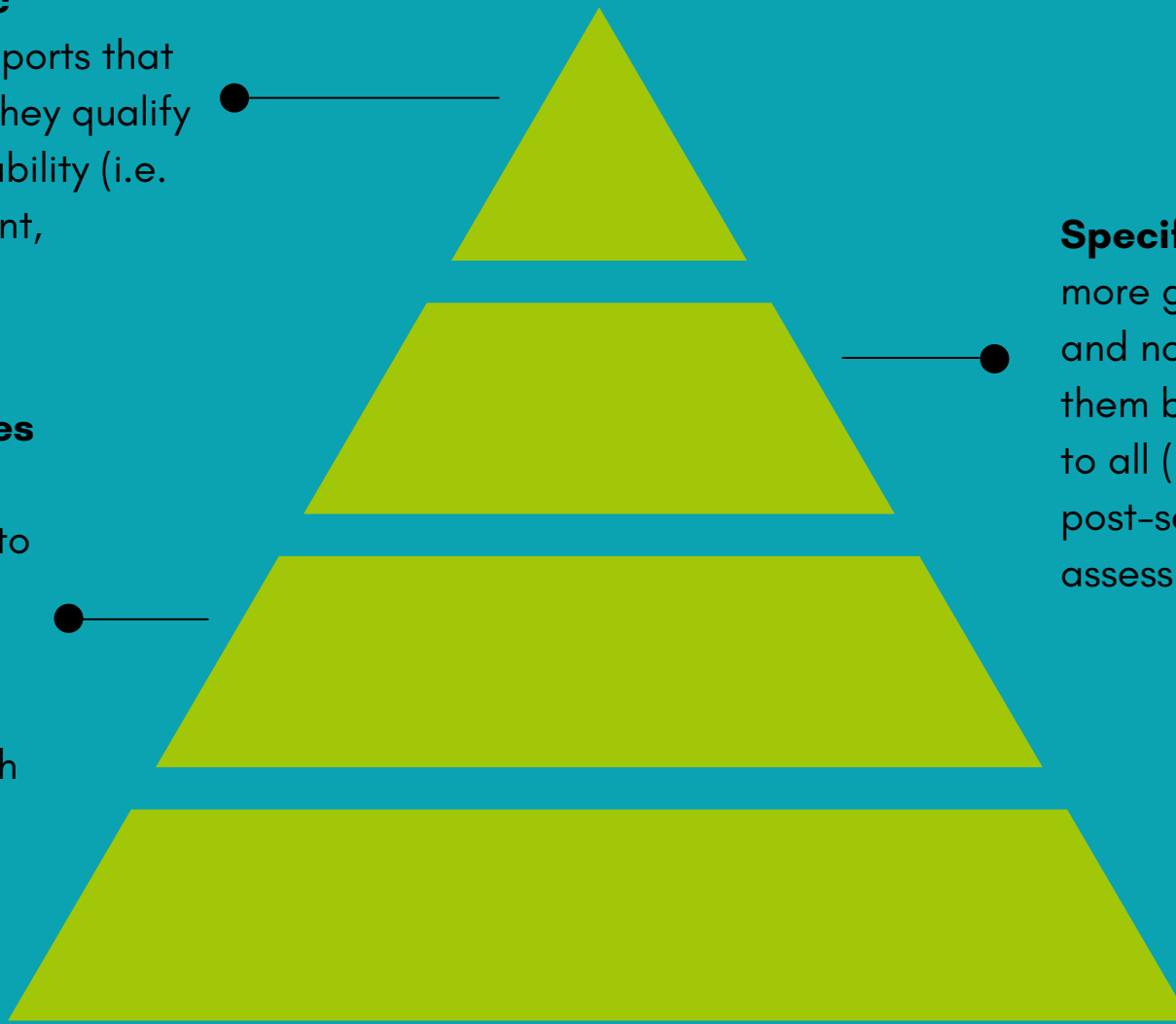
### Disability Specific

**Resources** are supports that one can access if they qualify for and have a disability (i.e. funding, employment, education)

### Generic Resources

are available to anyone from time to time in the community (i.e. sports, community based groups, faith communities)

**Specific Resources** are more governmental based and not everyone will use them but they are available to all (i.e. income supports, post-secondary supports, assessments)



**Natural Resources** are the relationships that we develop and support us throughout our lives (i.e. family, neighbours, friends)

Everyone utilizes at least one of the resources mentioned above in their lifetime. You and your loved one should be accessing all four, but try to focus less attention on disability-focused supports when it comes to community inclusion and more specifically on natural and generic resources.

# Supports Available from Birth-2

Early Intervention, PUF (Program Unit Funding), RSCD (Regional Collaborative Service Delivery), and FSCD (Family Support for Children with Disabilities) are four very prominent and important supports within this age group. It is crucial that you are always one step ahead of the services you and your loved one qualify for by applying for them as early on as possible.

## Early Intervention

Early intervention is key to accessing applicable disability supports and services in the beginning stages of your loved one's life. Early intervention is available at birth and can be utilized until your loved one is 3 1/2 years of age. For more information on this, you can speak to your doctor directly or visit <https://www.albertahealthservices.ca/findhealth/Service.aspx?id=5818>

## What is PUF?

PUF is Alberta Education funding allocated to school authorities that provides further support to children with disabilities as early as 2 years and 6 months of age who are attending early childhood education programs prior to Grade 1. This support can be accessed for a maximum of three years, with the last year intended for Kindergarten. School authorities are the ones who apply for this support, but the child must be eligible under the Special Education Coding Criteria to actually receive it.






For more information on PUF, visit [https://imforkids.org/program-unit-funding\\_puf](https://imforkids.org/program-unit-funding_puf) or contact your local school or school authority.

## What is RCSD?

RSCD is an approach where a coalition of service-providers (such as Alberta Health Services, school authorities, and other community stakeholders) work together to provide supports and programming that meet the learning and community needs of early childhood education and school-aged students with developmental disabilities. More relevant to this age group, an RCSD approach also supports children and youth with complex needs between the ages of birth-20 years. RSCD is funded through the Government of Alberta and distributed to the various service-providers in the 17 established regions across Alberta. For more information on this, visit the **Birth-2 Activities and Resources** section and look for the "**Regional Collaborative Service Delivery Factsheet.**"

## What is FSCD?

FSCD is a government based program that provides individualized supports and services to children with disabilities and their families. **In order to qualify for this services:**

-  The child must be under the age of 18
-  The individual applying for FSCD must be the child's parent or legal guardian
-  The child must reside in Alberta
-  The child has medical documentation that confirms either a diagnosis of a disability or health condition(s) that impacts their daily living
-  The child must be a Canadian Citizen or permanent resident

Along with providing information and referrals, FSCD offers funding for a wide range of supports and services that are based on each family's individual needs:

- individual and family counselling
- respite services
- aide supports
- child care supports
- specialized services for families of children with severe disabilities
- out of home placements
- assistance with some disability-related costs such as medical appointments, clothing/footwear, dental, medical supplies, prescription drugs, formulas, and diets

Families are still responsible in covering the typical costs of raising a child. Families should be accessing other relevant supports and resources available to them such as insurance coverage or health benefits plan before inquiring if FSCD will fund a similar service.

### FSCD Resource Links



*\*tap on each underlined statement to open the link*

- More info on [what you get out of FSCD](#)
- [How to apply](#)
- [FSCD office locations](#)
- [FSCD advisory committees](#)
- [Appealing an FSCD decision](#)
- Also check out the various documents for FSCD in the **Birth-2 Activities and Resources** section

### Questions to Ask

Every FSCD contract is different, so it is important that you know what to look and ask for to ensure that your family and your loved one's needs are being fully met and you understand how to navigate your individual contract. **Here are some questions to consider when communicating with your FSCD case worker:**

### FSCD Contract Questions

**Will my caseworker contact me, or do I have to contact them to set up a contract renewal meeting?**

**When is my contract renewal?**

**How do I submit claims for services that are used?**

**Is there someone who can help me if I have questions about submitting claims?**



**When will I receive my FSCD contract and when will I need to have it signed?**

## Respite Questions

Where can I find respite providers or staff?

Is there a list of agencies that can provide respite services to my family?

What wage should I pay my staff?

How many hours of supports will I receive?



## Specialized Services/Benefits Questions

Will I qualify for specialized services? (i.e speech pathology, occupational therapy)

What other supports can I access through my contract?

If I don't qualify, where else can I access these services?

Are there any supports for medical appointments and hospital visits?



Are there any supports for medical equipment and medications?

## Miscellaneous Questions

What is transition planning?

What is the conflict resolution process?



# More Supports and Resources

\*tap on each resource to open the link

## Child Care:



- [Inclusive Child Care Program](#)
- [Child Care Subsidy Program](#)
- [Child Care Lookup System](#)
- [ASap](#)
- [Pre-Kindergarten](#)

## Financial:



- [Child Disability Benefit](#)
- [Alberta Child Health Benefit](#)
- [Disability Tax Credit](#)
- [Employment Insurance Compassionate Care Program](#)
- [Registered Disability Savings Plan](#)

## Daily Living:



- [Alberta Aids to Daily Living \(AADL\)](#)
- [Augmentative Communication and Educational Technology Service \(ACETS\)](#)
- [Easter Seals](#)
- [211](#)
- [Alberta Supports Contact Centre \(ASCC\)](#)
- [InformAlberta](#)
- [Multicultural Health](#)
- [Jordan's Principle](#)
- [Tetra](#)
- [Family Resource Centres](#)
- [FASD Programs and Services](#)

## Health and Well-being:



- [Health Link](#)
- [Mental Health Helpline](#)
- [Office of the Health Advocate](#)

To stay organized and on top of the most prominent supports and services in this age group, go to **Birth-2 Activities and Resources - "Birth-2 Important Supports and Services Checklist"**

# Wrapping it Up



To end this section of the learning module, **here are some tips on how to effectively navigate supports directly from families themselves:**

Take the initiative to learn the medical language/jargon that service-providers use. This will help you in better understanding your loved one's situation and finding support that meets their individual needs.

Words to Know Resource:

<https://kidshealth.org/en/parents/special-needs-glossary.html>

Familiarize yourself with the different policies that regulate each service you qualify for to ensure that you and your loved one are getting as much support as you can out of them.

Do not get caught up in google! If you have any questions or concerns about your loved one, speak to a service-provider directly.

Do your own research around the different supports and services available, and try to find service-providers who share similar values and outlooks on life as you and your family. It is also important to build strong, healthy, and trusting relationships with such professionals.

If you connected with a service-provider who is not as knowledgeable or confident within disability perspectives as you'd prefer, you have the right to respectfully ask to be pointed in the direction of someone who is.

Be honest and open about your feelings, wants, needs and your loved one's with all service-providers you encounter.

Be transparent about the good, bad, and the ugly when it comes to your loved one and their circumstances. It can be difficult not to sugar coat things for fear of being judged, but service-providers need to know it all in order to support you and your loved one in the best ways possible.

# References

- "Gateway to Transitioning" Booklet
- "Welcome to the Family" Guide  
<https://open.alberta.ca/publications/9780778559320>





**ADVOCACY**

# Understanding Advocacy

## What is Advocacy?

Advocacy as a parent/caregiver of an individual with a disability means speaking on behalf of your loved one to ensure that their unique needs are being met and honoured. You are your loved one's most important advocate. You are the expert of your loved one and know them better than anyone else. This knowledge and how you begin to advocate for your loved one plays a crucial role in how they will live their life and advocate for themselves as they continue to grow.

## Importance of Parent/Caregiver Self-Awareness and Resiliency

Self-awareness and resiliency are two powerful skills to embody when advocating for your loved one. Self-awareness can be defined as being realistically familiar of who you are as an individual. It means knowing why we do what we do and how it impacts others. Having this familiarity with ourselves supports us in coping with relationships and experiences in our lives, such as the relationship you have with your loved one and your experience in advocating for them.

Resiliency is related to our ability to cope, adapt and bounce back after facing adversity. Advocating for your loved one will no doubt come with its challenges, so having a strong sense of resiliency supports you in being the best version of yourself and effectively pushing through barriers to advocacy. Both self-awareness and resiliency take time and continuous effort to establish and maintain. Engaging in regular self-care is a great way to develop and further these skills. **\*Go to: Personal Check-In Page - "Gateway to Maintaining Positive Well-Being", and "Self-Reflection Questions"**

## Stigma

As you begin to advocate for your loved one, you will notice and become familiar with stigma. Stigma is referred to as harmful attitudes or discrimination directed towards an individual or overall community with distinguishing characteristics such as disability, health condition(s), or mental illness. Unfortunately, there can be stigma in the very settings you expect to receive the most support and understanding from (family and friends, government services, doctor's, therapists, etc.)

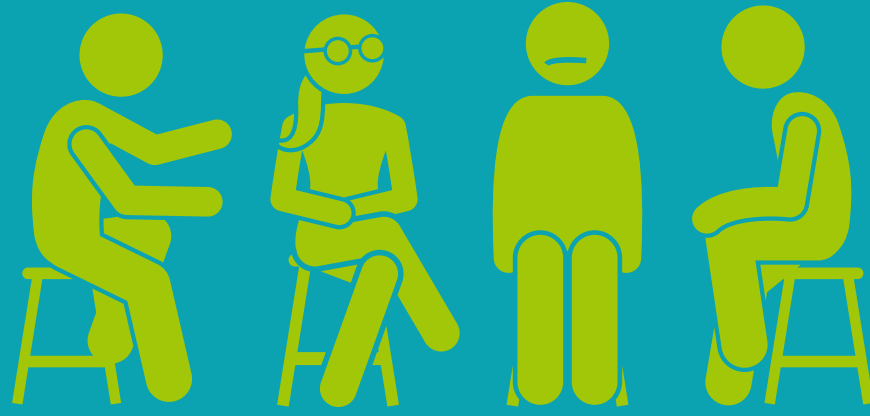
It is important that you are aware of stigma so that you can recognize it in your interactions with others and address it immediately. Developing strong advocacy skills will support you in this. **You can actively speak out or act against stigma when it happens by:**

- Respectfully questioning the individual as to where those ideas or behaviours came from with hopes to encourage them to reflect on their act
- Tell them how their comment or behaviour made you feel
- Take this as an opportunity to educate on disability
- Assess the relationship you have with the individual, especially if it is a service-provider, and decide whether or not this connection should continue
- Share three things with them about your loved one that you are proud of

"IT IS NOT OUR DIFFERENCES THAT  
DIVIDE US. IT IS OUR INABILITY TO  
RECOGNIZE, ACCEPT, AND CELEBRATE  
THOSE DIFFERENCES."



# Importance of Communication



Families have indicated that lack of communication between service-providers and parents/caregivers is a huge barrier to effectively advocating. This is especially apparent in services such as schools or day programs where parents or caregivers are not physically there to ensure that their loved one's needs are being met and taken care of. Having a clear method of communication between yourself and those who support your loved one not only helps you build healthy and trustful relationships with service-providers, but also creates a space for you to check-in with how your loved one is being treated.

Some families have created communication logs or booklets that they give to service-providers such as teachers, respite/support workers and activity instructors to engage with at the end of each day they support their loved one. **\*Go to: Birth-2 Activities and Resources - "Example of a Communication Log"** Others use social media as a platform for communication and have private Facebook pages where staff, family, and friends interact with each other to stay updated on their loved one's life. It is important that you establish a method of communication with service-providers that works best for you and your family.

# How Do You Advocate for Your Loved One?

There are various settings in which you will need to advocate for your loved one. Examples of these environments include schools, community programs, therapy settings, and hospitals. Whatever the scenario may be, **here are three steps of advocacy you can take when faced with an issue where your loved one is not receiving the care and attention they deserve:**



Have a clear understanding of the issue in which you are advocating for your loved one



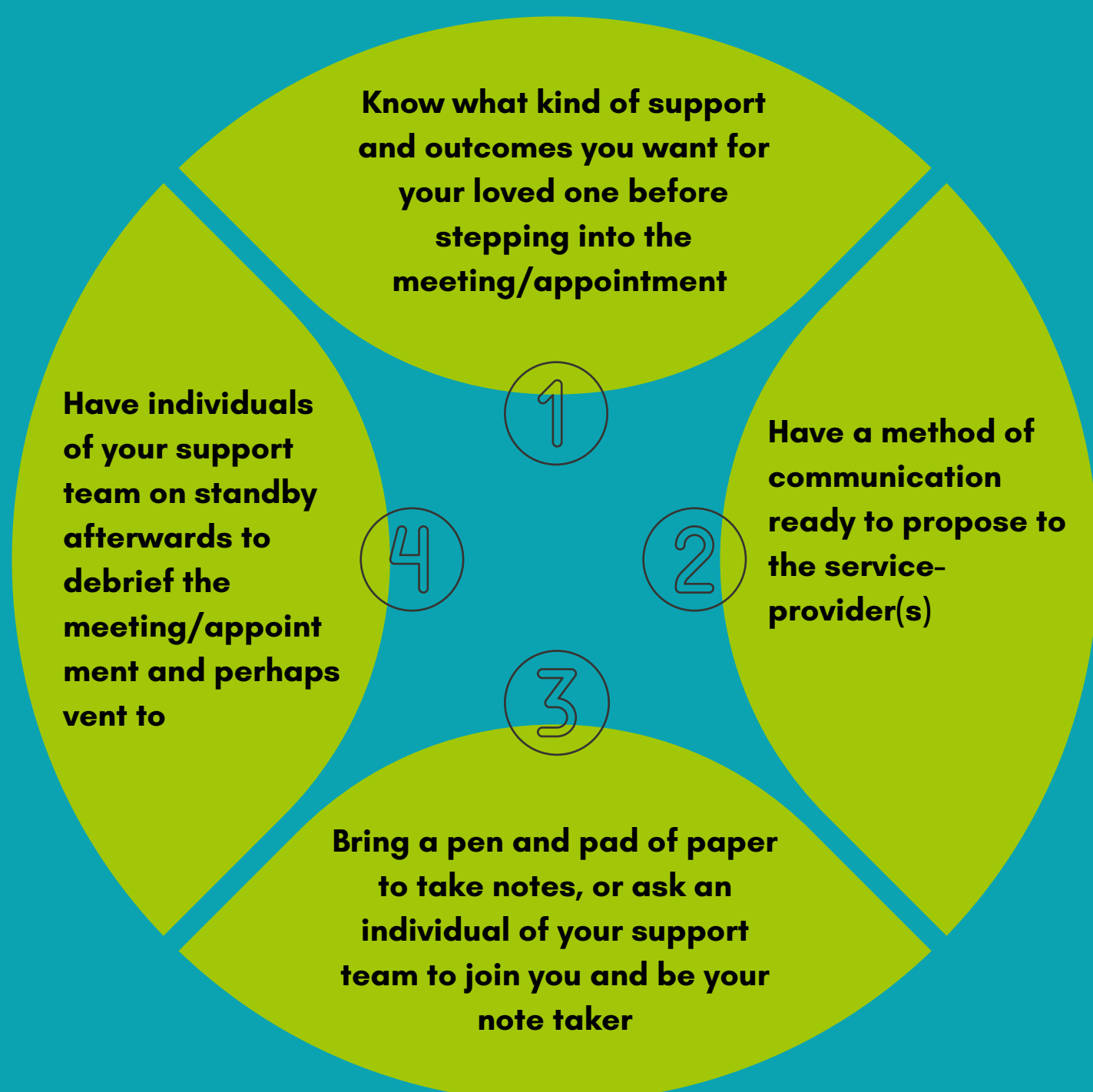
Think about what you want for your loved one, and keep an open mind to all possible solutions/ways to address the issue. Try to obtain as much information as possible in order to make an informed decision



Come up with and present a solution on how to move forward. Make sure to take into consideration both the potential positive and negative effects of this solution on your loved one

## Preparing for Meetings/Appointments

Being prepared prior to coming in contact with a new service-provider can be helpful to ease some anxiety and also support you in fully elaborating on you and your loved one's wants and needs within the working relationship you are about to establish. **Here are a few suggestions on how to get ready for meetings/appointments:**



# Tips for Advocating/Speaking Up



Believe in yourself and be confident in your choices – you are the expert of your loved one!



Keep a record of all notes you have taken and all documents received when engaging with service-providers.



Know your rights. Contact disability advocacy initiatives and community groups to get more information.



Get clear answers. Do not accept a verbal statement or denial of your request and instead ask for a written decision.



Use the chain of command. Speak to individuals who have the most authority.

# Wrapping it Up



The Advocate for Persons with Disabilities is an organization in Alberta that represents the rights, interests and well-being of individuals with disabilities. This can be a great resource for you to learn more about advocacy and encourage your loved one to be a self-advocate as they continue to grow.

Check out this link for more information!

<https://www.alberta.ca/advocate-persons-disabilities.aspx>



# References

- "Welcome to the Family" Guide  
<https://open.alberta.ca/publications/9780778559320>
- "Being an Advocate for Your Child"  
<https://raisingchildren.net.au/school-age/school-learning/working-with-schools-teachers/being-an-advocate>
- "What is Stigma?"  
<https://www.verywellmind.com/mental-illness-and-stigma-2337677#types-of-stigma>
- Difference Quote  
<https://musicandsunshine.com/blog/the-way-you-hold-your-phone-can-tell-a-lot-about-your-personality/>
- Resourcing Families: "Harness the Possibilities"



# **COMMUNITY INCLUSION**



# Understanding Community Inclusion

## What is Community Inclusion and Why is it Important?

Community inclusion means something different to everyone. It truly depends on your individual and family values and how you want your loved one to live in society. A universal understanding that families of individuals with disabilities share is that inclusion is not just about setting up opportunities for your loved one to engage with and be included in your local community, it is also supporting the community in understanding your loved one's abilities and how to work with their unique needs. Essentially, inclusion goes both ways.

A constant and typical expectation for your loved one should be community inclusion because it is detrimental to their social well-being and how they will live independent and wonderful lives as they age. Unfortunately we live in a world where the unique needs of individuals with disabilities are not fully accommodated for, so as parents and caregivers it is an important part of your role to find ways to foster community inclusion within your family and the outside world.

## 5 Dimensions of Inclusion



- **Social Cohesion:** this refers to sharing spaces and experiences with others who are different from yourself
- **Belonging:** this is a person's sense of where they fit in and how they feel a part of their community. Belonging comes from the connections and relationships you make in settings outside of the home
- **Community Involvement:** this relates to the extent to which you dedicate your time to supporting others and your community
- **Independence:** this is about self-determination and your ability to make the choices you want in life
- **Being Somebody:** this means engaging in self-discovery and finding out who you are and how others see you outside of the services you use

These 5 dimensions of inclusion can be helpful when understanding what community inclusion should look like for your loved one. Every individual needs a balance of all 5 areas in their lives to be their best selves.

# How to Foster Community Inclusion from Birth-2

**Sign up for activities that you and your loved one can do together with other children their age such as play groups, public library events, or faith/cultural community events**

**Start to think about the activities that you would like your loved one to engage in as they get older**



**Access a mixture of both inclusive and segregated or disability specific activities/programs/groups**

**Set the tone within your family dynamic as inclusive**

## **Signing Up for Activities:**

- Children within this age group learn and thrive the most from each other. Placing your loved one in environments with others who are around the same age not only fosters community inclusion, but it also supports their growth and development
- Attending activities regularly increases the chances of becoming known and getting to know others. These connections are an important piece of community inclusion
- Engaging in such activities *with* your loved one in this age group can further strengthen the bond you two have and also be a comfort to them as they begin to interact with the outside world

## **Thinking About Future Activities:**

- What type of activities did you enjoy as a child? What do you enjoy now as an adult?
- These questions can be the basis for brainstorming the activities you can begin to set up for your loved one as they age
- You will discover that as your loved one experiences new things and grows, they will develop their own interests. This will be a very important guide in how you foster community inclusion and what activities you support your loved one in engaging in

### **Inclusive vs Segregated Activities/Programs:**

- Inclusive activities or programs means that they are available to all individuals of different abilities
- Such activities may take some advocacy work towards accommodation, but inclusive experiences can be very meaningful in your loved one's life and absolutely worth the push
- They also support your loved one in overcoming social exclusion within society
- Daycare is a great example, as most daycares or early childhood programs have shifted towards a more inclusive approach **\*Go to: Birth-2 Activities and Resources - "Meaningful Inclusion in Early Childhood" video**
- Segregated activities/programs are dedicated specifically to individuals with disabilities and are accommodated based on such (autism support groups, Special Olympics, etc.)
- You will want to start with a mixture of both, but as your loved one gets older you should be focusing more on inclusive activities and programming
- Think about what accommodations are needed in the activities/programs you want your loved one to engage in rather than what is already accommodated for
- **Here are some check-in questions to keep in mind when supporting your loved one with accessing community activities and programming throughout their life:**
  - Are segregated activities/programs absolutely essential to their overall well-being?
  - If so, how can I support my loved one in moving away from that dependency?

### **Community Inclusion Within Family Dynamic:**

- In this age group, it can be beneficial to start with building a strong sense of community in your family home or with other family members for your loved one
- This sets the tone for your loved one on how they should be treated and engage in society
- You can do this by setting up activities that you can engage in together as a group in the community
- If you have other children, siblings will be your loved one's first and lifelong friends
- It is important that you nurture this connection and avoid shielding your other children from your loved one's disability
- It is quite natural for siblings to be involved and support each other. Typically siblings know how to best include their loved one in what is happening around them and can start doing this at a very young age
- Much of your attention will be on your loved one with a disability as they will need that little extra support and guidance, but make sure that you also dedicate energy towards spending time with your other children individually and express how appreciated and valued they are in the family unit
- If you have a partner, foster inclusion within that relationship by valuing and uplifting communication, honesty, and non-judgement **\*Go to: Welcome Package/"Gateway to Building Community" Guide - "What to Expect - Family Tension"**
- Family Gap Plan: <https://www.mother.ly/brene-brown-family-gap-plan-manage-stress>

# Wrapping it Up



It is important to note here that while you are working towards setting up opportunities for your loved one to engage with society, you should be dedicating time to include yourself in community as well. This could mean joining special needs parent/caregiver support groups online or in-person, playing on a sports team or attending a class. Whatever peaks your interests and gets you involved with others outside your household. Practice what you preach and don't just say how important getting out into the community is to your loved one, *show* it and take a well-deserved break while you're at it too!

# References

- Resourcing Families: "Harness the Possibilities"
- "Gateway to Transitioning" Booklet



# Moving Forward

We hope that this "**Birth-2 Learning Module**" has given you the knowledge and resources needed to begin navigating and creating a wonderful life for your little loved one.

So, what's next?

- Keep this learning module close and review it as your loved one transitions through this area of life
- Check out all the other great information in the **Birth-2 Activities and Resources** section
- If your loved one is coming up to the age of 3, consider interacting with the "**3-5 Learning Module**" and its accompanying activities and resources when you feel ready. Remember that being one step ahead of the game can support you in ensuring that you and your loved one are receiving all the relevant supports and information needed, but do not overwhelm yourself!
- Tell others you know or encounter about the **Caregiver Roadmap** module-based learning experience and the Gateway App overall

As you interact with the other learning modules across the lifespan you will notice some duplicate knowledge, resources, and activities. This is because we want to meet all parents, caregivers, and families where they are at in their journeys. We recognize that some parents and caregivers may not have learned their loved one has a disability and/or found out about this resource until later on in life.

If you encounter information that you have already engaged with, take it as a review or pass it on to someone else who you think it would be useful to.

