

3-5 LEARNING MODULE

Introduction

This learning module will centre the knowledge and actionable steps that families have deemed essential to engage with during the 3–5 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 3-5?

Typically within this stage of life children are transitioning into Preschool at 3 years and Kindergarten at 5. This can be both an exciting and anxiety-provoking time for both you and your loved one. If your loved one attended a centre or had a care provider other than yourself prior to this transition, they could be accustomed to being separated from you and adjusting to an unfamiliar space. This can make starting Preschool and Kindergarten much easier. With that being said though, if your loved one has been with the same care provider for awhile and has adjusted well, this uprooting to a new environment could trigger an emotional response that resets you all the way back to the beginning. Your loved one's reaction to these transitions really depends on their personality and their individual experiences up until this point in life.

Here are some helpful suggestions on how to support your loved one through their transition to Preschool and/or Kindergarten:



Find some children's books to read about separation or starting a new school to teach your loved one that this is a common part of life.



Remind them of how brave they were when they first started the care that they are transitioning out of.



Talk about Preschool/Kindergarten in a positive manner, and get your loved one excited about all the fun activities that are waiting for them at school!



Set an example by greeting your loved one's new teacher(s) or aide(s) warmly and with enthusiasm.



If your loved one has multiple teachers or aides, find a go-to support person that can be their main source of comfort and connection as they adjust. Make sure that this person is also willing to support your loved one in making friends with their class/group and fostering independence.



Remember to complete your goodbye ritual (hug, kiss, high-five, etc.) quickly and don't stall!



Take time to process and manage your own emotions during this time through self-reflection and self-care.

Inappropriate Attachments

Another thing that can make this transition to Preschool or Kindergarten 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.

Preschool and Kindergarten are perfect opportunities for your loved one to start forming new connections and attachments with others. 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?

Importance of Self-Determination

Self-determination can be understood as one's ability to control and determine their own life outcomes. Self-determination is an important skill to begin nurturing as early on as possible 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 foster self-determination for your 3-5 loved one:

- **Encourage choice making** by giving them the opportunity to pick between two choices. An example of this could be asking if they would prefer cereal or toast for breakfast
- **Promote responsibility** by delegating specific tasks around the home for your loved one to complete. An example of this could be cleaning up their toys or making their beds
- **Nurture independence** by encouraging your loved one to choose and act as they please. An example of this could be them having the freedom to pick their clothes out for the day and dressing themselves with little to no support from you
- **Support Communication** by encouraging your loved one to 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

For more information on how to further foster self-determination for your loved one, **go to 3-5 Activities and Resources** - "Fostering Self-Determination Among Children and Youth with Disabilities"

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:



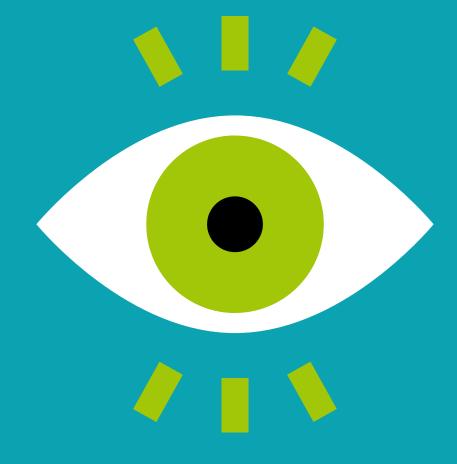
Wrapping it Up



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

- "Your Guide to an Easier Daycare Transition"
 https://www.sarahrosensweet.com/guide-guilt-free-daycare-transition/
- "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 3-5?

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 it is important that you shift your focus to what your loved one wants by simply fostering communication around their dreams and aspirations as early on as possible. 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 may take some time getting to know your loved one. You can ask others who interact with your loved one what catches their attention outside of the home. 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?

Remember that the possibilities for visioning are endless, and don't let anyone limit them for you and 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."

Tips For Planning and Implementing Visions



Create a vision board that uses imagery to capture your loved one's vision and what it entails as a reminder to what you are both working towards. *Go to: 3-5 Activities and Resources - "How to Create Vision Boards" & "The Big Picture"



If you are less of a visual learner and enjoy putting written thoughts on paper, practice writing a *vision statement*. This will support you in better understanding your loved one's vision. Share the statement with your loved one to make sure you are both on the same page.

*Go to: 3-5 Activities and Resources - "Writing a Vision Statement Activity"



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

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



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

- What do we need to complete the goals?
- Who needs to be involved for us 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 yourself and your loved one by asking questions like:

- What have been our strengths or successes?
- What needs more work or support?
- Is what we are doing today getting us 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.

Understanding Valued Roles

What Are Valued Roles?

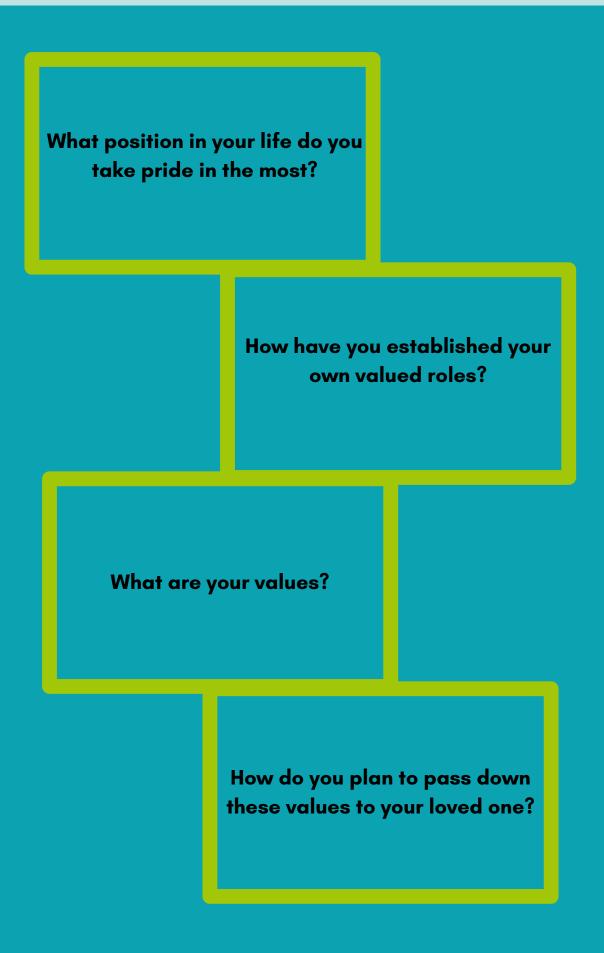
Valued roles are behaviours, relationships, responsibilities, and duties we carry out in life that are widely recognized and acknowledged within society. The roles we engage in tell others that we interact with about who we are, enhance our self-image, and encourage us to further develop our skills.

What Do Valued Roles Look Like From 3-5?

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, but starting within this age group you must also take into consideration what roles they want for themselves.

Your loved one will need a bit of an introduction to start understanding valued roles and the ones that they want to engage in. A good role to start fostering 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. You can also start encouraging the role of "helper" by delegating tasks that are helpful to you and other family members. Moreover, this teaches independent life skills in the process.

Below are some questions to further guide you in deciding what valued roles you'd like to begin fostering for your loved one. You can also check out **3-5 Activities and Resources - "Valued Roles Parent/Caregiver Activity"** for more support in this area.



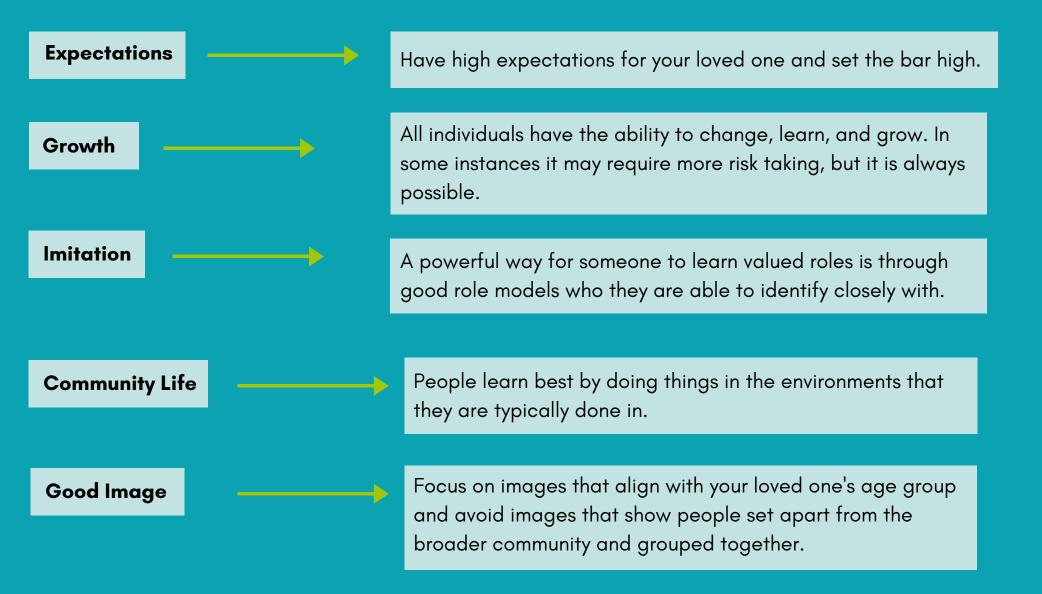
Once you start presenting valued roles to your loved one, pay close attention to their reactions and/or communicate with them as you go along to ensure that the roles they are engaging in align with their changing preferences and interests. Remain flexible, and adjust your influence and supports when 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 incorporating your loved one's interests in what these roles are. 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 support you in both creating and helping your loved one create valued roles for themselves:



For more information on Social Role Valorization, go to **3-5 Activities and Resources - "Social Role Valorization"**

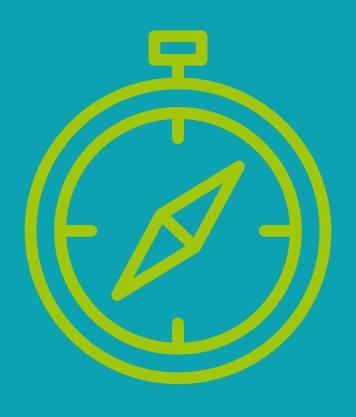
Wrapping it Up



Visions and valued roles are not static and are ever-changing as your loved one continues to 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"
- Vision Quote
 <u>http://www.picturequotes.com/limited-vision-quotes</u>



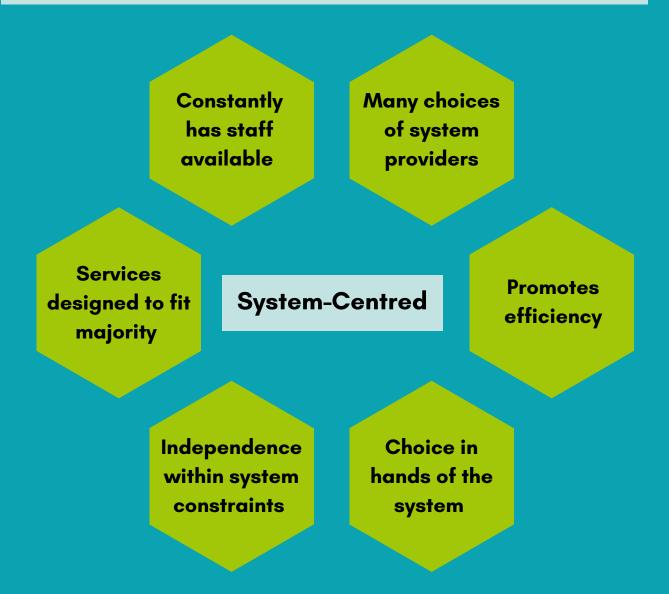
NAVIGATING SUPPORTS

Understanding Approaches to Supports and Resources

Person-Centred vs System-Centred Approaches

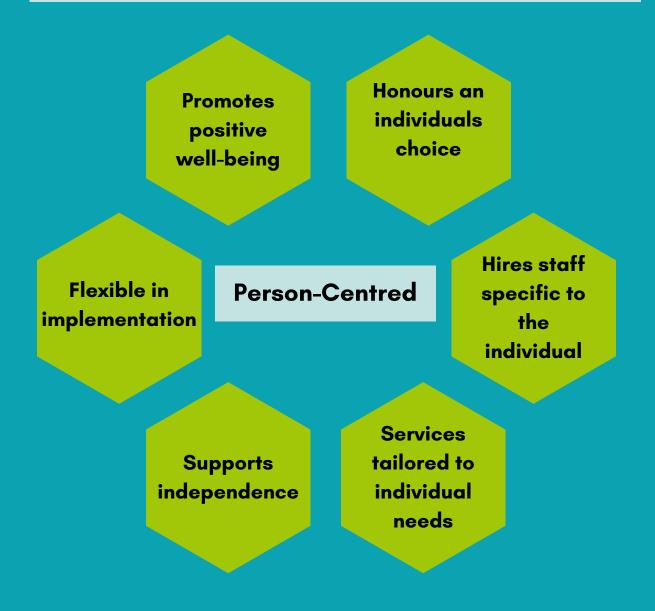
As you navigate supports and resources for your loved one you will notice that there are two prominent approaches utilized; person-centred and system-centred. Gateway strongly believes that focusing on a person-centred approach guarantees individuality of supports that are tailored to the unique needs 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.

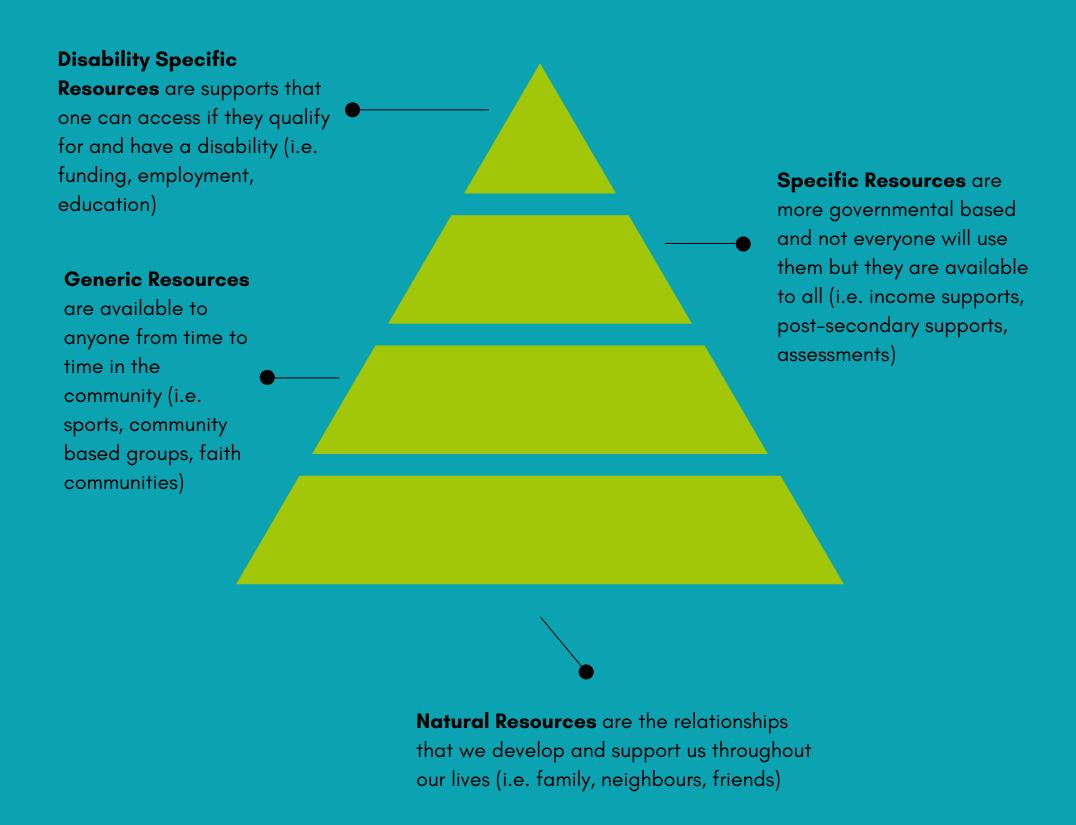
Person-centred also refers to Family Manage Supports where families are in charge of hiring staff for their loved one.





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



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 3-5

PUF (Program Unit Funding), RCSD (Regional Collaborative Service Delivery) and FSCD (Family Support for Children with Disabilities) are three 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.

What is PUF?

PUF is Alberta Education funding allocated to school authorities that provides further support to children with severe 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.

Mild/Moderate Funding is very similar to PUF, but provides early childhood education supports to children with mild to moderate disabilities as early as 3 years and 8 months of age with the last year still intended for Kindergarten.

> For more information on PUF and Mild/Moderate Funding, visit 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. 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 3-5 Activities and Resources section and look for the "Regional Collaborative Service Delivery Factsheet."

Getting Ready For School



It is important to plan ahead for when your loved one starts school in order to access early intervention programs within this setting. You can do this by contacting your local school and school authority as early on as possible. Most schools already have program and funding established such as PUF or RCSD, but you should still be checking in with the school you want your loved one to attend just in case there are any loose ends that need to be tied prior to your loved one's start date. This also supports the school in properly preparing for your loved one's arrival which makes the transition much easier for all involved.

For more information on how to plan and prepare for your loved one's first day of school, visit https://hvparent.com/6-ways-to-prepare-your-special-needs-child-for-the-school-year

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 service:



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 heath 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 3-5 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?



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 is my contract renewal?

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?





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/School Related:



- Inclusive Child Care Program
- Child Care Subsidy Program
- Child Care Lookup System
- Education in Alberta
- ASap
- Inclusive Education

Daily Living:



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

Financial:



- Child Disability Benefit
- Alberta Child Health Benefit
- Disability Tax Credit
- Employment Insurance Compassionate Care Program
- Registered Disability Savings Plan

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 **3-5**

Activities and Resources - "3-5 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-needsglossary.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



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.*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.)

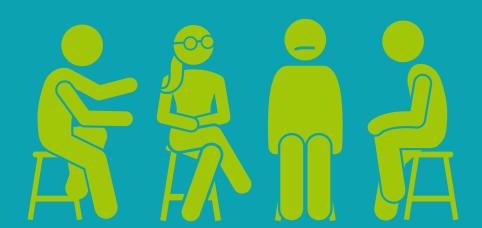
It is important that you are aware of stigma so that you can recognize it in your interactions with others and address it immediately. Developing strong advocacy skills will support you in this. **You can actively speak** out or act against stigma when it happens by:

- 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 3-5 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 begin teaching your loved one about consent and healthy boundaries as early on as possible 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 begin to teach your loved one about consent:

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

Explain to 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



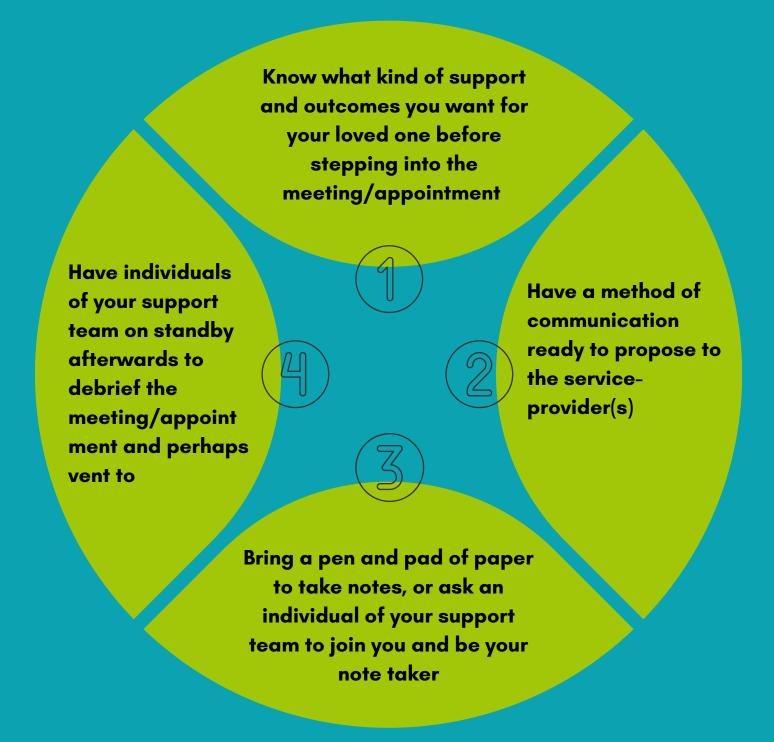
Think about what you want for your loved one, and keep an open mind to all possible solutions/ways to address the issue. Try to obtain as much information as possible in order to make an informed decision



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



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/advocatepersons-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
 <u>https://musicandsunshine.com/blog/the-way-you-hold-your-phone-can-tell-a-lot-about-your-personality/</u>
- 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 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



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 3-5 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
 3-5 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 3-5 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 3-5 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 3-5 Activities and Resources - "Caregiver/Loved One Qualities Activity"

How to Foster Community Inclusion from 3-5

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 start to get to know your loved one's interests in this age group and begin 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 an idea of where your loved one's interests lie, you can begin researching corresponding activities/programming. There is typically something for EVERYTHING, but if not...start your own group!
- 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

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:

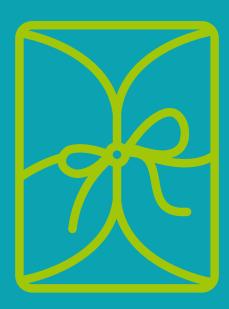
- Inclusive activities or programs means that they are available to all individuals of different abilities
- Such activities may take some advocacy work towards accommodation, but inclusive experiences can be very meaningful in your loved one's life and absolutely worth the push
- They also support your 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 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 that 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 or continue 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 "3-5 Learning Module" has given you the knowledge and resources needed to navigate and create 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 3-5
 Activities and Resources section
- If your loved one is coming up to the age of 6, consider interacting with the "6-11 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.