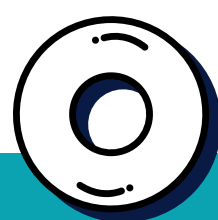
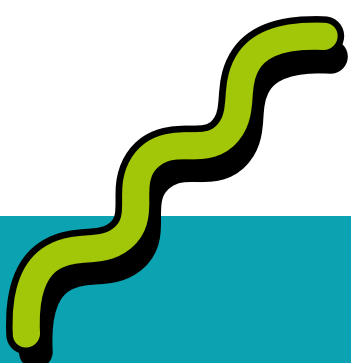
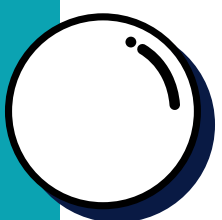
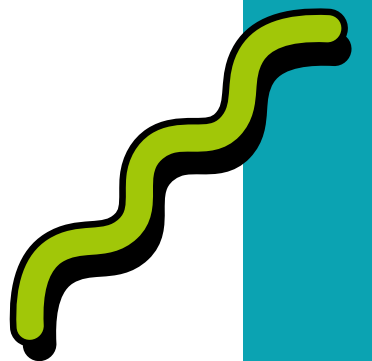


40-50 LEARNING MODULE



Introduction

This learning module will centre the knowledge and actionable steps that families have deemed essential to engage with during the 40–50 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.

Stages of a Transition

Although everyone copes with transitions in different ways, we all experience three stages while understanding the change process:

1

Ending/leaving the past: this is the initial reaction we experience when change is occurring. It can be either unconsciously or consciously. Typical emotions during this stage include shock, denial, anger, and frustration towards the loss that accompanies the transition. When your loved one is going through this stage of their transition, it is important for you to put on your active listening hat. Be a safe space for them and validate their feelings.

Here is a question to ask yourself when supporting your loved one through ending/leaving the past: *"Am I being empathetic and respectful of what my loved one is feeling?"*

2

Exploration/floating: this phase can be chaotic. It is the phase of not knowing. Not knowing who we are, where we want to go, and what is currently happening in our life. Typical emotions during this stage include fear, confusion, uncertainty, stress, indecisiveness, discouragement, skepticism, creativity, and ultimately acceptance. This is often the longest stage of a transition as we work to discover, explore, and accept our new reality. As the parent or caregiver, this is the stage where you start communicating with your loved one about adapting to change by explaining or modeling new ways of doing things until they find the right fit for them.

Here is a question to ask yourself when supporting your loved one through exploration/floating: *"Am I encouraging creativity and manifesting the environment that is needed for my loved one to find a new way to operate?"*

3

New beginnings/moving forward: this is the final stage where we begin to accept the new phase of life and the challenges that accompany it. Typical emotions during this stage include anxiety, hope, enthusiasm, and impatience. Individuals may start to physically doing things the new way, but until they fully identify with the new way the transition is not complete. The purpose of new beginnings is to be fully engaged in making the new way work. You should continue to support and hold space for your loved one at this point in their transition. Be honest and direct when they ask questions.

Here are two questions to ask yourself when supporting your loved one through new beginnings/moving forward: *"Am I celebrating their success and reinforcing the attitudes and behaviours needed to make the change?"* *"Am I a role model for the new way?"*

What do Life Transitions Look Like from 40-50?

Sometimes within this age group, individuals can feel saddened and stuck on what transitions are next for them in life as all the "typical" coming of age milestones have been completed. This can be referred to as a midlife crisis. It is important to note here that new realities and transitions do not have an age limit, and you should never limit your loved one (or yourself for that matter) in discovering what those are at any point in life. Remember, life is what you make it!

Below are some examples of potential/common life transitions from 40-50:

1 College/University or Other Life Long Learning Opportunities

Your loved one might be curious to pursue further learning opportunities. Whether this be in a college/university environment (its never too late to go back to school!) or other outside learning communities, It is still important for you as the parent/caregiver to support and encourage them in discovering their learning interests and help them find outlets where they can exercise their minds in a way that speaks to them. **Some questions that you can ask to foster this conversation are:**

? **What is your loved one interested in learning? Have them list 3 skills.**

? **Do they want to go to college or university?**

? **What classes, workshops or groups are available that reflect their interests and where are they?**

A learning community can be built in any setting where a group of people who share a common interest connect with one another and gain knowledge and life experiences together. **Here are some examples of how your loved one can build a learning community and engage in lifelong learning opportunities:**

- Community College non-credit classes
- Public Library programs
- Community leagues/groups
- Art Galleries
- Social Media
- Volunteering

For resources on inclusive learning, go to the **Navigating Supports** section of this learning module.

2 Changing Career Paths

If your loved one has already established a career, perhaps they are interested in changing paths and engaging in new work as a challenge. Employment is an important milestone for individuals with disabilities because not only does it provide them with an income, but it also fosters social participation and inclusion. Gateway offers various employment programs for job seekers 15-65 years of age. For more information on these programs and how to support your job seeker, visit <https://gatewayassociation.ca/inclusive-employment/> and check out the **Employment Section** in the **Learning Centre** on the **Gateway App**.

3 Continuing Care

Depending on the health and condition of your loved one at this age, there might need to be a reassessment of their living circumstances. Do they live on their own? Do they have roommates and/or home care staff? Who does their care? Have their care needs increased with age? After addressing these questions, **there are three continuing care solutions that you and your loved one can choose from:**

- **Home Care** - your loved one might already have this, but this option should be at the top of your list as you want to ensure that they are independently thriving in their own space for as long as possible
- **Supportive Living** - within this setting, your loved one is able to remain independent in a home-like living situation (such as a lodge or group home) and have immediate access to care supports
- **Long-Term Care** - this option should be last resort where your loved one's care needs have become complex and it is no longer safe for them to live independently in their home

For more information on continuing care options, visit <https://www.alberta.ca/about-continuing-care.aspx#jumplinks-0> and go to the **Navigating Supports** section of this learning module.

4 Planning for the Death of Parent(s) or Primary Caregiver and Loved One

These conversations can be tough, but facilitating them and having a plan as early on as possible carries benefits for both you and your loved one. It is important that you are already having open and honest communications about what death is and why it happens before getting into the legal preparation of estates and wills. Your loved one should be actively included in all estate and will planning, especially when it comes to themselves.

For information on how to talk to your loved one about death, visit <http://reifpsychservices.com/talk-to-someone-with-intellectual-disability-about-death/> and go to **40-50 Activities and Resources - "Advanced Care Planning Package"**

For information on will and estate planning visit <https://www.aflawyers.ca/estate-planning-for-persons-with-disabilities/> and <https://www.spectrumfamilylaw.ca/blog/2020/11/23/wills-estate-planning-guide-alberta/>.

Inappropriate Attachments and Self-Determination

In the earlier stages of your loved one's life, a healthy level of attachment to you is needed in order for them 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 individual can become overly dependant on you. 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, it hampers the individual's ability to be independent and successfully transition throughout the lifespan.

Here are some questions to keep in mind that reflect on the relationship you have with loved one as you continue to 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?

Self-determination can be understood as one's ability to control and determine their own life outcomes. Self-determination is an important skill to nurture in your loved one's life because it can set them up for successful transitions across the lifespan. **Here are some steps on how to encourage ongoing self-determination for your 40-50 year old loved one:**

- **Foster decision making** by presenting situations where your loved one gets to decide the best possible solution that fits their individual needs
- **Encourage problem solving** by providing them with a safe space to figure out solutions towards the challenges that arise in their life
- **Support goal setting and planning** by helping them identify an objective and cultivating a plan to achieve it
- **Promote responsibility** by strengthening their adult life skills like paying bills and budgeting ***Go to: 40-50 Activities and Resources - "Money and Budgeting"**
- **Nurture independence** by preparing and inspiring your loved one to engage in activities or tasks without your immediate support, such as attending a group or program that they are interested in alone or with a respite worker
- **Support Communication** by uplifting your loved one to self-express and share their feelings with you and deeply listening and validating them in the process

- **Provide reinforcement and feedback** by identifying to your loved one which behaviours are appropriate or inappropriate and teaching them why they are deemed as such. This supports your loved one's social emotional development
- **Reinforce self-directed behaviours** by praising them when they engage in monitoring or evaluating their own behaviours or provide their own reinforcement
- **Support self-awareness and self-knowledge** by fostering the skills they need to be aware of themselves and who they are
- **Encourage relationships and social connections** by connecting your loved one to the community

Pointers for an Effective Transition Process

It is important to note that there might be other transitions that your loved one will 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

Be flexible

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

What will the outcome be?

What is the purpose of the transition?

Family/Friends

You - you know your loved one better than anyone!

Provide information and structure on the transition process

What is the plan to make the change happen?

Lean on others around you for support

What part will each person involved play?

What are the options?

Gateway Association

Medical professionals, counsellors, and other practitioners

Understand failures as an opportunity for growth and learning

Show your loved one that they are on a learning curve when they try and do not succeed

Reframing Failures with 'Not Yet' Concept

Go to 40-50 Activities and Resources - "Not-Yet Parent Activity"

Praise the process they engage in

Focus on their perseverance, focus and improvements made

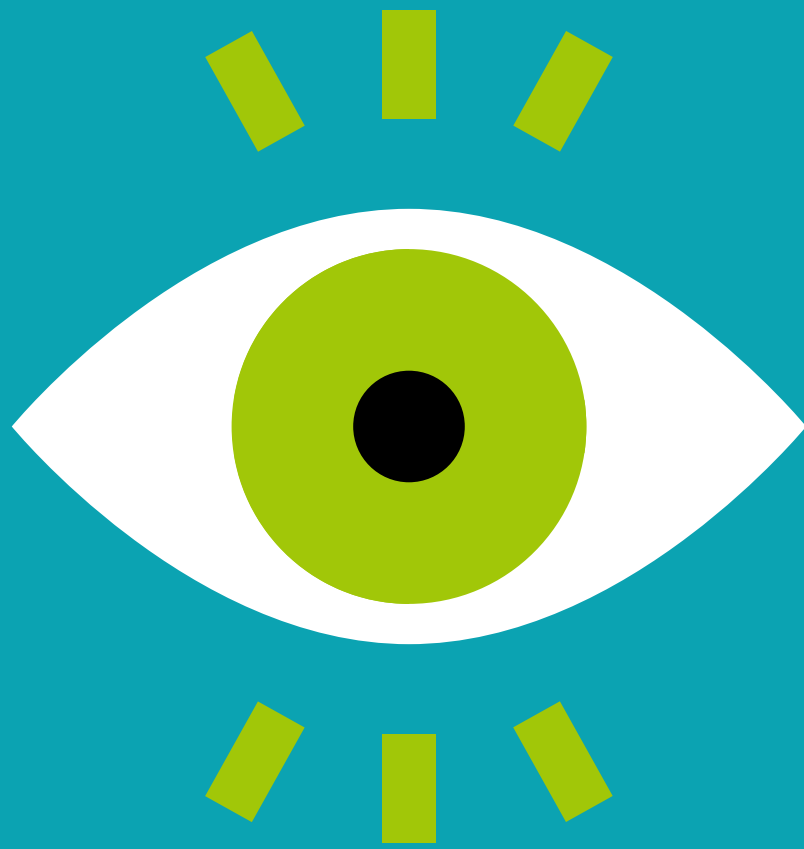
Wrapping it Up



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 continue to age.

References

- "Gateway to Transitioning" Booklet
- "Visioning and Valued Roles for Young Families" PowerPoint



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 40-50?

You will still play a significant role in supporting your loved one to create a vision for their immediate future, but within this stage of life the entire focus should be on what your loved one wants. This can be done by simply fostering communication around their dreams and aspirations. **Here are some ways that you can support your loved one in establishing and understanding their own vision:**

- When asking what your loved one's dreams and aspirations are, you may get some interesting answers. They may want to be a mermaid, superhero, live in a mansion, or be famous. It is important to try and get under the surface of where these dreams and aspirations are coming from. If your loved one wants to be a superhero, find out why. What makes being a superhero so attractive to them? It could be that they want to help others. Massaging out the meaning of these big dreams and aspirations will help you in setting a more realistic vision that you can begin to work on with your loved one that still stays true to what they want
- Never shut down your loved one's dream!
- If your loved one is non-verbal or has limited communication, encouraging them to create their own vision means playing off of who they are as a person and what makes them smile. You can ask others who interact with your loved one what catches their attention. You can also use pictures, videos, noises, and actions to help both you and your loved one understand what their dreams and aspirations are. Do not limit your loved one's potential just because they use a different form of communication than you!
- If your loved one is having troubles deciphering what their dreams and aspirations are, you can support the uncovering of them by introducing new activities, exploring the visions that others have around them, and encouraging your loved one to think deeper about what they want in life. What is most important to them right now? What does a good life look like for them?
- You can also introduce the Quality of Life Framework and use this tool as a basis for your loved one's visions going forward. ***Go to: 40-50 Activities and Resources - "Quality of Life Framework"**

Suggested Focus Areas for Vision



Good home: what would they want their future living arrangements to be like?



Learning: post-secondary or no? What other learning opportunities are they interested in?



Choice: how will they make their own choices in life?



Variety of relationships: what kinds of people do they want to be surrounded by? How will they foster these relationships?



Employment: how can their interests be connected to employment?



Building community: what community do they want to belong to? Who do they want to associate with?

Remember that the possibilities for visioning are endless, and don't let anyone limit them for your loved one. As you go along, always plan for the person and not the disability. There is no disability in a vision!



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

Moving Past Resistance

As you support and encourage your loved one through visioning, you may start to receive some resistance from them. There are many factors as to why they may act out in this way such as feeling pressured, not agreeing with what you or other family members suggest or not having a well-rounded idea of what they want their vision to be and how to pursue it. **If your loved one is engaging in resistance, here are a few ways that you can work through it:**

- Examine and assess the communication that is going on within the family and overall support unit. Are there open, honest, and respectful conversations being had between your loved one and all other members of their support circle?
- Ensure that you are having collaborative conversations with your loved one where their perspectives and emotions are being actively heard and validated
- If the resistance is coming from a disagreement between your loved one and either yourself or other members of their support circle, find a point of alignment where at least one thing is identified that everyone is on the same page about. Then, have a conversation around what small steps can be taken towards that
- Shift from directive communication with your loved one to indirect and be more of a coach

Tips For Planning and Implementing Visions



Encourage your loved one to create a *vision board* that uses imagery to capture their vision and what it entails as a reminder to what they are working towards. ***Go to: 40-50 Activities and Resources - "How to Create Vision Boards" & "The Big Picture"**



If they are less of a visual learner and enjoy putting written thoughts on paper, get them to write a *vision statement* instead. ***Go to: 40-50 Activities and Resources - "Writing a Vision Statement Activity"**



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

- *You can do (blank) this year/in the future to start moving towards the vision*
- *You can try (blank) to achieve your set goals*



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

- *What do you need to complete the goals?*
- *Who needs to be involved for you to achieve the goals?*



Get more people involved in planning and implementing the vision and share the 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 your loved one to think of potential visions that they may have never even thought of before.



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

- *What have been your strengths or successes?*
- *What needs more work or support?*
- *Is what you are doing today getting you closer to the vision?*

If your loved one is non-verbal or has limited communication, they may need some more guidance and support when working towards planning and implementing their vision. Stick with and rely on the form of communication that you typically use and remember to include them in this process as much as possible. This type of collaboration towards their life decisions shows them that they still have control and the ability to self-determine the paths they want to pursue across the lifespan.

Planning and Implementing Resources

**tap on each resource to open the link*

- [Empowering Abilities Life Plan Coaching Program](#)
- [Microboards](#) ***Please note this is a resource from BC, but it's information is still valuable for all families planning for their loved one's adult life**

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 40-50?

Valued roles are an important component towards connection, inclusion, and independence. You should still have an idea of the roles you want your loved one to carry, but you need to be focusing all your energy on finding out what roles they want for themselves. **Here are some questions that you can either ask yourself and/or your loved one directly to better understand where their valued role interests lie:**

What could your loved one teach others?

What product or service would they enjoy selling?

What positive qualities do others say they have?

What support would they need to help others?

Your loved one may need more of a push in understanding what valued roles work best for them. It is important that you pay close attention to their reactions and/or communicate with them to ensure that the roles they are engaging in align with their changing preferences and interests. Remain flexible, and adjust your influence and supports when needed.

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. With that being said, you should still be directly working from your loved one's interests when figuring out what their roles will be. No matter the circumstances, all individuals deserve the chance to establish and carry some type of valued position in their life.

Tips on Creating Valued Roles

Social Role Valorization is an idea widely used for encouraging positive transformation in the lives of individuals who are considered "disadvantaged" in society. **There are five core values of SRV that can guide you in supporting your loved one to create valued roles for themselves:**

Expectations



Have high expectations for your loved one and set the bar high.

Growth



All individuals have the ability to change, learn, and grow. In some instances it may require more risk taking, but it is always possible.

Imitation



A powerful way for someone to learn valued roles is through good role models who they are able to identify closely with.

Community Life



People learn best by doing things in the environments that they are typically done in.

Good Image



Focus on images that align with your loved one's age group and avoid images that show people set apart from the broader community and grouped together.

For more information on Social Role Valorization, go to: **40-50 Activities and Resources - "Social Role Valorization"**

Wrapping it Up



Visions and valued roles are not static and are ever-changing as your loved one continues to live their life. Their individual visions and valued roles will develop and change as they experience new opportunities and circumstances. As a parent or caregiver, developing and sustaining a well-rounded understanding of visioning and valued roles 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
- "Visioning and Valued Roles for Young Families" PowerPoint
- Vision Quote
<http://www.picturequotes.com/limited-vision-quotes>



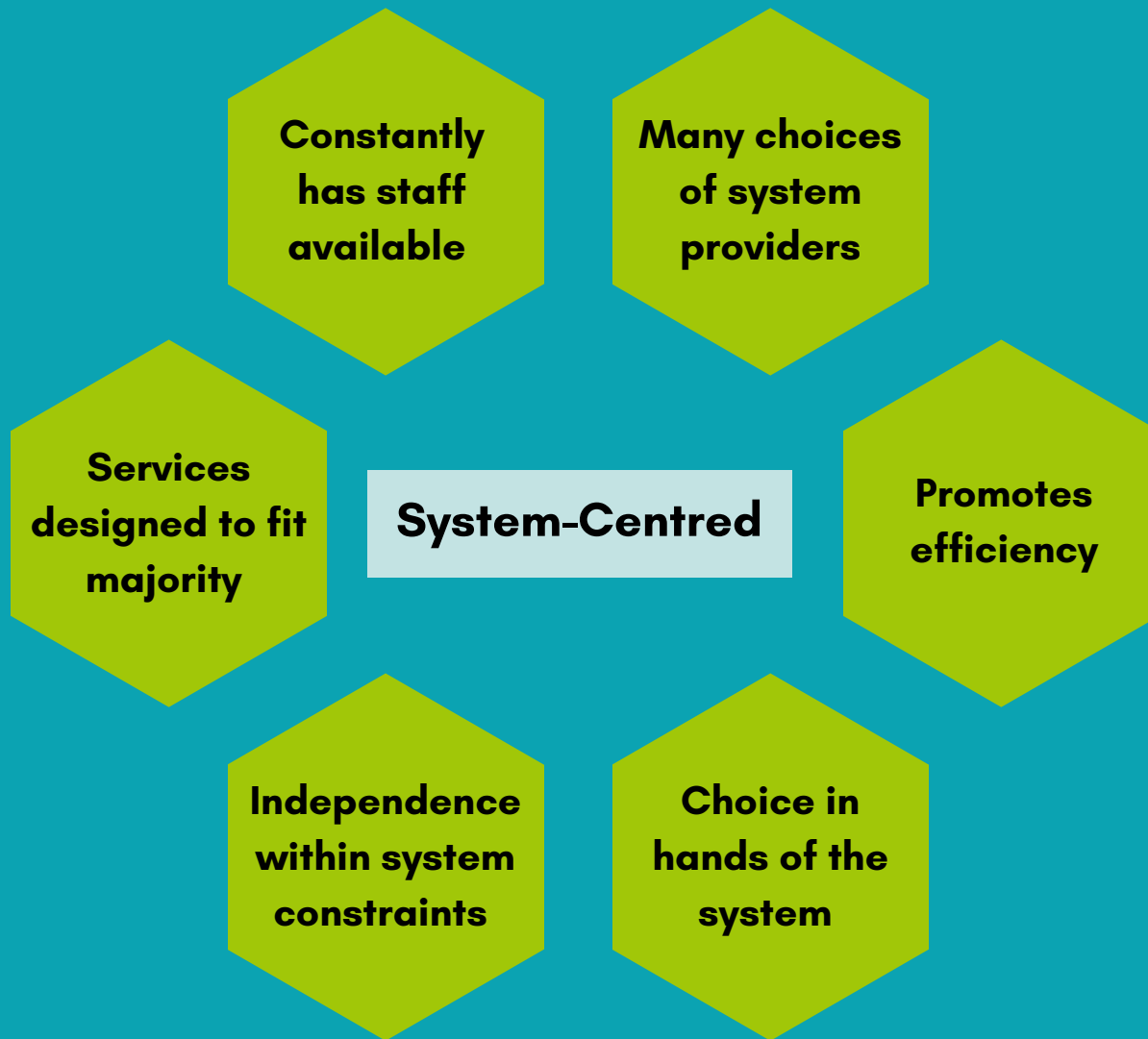
NAVIGATING SUPPORTS

Understanding Approaches to Supports and Resources

Person-Centred vs System-Centred Approaches

As you navigate supports and resources for your loved one you will notice that there are two prominent approaches utilized; 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

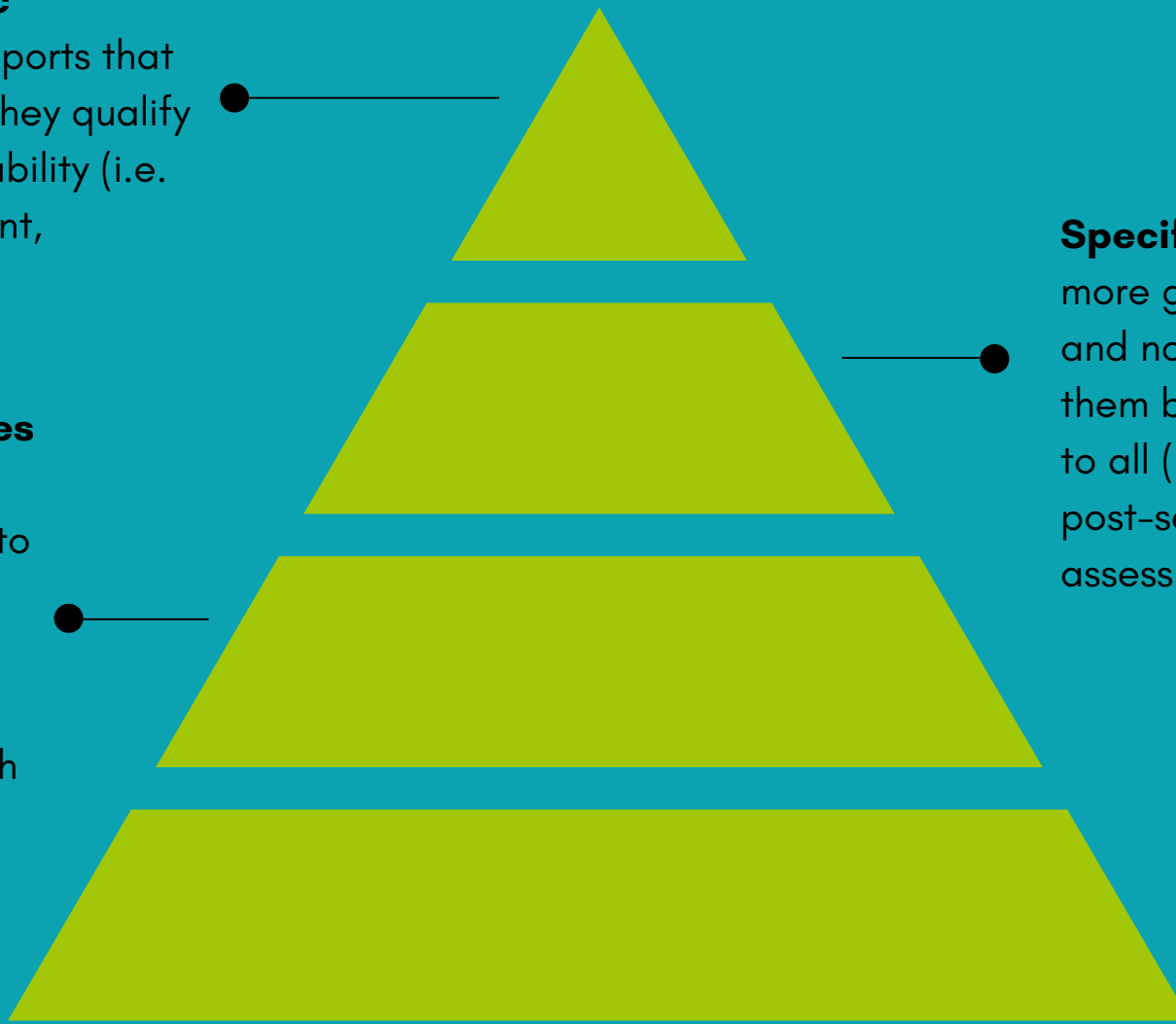
Disability Specific

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 40-50

AISH (Assured Income for the Severely Handicapped), and Public Guardianship and Trusteeship are two very prominent and important supports within this age group. It is crucial that you are always one step ahead of the services your loved one qualifies for by applying for them as soon as possible.

What is AISH?

AISH is financial and health benefits for individuals living with a permanent disability or medical condition that prevents them from earning a living. **In order to qualify for this service:**



Your loved one must be living with a lifelong or permanent disability



Your loved one must be at least 18 years of age



Your loved one requires employed related funding *NOTE: an individual can be employed on AISH, but the amount received is affected by income



Your loved one must live in Alberta and not be living in an institution (i.e corrections facility or psychiatric hospital)



Your loved one must be a Canadian citizen or permanent resident

For more information on how to apply for AISH, visit <https://www.alberta.ca/aish-how-to-apply.aspx>
For extra resources on what AISH provides, go to **40-50 Activities and Resources - "Tipsheet AISH Facts", "Tipsheet AISH Personal Benefits", and "Tipsheet AISH Health Benefits"**

Guardianship and Trusteeship

Some young adults may still require assistance with decision making. In this instance, the parent or caregiver can apply for guardianship. **There are other personal decision-making options to consider other than adult guardianship:**

**tap on each option to open the link*

- [Supported decision-making](#)
- [Personal directive](#) (an adult cannot have a guardian if they have a personal directive)
- [Specific decision-making](#)
- [Co-decision-making](#)

An individual in need of guardianship has the choice of receiving a private guardian (a person that is well-known to them) or a public guardian (appointed through the Office of the Public Guardian). The guardian's responsibilities include making decisions on various matters of the individual's life, but excludes any financial decision-making power. If the individual requires assistance with such, the guardian can also apply for **trusteeship**. The applications for guardianship and trusteeship can be done together or separately.

For more information on adult guardianship and trusteeship and how to apply, visit <https://www.alberta.ca/adult-guardianship.aspx#jumplinks-0>. If you require further assistance with the application process, you can reach out to [Alberta Supports](#).

What Happens When Your Loved One is Not Eligible for PDD?

There are cases where individuals do not meet the eligibility criteria for Persons with Developmental Disabilities supports. With this often comes a panic of what to do next. **There are various resources out there to access if your loved one does not qualify for PDD services:**



Gateway offers a transition resource fair every 3rd Wednesday of each Month at 7pm via Zoom. They discuss a range of topics and all parents, caregivers, and families are welcome to attend. For more information on this, visit <https://gatewayassociation.ca/not-pdd-eligible-now-what/>



Alberta Supports assists seniors, people with disabilities, job seekers, parents/caregivers and families gain access to various programs and services. Their focus areas also include homelessness, financial assistance, abuse, and family violence prevention. For more information on Alberta Supports, visit <https://www.alberta.ca/alberta-supports.aspx>



CHAT, which stands for Communities of Service Helping Albertans Transition, are meetings held for complex citizens where there is a concern they will encounter numerous gaps in service. For more information on this resource, go to **40-50 Activities and Resources - "What is CHAT?" and "CHAT Referral Form"**



211 Alberta can help you find programs and services in your community through a variety of support topic areas. Visit <https://ab.211.ca/> for more info.



Disability Related Employment Supports provides services to inspire individuals with disabilities to succeed in school and obtain rewarding and meaningful careers. For more information on this service, visit <https://www.alberta.ca/disability-related-employment-supports.aspx#toc-1>

More Supports and Resources

*tap on each resource to open the link

Post-Secondary/Lifelong Learning/Employment



- [On Campus Program](#)
- [Inclusion Alberta - Inclusive Post-Secondary](#)
- [Resources for Students with Disabilities](#)
- [ALIS](#)
- [Transitional Vocational Program](#)
- [Transition to Employment Services](#)
- [Disability Related Employment Supports](#)
- [Internship for Persons with Disabilities](#)
- [Disability Employment Awareness Month](#)
- [Meetup](#)

Financial:



- [Employment Insurance Compassionate Care Program](#)
- [Registered Disability Savings Plan](#)
- [Canada Student Grant for Services and Equipment](#)
- [Canada Student Grant for Students with Permanent Disabilities](#)
- [Application for Refund of Federal Excise Tax on Gasoline](#)
- [Canadian Government Grants for Disabled Homeowners](#)

Health and Well-being:



- [Health Link](#)
- [Mental Health Helpline](#)
- [Office of the Health Advocate](#)
- [Protection of Persons in Care](#)

Daily Living:



- [Alberta Aids to Daily Living \(AADL\)](#)
- [Augmentative Communication and Educational Technology Service \(ACETS\)](#)
- [Easter Seals](#)
- [211](#)
- [Alberta Supports Contact Centre \(ASCC\)](#)
- [InformAlberta](#)
- [RAMP](#)
- [Multicultural Health](#)
- [Tetra](#)
- [Access2](#)
- [Air Canada Accessibility Services](#)
- [WestJet Attendants](#)
- [Home Care](#)
- [Continuing Care Options](#)
- [Community Access for People in Continuing Care](#)
- [Affordable Housing Programs](#)
- [Family Resource Centres](#)
- [Specialized Support Services](#)
- [Brain Injury Supports](#)
- [Parking Placards](#)
- [Driver's License Test Prep](#)
- [FASD Programs and Services](#)

To stay organized and on top of the most prominent supports and services in this age group, go to **40-50 Activities and Resources - "40-50 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
- "AISH Eligibility Tipsheet"



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. During this stage in their life you will still play a crucial role in advocating for your loved one, but it is important that you also begin passing down the skills needed to promote and stand for themselves.

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. ***See Personal Check-In Page - "Gateway to Maintaining Positive Well-Being", and "Self-Reflection Questions"**

Stigma

As you 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.)

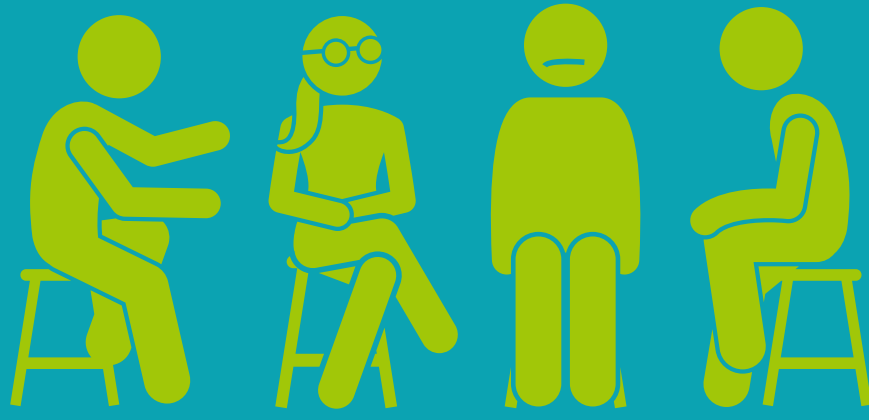
It is important that you are aware of stigma so that you can recognize it in your interactions with others and address it immediately. Developing strong advocacy skills will support you in this. **You can actively speak out or act against stigma when it happens by:**

- 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 and Consent



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. ***See 40-50 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.

Consent

Consent is also a significant communication tool to incorporate in service-provider relationships. It is crucial that you teach your loved one about consent and healthy boundaries to not only foster and increase their autonomy, but ensure their safety within the various working and personal relationships they will have in their lifetime. **Here are some ways in which you can actively nurture consent with your loved one:**

Always give your loved one the opportunity to make choices and have opinions on whether they want to do something or not

Remind your loved one that their body belongs to them and if they don't want to be hugged, touched, tickled or kissed than they have the right to say so



If your loved one has limited communication or is non-verbal, come up with hand gestures that represent when they do or do not consent to something

If the medical practitioners you encounter do not ask for permission before each time they touch/examine your loved one, tell them that you are focusing on fostering consent and ask them if they can support you in doing this

How to 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



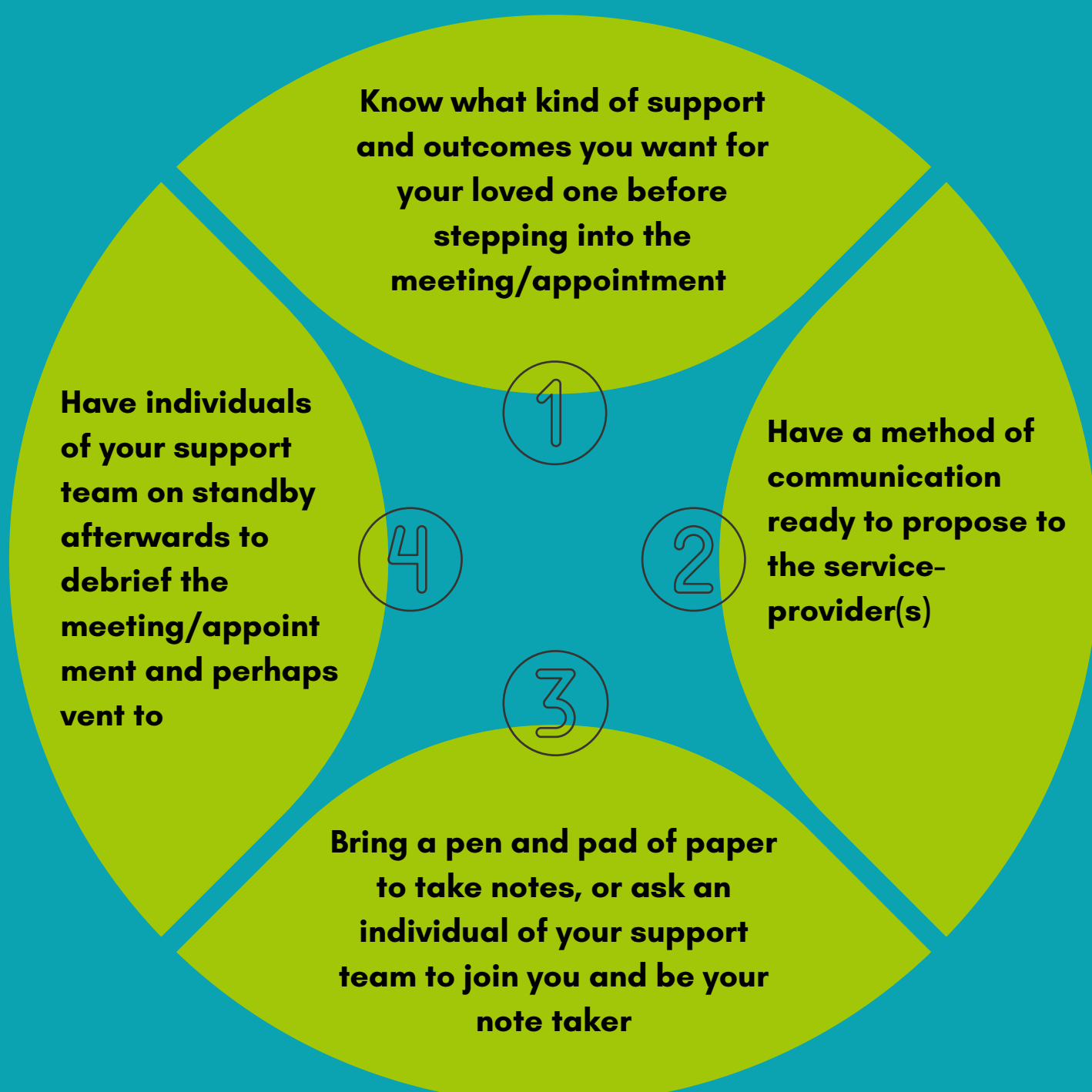
Think about what you and your loved one wants for them and keep an open mind to all possible solutions/ways to address the issue. Try to obtain as much information as possible in order to make an informed decision



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

Supporting Your Loved One in Being a Self-Advocate

What is Self-Advocacy?

Self-advocacy is best defined as our "voice" that gives us the ability to represent ourselves in the world. It is a skill that can be developed by learning how to better manage predicaments we find ourselves in and promote what is individually important to us. Self-advocacy is an important skill to foster with your loved one because it supports them in going on to live independent and meaningful lives.

Self-Advocacy Characteristics

Self-Awareness

- Interests, strengths, & preferences
- Goals & dreams
- Support/accommodation needs
- Characteristics of one's disability or health condition
- Responsibilities

Knowledge of Rights

- Personal and community rights
- Human service rights
- Consumer rights
- Educational rights
- Steps to advocate for change
- Knowledge of Resources
- Support/accommodation needs

Communication

- Assertiveness
- Negotiation
- Body language
- Use of assistive technology
- Listening
- Compromise

Leadership

- Knowledge of group's rights
- Advocating for others or for causes
- Knowledge of resources
- Organizational participation

Tips for the Self-Advocate



You have the power to live the life that you want to live.



Being a strong self-advocate means balancing both assertiveness and respectfulness. You have a right to promote and speak up for your wants and needs, but it can make things go smoother if you present those wants and needs to others respectfully.



Being a self-advocate can come with its challenges, but never give up!



Practice speaking up for yourself by writing down what you will say ahead of time or talking it through with a friend.



It can take time to develop such a skill, and there may be some days where you run into an obstacle or just don't feel like advocating. Be patient and kind to yourself.

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"
- "It's Never Too Late to Teach Children about Consent and Boundaries"
<https://www.washingtonpost.com/news/parenting/wp/2015/02/13/its-never-too-early-to-teach-children-about-consent-and-boundaries/>



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. 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



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.

- **Social Cohesion:** this refers to sharing spaces and experiences with others who are different from yourself ***See 40-50 Activities and Resources - "Caregiver/Loved One Activities Activity"**
- **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 ***See 40-50 Activities and Resources - "Caregiver/Loved One Belonging Activity"**
- **Community Involvement:** this relates to the extent to which you dedicate your time to supporting others and your community ***See 40-50 Activities and Resources - "Caregiver/Loved One Strengths Activity"**
- **Independence:** this is about self-determination and your ability to make the choices you want in life ***See 40-50 Activities and Resources - "Caregiver/Loved One Independence Activity"**
- **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 ***See 40-50 Activities and Resources - "Caregiver/Loved One Qualities Activity"**

How to Foster Community Inclusion from 40-50

Ask your loved one what type of activities they are interested in and start looking into age appropriate programming in your community based off of that

Create and utilize a positive introduction of your loved one



Access a mixture of both inclusive and segregated or disability specific activities

Set the tone within your family dynamic as inclusive

Asking Your Loved One About Their Interests:

- It is important that you are well aware within this age group of your loved one's interests and are fostering community inclusion around them
- Your loved one may not know how to articulate those interests, so it could be useful to continue to introduce different activities that you think they might like while being mindful of how they react during or after each activity
- Their interests may change and fluctuate as they age, so remain flexible and always check-in with your loved one
- Once you have a strong sense of where your loved one's interests lie, you can begin researching and signing up for corresponding activities/programming. There is typically something for EVERYTHING, but if not...start your own group!
- You can also include your loved one in this process by encouraging them to do their own research and even having them reach out themselves to sign-up for the activities and programs they want to engage in
- Attending activities regularly increases the chances of becoming known and getting to know others. These connections are an important piece of community inclusion

Positive Introduction:

- How and what you communicate about your loved one has a significant impact on how others understand and interact with them
- By establishing an introduction with positive information about your loved one, you can support others in welcoming them and connecting with them
- In some environments such as medical settings, you may have to use language that focuses on disability and medical conditions. When interacting with family, friends and the overall community you should be utilizing language that focuses on your loved one as an individual rather than their disability
- **Ways that you can begin to positively introduce your loved one to others include:**
 - talk about their place in your family unit
 - discuss their interests and qualities
 - it can be helpful to make a list of these things to support you in drafting a few ways in which you can positively introduce your loved one
 - some families have created a short booklet of information and photos of their loved one to share with others they meet in community activities, childcare centres, and schools

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
- Segregated activities/programs are dedicated specifically to individuals with disabilities and are accommodated based on such (autism support groups, Special Olympics, etc.)
- You should be focusing more on inclusive activities and programming within this age group
- 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:

- It can be beneficial to build 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
- 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 "**40-50 Learning Module**" has given you the knowledge and resources needed to continue to navigate and create a wonderful life for your 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 **40-50 Activities and Resources** section
- If your loved one is coming up to the age of 51, consider interacting with the "**51-65 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 have not 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.

