

FAMILY VOICE OF LANARK COUNTY



Leeds and Grenville
Family Network



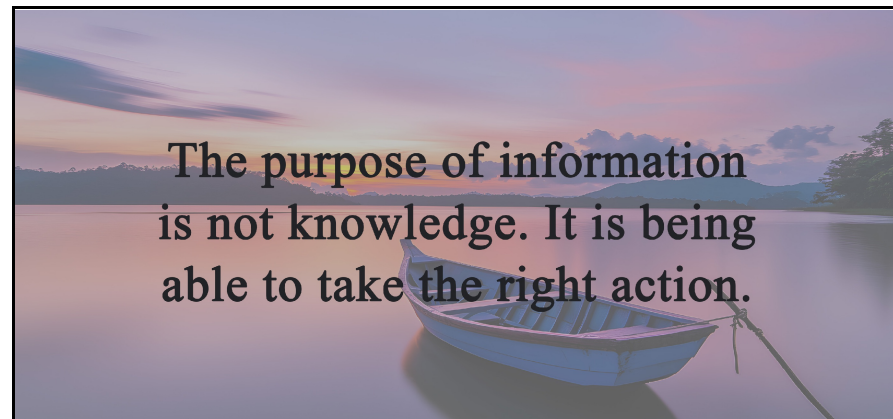
Kingston and Area
Family Network

FAMILY SUPPORT NETWORKS

COLLABORATING TO PROVIDE RELEVANT, IMPORTANT & ESSENTIAL

RESOURCES, MATERIAL, ACTION PLANS & ADVOCACY TOOLS HANDBOOK

**TO ASSIST & ENABLE INDIVIDUALS, THEIR FAMILIES & SUPPORT CIRCLES/NETWORKS
TO CREATE QUALITY OF LIFE OPPORTUNITIES & OUTCOMES**



Developed by: **FAMILY VOICE OF LANARK COUNTY (FVLC)** an affiliate of Family Alliance Ontario (FAO): <https://familyvoiceoflanarkcounty.com>
In Collaboration with Leeds Grenville Family Network <http://family-alliance.com> & Kingston & Area Family Network <http://family-alliance.com>

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The creation and development of our

RESOURCES, MATERIAL, ACTION PLANS & ADVOCACY TOOLS HANDBOOK

has been made possible by a funding grant received through an application process to Community Living Ontario (CLO).

Our three Family Support Networks (FSN) are grateful that we were chosen as recipients of the funding. As facilitators of our individual Family Support Networks (FVLC, LGFN, K&AFN) we support family members, support circles and individuals who have developmental disabilities. It is our goal to ensure the funding we received will assist and motivate others to connect with family networks in their area and region – like-minded organizations – that can provide ongoing opportunities to learn and connect with others for support and assistance.

Building relationships has been essential in our efforts to change attitudes, create lifestyles of choice and promote citizenship rights for our family members. **ACTION** leads to tangible outcomes. Encouraging one person to take **ACTION** has inspired others to follow suit. The momentum can lead to collective change and positive social movements.

The value and importance of advocacy individually and collectively at local and provincial levels by our Family Support Networks is an essential and powerful tool. Families have one of their most powerful tools – their personal stories!

Our FSN's align with the standards and beliefs promoted by Community Living Ontario (CLO):

<https://communitylivingontario.ca>

“It is our belief that all people, regardless of disability, can live within their community, with appropriate supports. We also believe that people should exercise their right to voice and choice in determining where they live and with whom they live.”

VALUE AND IMPORTANCE OF FAMILY SUPPORT NETWORKS

What Families Say About the Importance & Value of Belonging to a Family Support Network

“FVLC is a free, non-judgmental advocacy group that focuses on real-life issues . . . Participating in this group provides an opportunity to be with people who have a common purpose and understanding of one another. Our children also benefit from an enhanced support system – as well as getting to know one another . . .

Benefits include: Feeling less lonely, isolated or judged; reducing stress, depression anxiety or fatigue; talking openly and honestly about your feelings; improving skills to cope with challenges; staying motivated; gaining a sense of empowerment control or hope; improving understanding of developmental disability and your own experience with it; getting practical feedback about service options; learning about health, economic or social resources; making a friend along the way; social gatherings where our special children are welcome.”

Amy B.

“The type of support from this group is amazing! The facilitators not only provide group support at meetings but also provide advocacy and individualized support . . .”

Debi M.

“As one of the organizers of FVLC, (2007), our main purpose was to unite families who shared the common goal of creating a better life for the children. Information sessions and resources are offered to families to raise awareness of – what can be available and not just what is currently offered in the county or province. Our family is in the senior category and we see many of the younger families still experiencing the same problems and issues that we faced years ago. We provide relevant information to families, have guest speakers and discussions.”

Cora N.

“I am a sibling of a wonderful brother who has faced many challenges in his life. I have observed my parents constant struggle to give him the most normalized lifestyle possible and the opportunities that myself and others are entitled to without question. My career is in the developmental services field and I am constantly amazed that family members are unaware of what their family member can access and/or request to assist them to have a meaningful, hopeful and fulfilling life. I have attended meetings organized by the FSN and it is obvious the information given to families is interesting, encouraging and helpful. It is also beneficial to connect with other Family Groups through Webinars and Zoom Sessions. I feel the FSN is a valuable resource for families – nice to have some food too as many are coming directly from work and can relax a little after a busy and perhaps stressful day. We have seen where the experience of one family is valuable help to another. Families helping families. A wonderful concept.”

Pauline A.

VALUE AND IMPORTANCE OF FAMILY SUPPORT NETWORKS (cont.)

What Families Say About the Importance & Value of Belonging to a Family Support Network (cont.)

“I have an uncle with a developmental disability whom I love very much. I attend meetings because I want to learn what I can do now so that I can make sure he continues to have a good life in the future when my grandparents are no longer able or present. All the different topics and issues that come up in discussions would be overwhelming if I didn’t have the opportunity to familiarize myself gradually with how to best support and advocate for my uncle when it comes time for me to step in. I have also requested that I have an opportunity to learn more specific details relating to my uncle’s funding – how his Microboard works and what role I can play to ensure a smooth transition when the time comes.”

Dylan R.

“I believe the ‘Support Group’ is very helpful for families who need information and support for their family member. I have recommended the FSN to families for help and advice.”

Sue T.

“As a parent of a son with a disability I cannot express how important it is to have other parents and groups to talk with and share concerns. Most of our children do not have the same disability but the caring and needs are similar. I have been advocating for my son since he started kindergarten. I was previously involved with our local Community Living Association, SEAC, and Family Voice since it started. A few of us have been around for 38 years or more. It is important to help families with younger adult children as much as we can to let them know they are not alone and help them find information they need. As we know, the government changes its rules and regulations frequently, so having more people keeping abreast of the changes helps. I believe strongly that parent and family groups are very important resources and much needed.”

Brian & Debbie T.

“FVLC literally saved my sanity! I needed housing and supports for a young homeless 23-year-old young woman who I cared about deeply. She was wheelchair bound and has a developmental disability. I felt that systems sent me on a ‘wild goose chase’. After 18 months I felt completely deflated – physically & emotionally exhausted and discouraged. I was not getting anywhere trying to find help for the young woman – then I found FVLC! The facilitators directed me to the DSO to secure a service provider and begin the process helping to acquire housing and financial supports and much more for her to live a better quality of life. It was complicated, arduous, very long and a very difficult process. I couldn’t have navigated the process without FVLC supporting me every step of the way. FVLC is an essential support for families and their children and adults with developmental disabilities. The sharing of information and examples of those who have gone through situations before us is beyond invaluable!”

Susan C.

VALUE AND IMPORTANCE OF FAMILY SUPPORT NETWORKS (cont.)

What Families Say About the Importance & Value of Belonging to a Family Support Network (cont.)

“We’ve found by attending Family Voice of Lanark County, there are numerous benefits, including emotional support, shared experiences and practical advice. It provides a safe space where parents and caregivers can connect with others facing similar challenges, reducing feelings of isolation and stress. The group also serves as a valuable resource for important topics such as estate planning, navigating the various government programs and securing a stable future for our children. Parents can learn about financial planning, special needs trusts and government benefits to ensure their child’s long term well-being. Additionally, discussions about housing options empower us to explore opportunities that allow our children to live independently or in supportive communities of their choice when parents are no longer able to provide care.

While we often leave with scribbled notes that prompt us to perform additional research, the group fosters a sense of community and empowerment, helping us all feel more confident and prepared for the future. We have personally benefited from the knowledge of the group and our daughter is and will continue to be better equipped as a result.”

Chris & Kim L.

“What I find most beneficial is the information that helps our family best support our daughter in our community. Motivation and support from parents & families in similar situations; a lot of personal support during my daughter’s transition out of high school – at monthly meetings and creating a budget that would best support her.”

Julie W.

“As a facilitator, it is extremely rewarding to see the growth and cohesiveness of our FSN. We are grateful for the grant we receive from the Ontario Caregiver’s Association (OCA). Info@ontario.caregiver.ca Families are able to come together in an independent, welcoming space on a consistent basis, share a light supper and build relationships. We have witnessed some very strong and confident advocates emerging in our FSN. Providing more intensive support as needed enables families to take the action required. Sharing experiences and describing how barriers were overcome has been a catalyst to strengthen self confidence and provide motivation to others.”

Joyce R.

VALUE AND IMPORTANCE OF FAMILY SUPPORT NETWORKS (cont.)

What Families Say About the Importance & Value of Belonging to a Family Support Network (cont.)

“Information is shared and discussed that helps us to better support our son; a lot of beneficial advice during a time when we had difficulty finding respite & support workers which resulted in us finding support workers who were a great fit for our son.”

Wendy H.

“What I find beneficial from participating in a family support group is getting more information explained from experience. I brought my adult son to a meeting and he enjoyed it.”

Barbara S.

“As a sibling of a brother who has a developmental disability what I feel has been beneficial to me is: attending meetings and participating in discussions; having opportunities to engage in informal chats; socializing; developing relationships that are not only beneficial to me and my brother now, but will continue to be important in the future. I appreciate the connections I have been able to make in our support group and I know I will feel comfortable to reach out to others in the future. It is important to not feel alone or isolated as my role and the support my brother requires in the future changes.”

Robyn R.

“Having just moved to Lanark County with our 20-year-old daughter, the FSN has offered an invaluable opportunity for us to meet other parents of adults with disabilities and learn from them. Friendships we have developed have resulted in additional get togethers and activities – enhancing our daughter’s integration into this lovely community. We have also valued deepening our knowledge and relevant legal, financial, political and funding issues from discussions with other parents, caregivers, speakers. We feel more confident in navigating the complexities of supporting our daughter. Our motivation to organize an independent housing situation for our daughter rather than waiting for a group home spot has been strengthened by listening to other families’ successful experiences of doing the same.”

Eugene & Kathleen

VALUE AND IMPORTANCE OF FAMILY SUPPORT NETWORKS (cont.)

What Families Say About the Importance & Value of Belonging to a Family Support Network (cont.)

“Ongoing advocacy by and for individuals with disabilities and their families is critical and has been a primary focus of LGFN. MCCSS has created “Journey To Belonging” which is Developmental Services’ plan to reform the service system which on the surface is to provide people with disabilities with supports to make it easier for people to live in and participate in community life and have the life they want including control over whom they live with and how they live. As a parent and long time advocate, I believe that major changes need to occur including listening to those most directly affected by the decisions that are made. One of the most important changes is that this government must include voices of people with disabilities and their loved ones. Presently, MCCSS is looking to traditional service providers that have a vested interest in keeping the system the way it is instead of including those most affected by decisions made and who are committed to creating a separate stream of Individualized Direct Funding Options and Opportunities.”

Betty Daley, LGFN

“Although I am not able to attend meetings, FVLC has been a source of ongoing support by providing me with information and hands on assistance. I was completely stressed out dealing with the school my daughter attended. The principal had attempted to change the school my daughter attended by having me sign a transportation form, giving my approval to send her by bus to a completely different school. There was no IPRC held, I felt like it was just a ‘done deal.’ I felt I had no option until I received assistance from FVLC. One of the facilitators provided me with information about the Education Act rules and regulations. She told me that what the principal was attempting to do was contrary to the Education Act and they absolutely could not change my daughter’s school placement without calling an IPRC meeting. My permission and signature were requirements to move my daughter to a different school. Even if there was a recommendation from the IPRC to change her school, as a parent, I could disagree and request an Education Appeal of the IPRC decision. Thankfully the situation didn’t get to that point. I received assistance from the FSN to write a letter to the Superintendent of the school board advising that the Education Act was being obstructed by the principal of the school. I received a response immediately. The superintendent set up a meeting, the FSN facilitator attended with me for support, and having that support definitely gave me the confidence and courage I needed to address my concerns. The end result was the development of a ‘Success Plan’ for my daughter and she was provided with the additional support she required at her local school immediately!”

Bonnie M.

VALUE AND IMPORTANCE OF FAMILY SUPPORT NETWORKS (cont.)

What Families Say About the Importance & Value of Belonging to a Family Support Network (cont.)

“In order for true inclusion to be realized, we must continue to advocate for lifestyles that represent true inclusion in all aspects of community. I am a sibling of a brother whom my mother was able to set free from life in an institution. Having lived that experience and pain with my brother has given me a passion to ensure that our loved ones ‘Never Go Back’ to the horrors of institutional life. I believe it is essential to document people’s stories to enable them to heal. It is also important to bring to light and recognize how people with developmental disabilities were unjustly treated. Despite making progress, people with developmental disabilities are still living with issues of systemic control, bureaucratic inefficiency, and barriers to autonomy and true inclusion. While institutions may have closed, it seems the legacy of institutionalization persists in the form of service systems that limit individual’s ability to direct their own lives and have the same ‘say so’ over their lives as other citizens. The way funding is structured, being tied up in agency controlled services, appears to perpetuate dependency rather than fostering independence and self-determination. This is the inherited systematic institutionalization and ableism which so many of us are working hard to mitigate. This can create a cycle where individuals are forced to navigate an inflexible system that prioritizes its own processes over their personal needs and desires of individuals with developmental disabilities. A more empowering approach would be to provide direct funding to individuals, enabling them to choose how they wish to live and the specific supports they require to thrive in communities. Reducing bureaucratic overhead could make the system more efficient and cost effective.”

Vici Clarke, Kingston & Area FSN

“I am the mother of a severely disabled adult child with medical complexities. Having no family in the geographical area, I look to paid supports for assistance. Several years ago, I joined Lanark Family, a support group for parents such as myself. They have been invaluable to me. Having the ear of the people who are in a similar situation makes me feel I am not alone. The leaders of this group have been working within the world of disability for much longer than me and offer much knowledge and experience in the group. They share resources and information on a variety of topics and help to clarify services within the Ministry and Developmental Services. Parents and caregivers share information and get advice from each other. I would almost say that it serves as a lifeline, especially for a single parent such as me. There are times when I get a little burnt out worrying about my son’s future. I am trying to keep him at home as long as possible and provide for him after I am gone, rather than send him to a residential home. That used to be a pipe dream for me, but sitting within this group where others have done what I dream of, encourages me to work toward a future where he is living his best possible life, supported in his own home. I look forward to continued support from this group and hope they will get funding to continue this valuable service.”

Alina J.

TRANSFORMING ACTION INTO POTENTIAL & PROGRESS

“**ACTION** is the process of translating thoughts, ideas or intentions into tangible outcomes. It is when you move from merely contemplating or planning something to actively doing it. It is about stepping out of the comfort zone and embracing forward momentum, no matter how small or large the steps may be. It often requires courage, determination and focus, especially when faced with challenges and uncertainties. In essence, **TAKING ACTION** is what transforms potential into progress – it is the heartbeat of accomplishment.”

It is our hope that our handbook will provide insight, motivation and concrete “**TOOLS**” leading to ongoing **ACTION**. There is an incredible amount of information and topics that are currently discussed relating to assisting our family members and/or people we care about deeply to have a better quality of life. It can be completely overwhelming and our families have effectively expressed their feelings. By utilizing our **ACTION TOOLS**, we have been successful in assisting individuals to identify their priority area(s). Knowing **WHERE** and **HOW** to start to take **ACTION** has been beneficial and effective to assist families to identify priorities.

From the many years that we have been involved in FSN’s, having speakers, providing information/resources to families, has definitely been helpful. It exposes people to information and possibilities. However, what we realized was that there is a gap between simply receiving information and actually understanding, implementing and moving forward. The **ACTION TOOLS** we use to close the gap are: Providing Action Oriented Frameworks – a variety of forms, relatable examples, roadmaps to move accomplishments forward, e.g. checklists, mentorship, coaching and personal examples of how families were able to move forward. We provide support beyond the monthly meetings as required. We are only a phone call or email away – which has been helpful in eliminating people feeling overwhelmed, frustrated and/or exhausted. An understanding voice, ideas, or suggestions sometimes are all it takes to get someone out of a rut and be able to move forward.

FAMILY VOICE OF LANARK COUNTY

IDENTIFYING ACTION PLAN AREAS

Date _____

ACTION PLAN AREA *(Please mark an X in the box area of all required Action Areas)*

DSO – PASSPORT Disability Support Funding	ODSP – Income Supp	FINANCIAL	INDIVIDUALIZED HOME OPPORTUNITY	EDUCATION	HEALTH
<input type="checkbox"/> Eligibility Process <input type="checkbox"/> Assessment Process/Issues <input type="checkbox"/> Change of Circumstances <input type="checkbox"/> Other (Identify) _____ _____	<input type="checkbox"/> Process @ Age 18 for ODSP eligibility <input type="checkbox"/> Boarder vs. Renter <input type="checkbox"/> Medical Needs Allotment <input type="checkbox"/> Employment <input type="checkbox"/> Disability Tax Credit Form T2201 <input type="checkbox"/> Other (Identify) _____ _____	<input type="checkbox"/> Registered Disability Savings Plan RDSP <input type="checkbox"/> CRA Eligible Medical <input type="checkbox"/> CRA Caregiver Credit <input type="checkbox"/> WILL/Estate Plan <input type="checkbox"/> Henson Discretionary Trust <input type="checkbox"/> Life Insurance → Discretionary Trust <input type="checkbox"/> Income Tax <input type="checkbox"/> Other (Identify) _____ _____ <input type="checkbox"/> Microboard	<input type="checkbox"/> Creating VISION <input type="checkbox"/> Concrete VISION <input type="checkbox"/> SUPPORT Funding <input type="checkbox"/> Rent/Own <input type="checkbox"/> Home Maintenance Expenses <input type="checkbox"/> BUDGET <input type="checkbox"/> Individualized Support Funding <input type="checkbox"/> Other (Identify) _____ _____ TRADITIONAL RESIDENTIAL <input type="checkbox"/> GROUP HOME <input type="checkbox"/> FAMILY HOME <input type="checkbox"/> AGENCY Managed APARTMENTS <input type="checkbox"/> Other (Identify) _____ _____	<input type="checkbox"/> Preschool Inclusion <input type="checkbox"/> Elementary Inclusion <input type="checkbox"/> Circle of Friends <input type="checkbox"/> Individual Education Plan (IEP) Accountability Measurable Outcomes <input type="checkbox"/> IPRC Process <input type="checkbox"/> Appeal/Tribunal <input type="checkbox"/> Transition Planning <input type="checkbox"/> High School Inclusion <input type="checkbox"/> Certificate vs Diploma <input type="checkbox"/> Continuing Education <input type="checkbox"/> Employment (JOBS) <input type="checkbox"/> JOBS <input type="checkbox"/> Other _____ _____	<input type="checkbox"/> Homecare – Traditional <input type="checkbox"/> Family Managed Home Care (FMHC) Application Process <input type="checkbox"/> FMHC concerns/issues <input type="checkbox"/> Other (Identify) _____ _____

FAMILY VOICE OF LANARK COUNTY – A C T I O N – CHALLENGE

“Nothing happens until something moves” – Albert Einstein

Identify your priority area – start the A C T I O N process

#	ACTION	Start Date	What Steps did you take <i>Identify</i>	What still needs to be done <i>Identify</i>	Outcome	✓ Date

FREQUENT DISCUSSION AND ACTION TOPICS

The following are some of the main topics raised by families that can cause confusion and concerns. We provide information, material and resources and encourage families to investigate and research topics further to determine what specific **ACTION** they can take depending on each individual situation and their child's age.

Families are your greatest source of information because they have the lived experience. If you are “on overload” about the vast amount of information that exists with regards to having a young and/or adult child with a developmental disability – you are not alone. The following are examples of family inquiries and areas of interest.

DEVELOPMENTAL SERVICES ONTARIO (DSO)/PASSPORT FUNDING <https://www.dsontario.ca>

The following is a short summary of our discussions – complete information on above DSO website.

- If your child received Special Services at Home Funding before the age of 18 that does not automatically qualify them for Passport Funding.
- Families should start the application process – which leads to a DSO Assessment prior to the individual turning 18.

ELIGIBILITY

In order to apply for services, you will need to prove:

- Developmental Disability – proof of an early diagnosis or a psychological assessment by a registered psychologist relating to cognitive functioning, adaptive function and age of onset. Even if an individual had Special Services at Home Funding prior to age 18, it does not automatically qualify the person for PASSPORT Funding. Keep all medical reports.

FREQUENT DISCUSSION AND ACTION TOPICS (cont.)

DSO ASSESSMENT

- Many families have found the assessment process to be exhausting for them as well as their adult children.
- Families can request that their child not be present for the Support Intensity Scale (SIS) part of the Assessment as it is difficult for the child to be present when medical, behavioural and/or learning needs/deficits are discussed.
- Families have identified that they are reluctant to say things in front of their child – a consistent concern expressed by many families. They feel having their child present can result in inability to provide a clear identification of needs which could result in inaccurate scoring.
- If deemed eligible for Developmental Supports & Services, the amount of Funding a person initially receives is \$5,500.00.

CHANGE OF CIRCUMSTANCE REASSESSMENT

Can be requested when the student is in their last year of school. It can also be requested if there are any other significant changes in the family or individual's life. Many families do not understand the DSO process and their children end up sitting home with little support. In some situations in rural areas, transportation is a fairly high expense. If the entire \$5,500.00 were used for support hours, @ \$25.00 per hour, it would amount to 220 hours per year or 4.23 hours per week. Families have reported that sitting at home day after day caused regression, depression and loss of motivation.

- When a student with a developmental disability finishes school, it can create a huge void in their life. Prior to this occurring, families should assist their child to create an **ACTION PLAN** for their life in the community – and not wait until the last minute. FVLC has developed a Transition Handbook: PERSON DIRECTED→OUTCOME BASED TRANSITION PLAN HANDBOOK FOR YOUR “**LIFE AFTER SCHOOL**” – available on FVLC website: familyvoiceoflanarkcounty.com

VALUE & IMPORTANCE OF TRANSITION PLANNING FROM SCHOOL TO THE COMMUNITY

TRANSITION FROM SCHOOL IS NOT AN EVENT – IT IS AN EVOLUTION OF PLANNING

Too often, schools have considered Transition Planning – a one meeting event in the last year of school – Start forming ideas at age 14 or 15

AVOID THE VOID

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
A.M.		?	?	?	?	?	
NOON		?	?	?	?	?	
P.M.		?	?	?	?	?	

CREATE YOUR OWN LIFE AFTER SCHOOL PLAN

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
A.M.							
NOON							
P.M.							

DON'T KNOW WHERE TO START? EXPLORE OPTIONS FROM OUR ACTION CHECKLIST

#	CATEGORY	GOALS DREAMS	CURRENT SITUATION	WHAT is NEEDED Support, Skills, Strategies, Resources	ACTION To Be Taken	WHO is Responsible	SPECIFIC Timelines	Date Achieved	Follow Up Date
1	Continued Education								
2	Ongoing Learning/Skill Development								
3	Co-op Job Training								
4	Community Involvement								
5	Further Develop Talents/Gifts								
6	Expand Friendships								
7	Recreational								
8	Travel								
9	Future Living "Home"								

DON'T KNOW WHERE TO START? EXPLORE OPTIONS FROM OUR ACTION CHECKLIST (cont.)

#	CATEGORY	GOALS DREAMS	CURRENT SITUATION	WHAT is NEEDED. Support, Skills, Strategies, Resources	ACTION To Be Taken	WHO is Responsible	SPECIFIC Timelines	Date Achieved	Follow Up Date
10	Transportation								
11	Financial SUPPORT FUNDING								
12	Financial Security – INCOME ODSP								
13	Financial Security – PAID EMPLOYMENT								
14	Financial Security – RDSP DISC. TRUST								
15	IMPORTANT DOCUMENTS & INFO.								
16	OTHER – WHAT IS “IMPORTANT TO YOU”								
17	YOUR DREAM & VISION								

TRANSITION ACTIVITY/SUPPORT BUDGET TO HAVE A MEANINGFUL LIFE IN COMMUNITY

#	Activity/Area of Support Required	Activity Fees		Support Worker/ Facilitator Costs		Total Cost per Month	Total Cost per Year
		Wk	Yr	Wk	Yr		

For Information relating to Ontario Ministry of Education Transition and IPRC process (regulations)
[Ontario Ministry of Education: Special Education Ontario Transition Planning](#)
[Ontario Ministry of Education: IPRC Process Identifying Students with Special Needs](#)

SOURCES OF INCOME AND DISABILITY SUPPORT FUNDING

ONTARIO DISABILITY SUPPORT PROGRAM (ODSP)

<https://www.ontario.ca/page/ontario-disability-support-program>

Individuals and their families should apply for ODSP prior to the person reaching the age of 18 years (approximately six months before 18th birthday). At that time a Disability Determination Package is provided which must be completed by the individual's healthcare provider. The income is for basic needs – food, shelter, clothing. Additional amounts could be available for medical needs and/or for other expenses – refer to website for specific details.

PASSPORT FUNDING

<https://www.dsontario.ca>

The base amount of Passport Funding is \$5,500.00 if a person is deemed eligible. Additional amounts depend on individual needs (as per DSO Assessment) and resources.

REGISTERED DISABILITY SAVINGS PLANS (RDSP)

<https://www.canada.ca/en/services/benefits/disability.html>

Families should research details about the RDSP investment prior to investing. It is a “long-term savings plan” designed to help individuals with disabilities to save for their future. It allows contributions to grow tax-free and the government may provide additional contributions through grants and bonds. The following is just our short summary – check out the information yourself.

Government Contributions – will match contributions to a maximum of \$70,000. Annually the “**Savings Bond**” portion from the Government could be from **\$1,000.00 annually** – with a lifetime maximum of \$20,000. No contributions are required to receive to receive the bond.

The Government also provides a “**Grant (CDSG)**” annually. The Government matches the first \$500 you contribute at a rate of 300% – providing \$1,500.00 in grants. The government matches the next \$1,000.00 you contribute at a rate of 200%, providing **\$2,000.00 in grants**” annually.

Together that is a **total of \$3,500.00** in grants for a \$1,500.00 contribution.

SOURCES OF INCOME AND DISABILITY SUPPORT FUNDING (cont.)

REGISTERED DISABILITY SAVINGS PLANS (RDSP) (cont.)

The RDSP can be opened prior to an individual turning 18 years old. Individuals can apply for a social insurance number at age 12.

Government Contributions are made for 20 years. In order to not be penalized, by having to pay back a portion of the Government Contribution, there is a requirement to wait 10 years from the last government contribution. Withdrawing funds prior to that can trigger a repayment of \$3.00 for every \$1.00 withdrawn.

To avoid repayment, funds must remain in the plan for at least 10 years after the last grant or bond received. Regular withdrawals must start by December 31st of the year the beneficiary turns 60 years old. However, if the plan was started for example, when an individual was 18, contributions would be made until age 38 and withdrawals could start at age 48.

An additional requirement to open an RDSP is the beneficiary must be approved for the “Disability Tax Credit” (DTC). For general information, refer to website at: Canada.ca/RegisteredDisabilitySavingsPlan

It is important to file income taxes every year to ensure that grant entitlements are calculated using the most up-to-date income information.

DISABILITY TAX CREDIT

[Canada Disability Tax Credit](#)

The Disability Tax Credit (DTC) is designed to help individuals with disabilities or their supporting family members reduce the amount of income tax they pay. Its purpose is to offset some of the additional costs associated with living with a disability. To qualify, an individual must have a severe and prolonged impairment certified by a medical practitioner. Once approved, the credit can be claimed during tax filing. Any unused portion may be transferred to a supporting family member.

SOURCES OF INCOME AND DISABILITY SUPPORT FUNDING (cont.)

ADDITIONAL BENEFITS – MAKE SURE INCOME TAX IS FILED

Individuals typically start filing taxes when they have taxable income or are eligible for tax credits such as Disability Tax Credits (DTC). Once the individual with a disability reaches the “age of majority” (in Ontario 18), they can file their own tax returns if they have income and wish to claim credits like the DTC.

A recent question raised by a parent was “Should I sign the income tax return for my son who has turned 18?” The form indicates signature of “legal representative.” The term “legal representative” could be misinterpreted if the context isn’t clear. The suggestion made to the parent was to use the “AUT-01 form” which would specifically define the representative’s role and access level. It is recognized by Canada Revenue Agency (CRA) as an official authorization. It can be updated or revoked if circumstances change. The individual with a disability can also sign the Income Tax Form to the best of their ability. The AUT-01 form can be downloaded from the CRA’s official page:

<https://www.canada.ca/en/revenue-agency/services/forms-publications/forms/aut-01.html>

Filing an Income Tax Return can also provide an individual with additional income benefits which is based on income. It is essential to file taxes to access the following:

ONTARIO TRILLIUM BENEFIT (OTB)

The annual entitlement for the Trillium Benefit could be up to \$360.00 per year depending on income. Revenue Canada (CRA) will determine if a person is entitled based on information provided on the income tax return.

HST CREDIT

This is a tax free quarterly payment to help individuals and families with low to modest incomes offset the HST they pay. Payments are made in July, October, January and April. The amount depends on income and family size.

SUPPORTED DECISION MAKING, POWER OF ATTORNEY, GUARDIANSHIP

Once an individual turns 18, they are considered an adult in the eyes of the law and parents no longer have automatic authority.

SUPPORTED DECISION MAKING (SDM) – “enables a person to make his/her own decisions with the help of others.”¹

For additional information refer to Pooran Law: Supported Decision-Making & Supporting Entities.
<http://pooranlaw.com>.

For many individuals with developmental disabilities, their families and advocates, SDM is preferred because the individual's rights, autonomy and independence are maintained. Supported Decision Making (SDM) is increasingly recognized as a legal decision-making process in various jurisdictions. Largely due to the strong advocacy of families in standing up for the rights of their adult children, we have two fairly recent cases in Ontario that have definitely advanced the rights of individuals with developmental disabilities with regards to SDM.

CASE # 1: Is a powerful example of how advocacy and public attention can lead to policy changes. Brendan Kennedy, a reporter with the Toronto Star brought attention to a case where parents filed a human rights complaint against the Ministry of Health (MOH) This was related to their daughter, who had been receiving funding through the Family Managed Home Care Program (FMHC) prior to turning 18 years of age. When their daughter turned 18, the MOH advised the parents that they required guardianship in order for their daughter to continue receiving funding through the FMHC program. The parents opposed guardianship as they believed it would undermine their daughter's autonomy and rights. Their advocacy highlighted the importance of supported decision making as an alternative to guardianship. Following media coverage, the Ministry of Health reversed its policy, no longer requiring guardianship for adults with developmental disabilities to access FMHC funding.

For information about the Ministry of Health Family Managed Home Program: [Ontario Health at Home](#).

¹ Bach and Kernzer at page 53

SUPPORTED DECISION MAKING, POWER OF ATTORNEY, GUARDIANSHIP (cont.)

SUPPORTED DECISION MAKING (SDM) (cont.)

CASE# 2: (2024 ONCA 520) There is a case where Community Living Ontario (CLO) acted as an intervenor, for People First, represented by PooranLaw. ARCH Disability Law Centre was also involved. The case J.F.R. v. K.L.L. (parents) involved their 24-year-old adult son with Down Syndrome and raised significant questions about autonomy and decision making rights for adults with developmental disabilities. The court's decision touched on the importance of recognizing the capacity of individuals to make decisions about their lives, even when they require support.

This case is a significant legal decision in Ontario that advances the rights of individuals with intellectual disabilities. The Ontario Court of Appeal emphasized the importance of involving adults with disabilities in decisions that directly effect their lives. This case arose from a divorce proceeding where the parents disagreed about the living arrangements of their 24-year-old son.

The court reaffirmed the presumption of capacity, meaning that individuals with disabilities are presumed capable of making decisions unless proven otherwise. The decision aligns with the principles of the United Nations Convention on the Rights of Persons with Disabilities, particularly Article 19, which emphasizes the right to choose one's living arrangements.

archdisabilitylaw.ca

communitylivingontario.ca

Pooranlaw.com

peoplefirstontario.com

POWER OF ATTORNEY (POA)

Many people have a POA in the event of a medical emergency and /or other situation where the person was not able to give their consent. In the situation of a person with a developmental disability, a POA, could be in place relating to a situation comparable to when any of us would be in a situation that would require next of kin or a person close to us to speak on our behalf.

SUPPORTED DECISION MAKING, POWER OF ATTORNEY, GUARDIANSHIP (cont.)

GUARDIANSHIP

This is a legal arrangement where a court appoints a person (the guardian) to make decisions on behalf of another individual (the ward) who is unable to manage their own affairs due to age, disability, or incapacity. Guardianship can cover personal, financial or medical decisions, depending on the scope granted by the court.

The drawbacks to guardianship are: loss of autonomy – significantly limits independence in many aspects of their life; it involves a court process which can be costly and emotionally challenging for all parties involved; potential for abuse – in some cases guardianship can lead to misuse of power and financial exploitation if the guardian does not act in the ward’s best interests.

If a parent has guardianship of their adult child with a disability, when the parent dies, guardianship does not automatically transfer to someone else. Instead, the court typically steps in to determine next steps.

What could occur is “Successor Guardian” if the parent has named a successor guardian in their guardianship plan or Will, the court may appoint that person, provided they are willing and/or suitable for the role. If no successor guardian was designated, another family member, friend or interested party can apply to the court. If no one is available or willing to take on the role, the responsibility may fall to a public guardian or trustee depending on the jurisdiction.

WILL & ESTATE PLANNING

Having a WILL with a “discretionary trust” when you have a child with a developmental disability is crucial for parents of children or adult children with developmental disabilities for several reasons:

- **Protecting Government Benefits – many individuals with developmental disabilities rely on government disability benefits, which often have strict income and asset limits. A discretionary trust ensures that any inheritance does not disqualify them from receiving these benefits, as the assets in the trust are not considered their personal assets.**

****A discretionary trust is often called a Henson Discretionary Trust because of a landmark legal case in Ontario, Canada, involving Leonard Henson. In the 1980s, Henson set up a trust for his disabled daughter, Audrey, to ensure she could benefit from his estate without losing access to government disability benefits.***

SUPPORTED DECISION MAKING, POWER OF ATTORNEY, GUARDIANSHIP (cont.)

WILL & ESTATE PLANNING (cont.)

- **Financial Security** – A discretionary trust allows parents to set aside funds for the long term care and support of their child. The trustees can manage these funds to cover expenses like housing, medical care, and other needs, ensuring financial stability throughout the child’s life.
- **Flexibility and Control** – Parents can specify how the funds in the trust should be used, giving them peace of mind that their child’s needs will be met. The trustee has the discretion to distribute funds as needed, providing flexibility to adapt to changing circumstances.
- **Protection from Exploitation** – Individuals with developmental disabilities may be vulnerable to undue influence or financial exploitation. A discretionary trust safeguards their inheritance by placing it under the control of a trusted trustee(s).
- A home can also be left to a child with a developmental disability to enable them to have stability in their life.

Community Living Ontario has a resource booklet “Inspiring Possibilities: Estate Planning Guide” created by PooranLaw in collaboration with Community Living Ontario. It provides a comprehensive roadmap for estate planning, including Wills, trusts and benefits for Ontarians with disabilities. You can access the guide directly on the (PooranLaw website) <https://pooranlaw.com/2020-inspiring-possibilities-estate-planning-guide/> or through (Community Living Ontario) <https://communitylivingontario.ca/wp-content/uploads/2022/01/ENG-Wills-Estate-Planning-Guide-2022.pdf>).

MICROBOARDS

A Microboard is a small, dedicated group of family and friends who come together to support an individual with developmental disabilities. This group forms a non-profit organization to help the individual plan their life, advocate for their needs, monitor services, and connect with the community. Microboards are designed to empower individuals by ensuring their voices are heard and their goals are prioritized. They can also manage funding and create personalized services to meet the individual's unique needs.

<https://www.microboardsontario.com>

SUPPORTED DECISION MAKING, POWER OF ATTORNEY, GUARDIANSHIP (cont.)

MICROBOARDS (cont.)

Setting up a Microboard for a child with a developmental disability can provide numerous benefits, both while parents are alive and after they pass away. Here's how it helps in both scenarios:

While Parents Are Living:

- **A Microboard can be a vehicle for succession planning. It creates a formalized group of family and friends (who already know their son or daughter). It provides transition and opportunity learn and understand the needs, preferences and goals that are at the centre of all decisions i.e. supported decision making which fosters the person's self determination and empowerment.**
- **A Microboard can manage and oversee funding and supports, ensuring the person receives the best care and opportunities.**
- **By involving others in their child's life to understand and share in planning, parents can be more confident about their child's future.**

After Parents Pass Away:

Microboards –

- **Provide continuity of care, stability and consistency in the person's life.**
- **Is a legal entity, making it more sustainable and reliable over the long term.**
- **Is a supportive decision making team – ensuring the person's best interests are always at the forefront.**
- **Ensures that the VISION remains central to all planning effort, prioritizing the respect an implementation of citizenship values and rights throughout the process.**

“THE RIGHT TO EXERCISE VOICE AND CHOICE TO DETERMINE – WHERE YOU LIVE AND WITH WHOM”

Many individuals and their families have demonstrated a clear preference into ensuring their children have an opportunity to have a home of their own in the future. Many individuals with developmental disabilities have complex and/or medical needs. They require 24/7 support. Many families are being diligent in efforts to assist their adult children to have a PLAN developed for their child’s future home.

Some of the vehicles that can be used to support a home of choice are:

ODSP – in addition to basic needs – can be used for rent and/or home expenses

DISABILITY SAVINGS PLAN (RDSP) – can provide tax free income in the future

INSURANCE POLICY – designated to a discretionary trust – additional expenses

Family Voice of Lanark County developed a PERSON- DIRECTED HOME LIVING OPTIONS fo HANDBOOK for Individuals, Their Families & Support Network Teams (2018). <https://familyvoiceoflanarkcounty.com>

*“The Future is not something we enter.
The Future is something we create.”*

FVLC Handbook identifies “STEPS” and forms to assist individuals to develop a clear “VISION” in order to move forward with planning for a home and supports required, i.e.:

STEP 1: GETTING STARTED

STEP 2: CLARIFYING YOUR VISION

STEP 3: TAKING ACTION/TEAM BUILDING

STEP 4: PERSON-DIRECTED PLANNING

STEP 5: CHARTING THE PATH

STEP 6: THE BUDGET

STEP 7: YOUR HOME – A Home that is Right for YOU

“THE RIGHT TO EXERCISE VOICE AND CHOICE TO DETERMINE – WHERE YOU LIVE AND WITH WHOM” (cont.)

Developmental Services Ontario also has a Housing Toolkit which can be downloaded:
[Developmental Services Ontario \(DSO\) Housing Toolkit](#)

Many families have a keen interest in creating a future home for their son or daughter who has a developmental disability. The major barrier is **SUPPORT FUNDING**. With individuals who have higher needs requiring 24/7 support, even when families are diligent about ensuring financial opportunities are in place – as previously identified, it would not cover the long term costs of providing supports to meet the needs of a person living in their home of choice.

We do have families in our FSN’s who have accessed the DSO Housing Toolkit and listened to their Webinars. A major barrier identified by families – that does not enable them to move forward – is the absence of disability support dollars to provide support in a home of choice.

CONCERNS IDENTIFIED BY INDIVIDUALS, FAMILIES AND ADVOCATES

- Absence of support funding dollars for non-traditional homes of choice.
- Traditional residential options are expensive – it is too often a “placement” not a choice.
- Individuals do not have opportunities to present their preferences at the Service Providers’ “Tables” – decisions are made by Agency Personnel.
- The DSO initially kept a list of what type of home living choice a person would choose in the future – parents have reported that currently does not occur – advised that there is “no list.”
- The DSO Assessment does not identify families who request non traditional home options.
- Voice and Choice of where a person wants to live is restricted and all too often “crisis based.”
- Advocacy efforts and inquiries have heard that there is a possible 52,000 individuals on waiting list for funding.
- Advocates have identified serious concern that the system continues to be based on crises.
- A system based on crises is not sustainable – Families need to be equal partners in long term solutions for their children – Solutions based on their own **VOICE** and **CHOICE!**

INDIVIDUALIZED PERSON-DIRECTED FUNDING – PROMOTES EMPOWERMENT & AUTONOMY

The following points have been identified by advocacy groups and parents to emphasize the empowering nature of individualized funding and its role in fostering self-determination and citizenship:

Empowerment and Autonomy

- “places decision making power directly in the hands of the individuals”
- “a mechanism for personal choice and control over one’s life”
- “enabling individuals to design their own supports based on unique needs”

Self-Determination

- “promoting self-direction living through personalized funding”
- “a pathway to independence and self-reliance”
- “Supporting individuals to take charge of their own lives and futures”

Individuality and Citizenship

- “recognizing individuals as active, contributing members of their communities”
- “funding that celebrates individuality and respects personal preferences”
- “a model that sees people as citizens, not clients”

Community Inclusion

- “fostering meaningful participation in community life”
- “breaking down barriers to inclusion by tailoring supports to the individual”
- “creating opportunities for individuals to live, work, and thrive as valued members of society”

INDIVIDUALIZED PERSON-DIRECTED FUNDING – PROMOTES EMPOWERMENT & AUTONOMY (cont.)

The Individualized Funding Model of Support has transforming potential. It moves away from one-size-fits-all approaches to person directed solutions; replaces institutionalized client care models to community based, self-directed and citizenship models; it is a tool for dignity, inclusion, personal growth.

Individualized Funding in Ontario has a long and storied history as a pathway to inclusion and empowerment. Emerging as a citizenship-based model in the 1990s, it was championed by families, advocates, and organizations like the Individualized Funding Coalition for Ontario (IFCO) e.g. “Linking Individualized Supports and Direct Funding: Making Money Work for People” by John Lord and Peggy Hutchinson (1993); “Individualized Funding: A New Vision” (1998 Symposium). Individuals can connect to the Individualized Funding Coalition at: <https://individualizedfunding.ca/> or by email: individualizedfundingcoalition@gmail.com

Community Living Ontario (CLO) also has a document (2021) Direct Funding for Developmental Services in Ontario : A Path Forward. It provides information relating to the Benefits of Direct Funding and also examples of how other Provinces in Canada (Alberta and British Columbia) as well as information relating to New York State’s Self-Directed Services Program and Australia’s National Disability Insurance Scheme.

In essence, individualized funding paves the way for full inclusion and participation, affirming that true citizenship is not a privilege – it is a right, and everyone deserves to live as equal members of society.

By providing direct funding to individuals, this approach ensures that they can tailor their support systems to align with their unique needs, preferences and aspirations. It moves away from one-size-fits-all model. It represents the culmination of efforts to remove systemic barriers, offering freedom to make choices about their lives, care and support – just like any other citizen.

INDIVIDUALIZED FUNDING – A POWERFUL TOOL – PAVING THE WAY FOR CUSTOMIZED HOME SUPPORTS

FVLC in their previous Handbook Person-Directed Home Living Options (2018) has provided ideas and forms to assist families to start to think about the type of living opportunity that would best suit the needs of their adult children and what type of support would be required.

The importance of creating individualized home opportunities and providing customized supports for individuals with developmental disabilities cannot be overstated. Creating tailored home environments and ensuring access to individualized funding are critical steps toward fostering independence and dignity for individuals with developmental disabilities. Every person is unique with their own strengths, needs, and aspirations. By designing living opportunities that reflect their preferences and providing funding for personalized supports, we enable them to thrive in their communities. Tailored living arrangements and funding pave the way for a society that values and uplifts every member. Investing in these initiatives isn't just about support – it's about honouring the humanity and potential of all individuals.

The following page contains a form representing a 24 hour period in a person with developmental disability's life. It is a place to start to identify how many hours a parents actually provide of support.

Shade in the chart with different colours, representing the different types of support your son or daughter is currently receiving – Examples are below.

PARENT SUPPORT HOURS
VOLUNTEER/OTHER HOURS



PASSPORT FUNDING HOURS
OTHER HOURS (Identify)



The next step would be to identify what type of support is provided in each category. For example, if families are providing support from 7:00 – 9:00 provide details of what type of support. If families are providing support from 4:00pm to 12:00am provide specific details. If your child receives Passport Funding or SSAH – shade in the hours when this type of paid support is utilized. By going through this exercise it should provide you with a clear picture of how much support is provided by parents and/or others. If you, at some point in time, become unable to provide the support – who and how will the gap in support be provided?

INDIVIDUALIZED FUNDING – A POWERFUL TOOL – PAVING THE WAY FOR CUSTOMIZED HOME SUPPORTS (cont.)

CHART SHOWING SUPPORT HRS. PARENT SUPPORT – PASSPORT FUNDS – VOLUNTEER – OTHER (Identify)

	Time of Day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM	7:00 – 8:00							
	8:00 – 9:00							
	9:00 – 10:00							
	10:00 – 11:00							
	11:00 – 12:00							
PM	12:00 – 1:00							
	1:00 – 2:00							
	2:00 – 3:00							
	3:00 – 4:00							
	4:00 – 5:00							
	5:00 – 6:00							
	6:00 – 7:00							
	7:00 – 8:00							
	8:00 – 9:00							
	9:00 – 10:00							
	10:00 – 11:00							
	11:00 – 12:00							
AM	12:00 – 1:00							
	1:00 – 2:00							
	2:00 – 3:00							
	3:00 – 4:00							
	4:00 – 5:00							
	5:00 – 6:00							
	6:00 – 7:00							

RESOURCES, MATERIAL, ACTION PLANS & ADVOCACY TOOLS

PARTNERS FOR PLANNING (P4P) offers a wide variety of courses and webinars designed to support individuals and families in planning for the future. Topics include Registered Disability Savings Plans (RDSP), education advocacy, mental health and future planning with siblings in mind. Courses are also offered e.g. “Values in Planning and Facilitation,” facilitating microboards, and events such as “Lunch & Learn” sessions and workshops on wills and estate planning, alternatives to guardianship. One of the most recent courses available is Person Directed Planning: Crafting Your Individualized Housing Plan. <https://www.partnersforplanning.ca/>

FAMILY ALLIANCE ONTARIO (FAO) is a family-based, non-profit organization dedicated to supporting individuals with developmental disabilities and their families. They focus on promoting human rights, citizenship rights, and inclusive communities. FAO collaborates with family networks across Ontario to amplify their collective voice and work towards shared goals. Family Support Networks provide mutual support and resources to improve the lives of individuals with developmental disabilities. <https://family-alliance.com/>

We hope our Handbook has assisted in providing valuable information. Our goal is to support and inspire and we are confident that together, meaningful change is possible.

FAMILY VOICE OF LANARK COUNTY: Joyce Rivington – familyvoice@gmail.com

FAMILY VOICE OF LANARK COUNTY: Cora Nolan – familyvoice@gmail.com

LEEDS, GRENVILLE FAMILY NETWORK: Betty Daley – alliance@family-alliance.com

KINGSTON & AREA FAMILY NETWORK: Vici Clarke – alliance@family-alliance.com

This is the *final page* of our Handbook – but hopefully it is the **FIRST PAGE of a **NEW JOURNEY** for those of you who have not had the opportunity to travel on the path – forged by those who have ventured before into the realm of **INDIVIDUALIZED FUNDING**. Each step marked by courage and determination. The journey is far from easy, with barriers and challenges along the way. Those who persist discover something truly amazing! They see their sons and daughters thrive, embracing the freedom to truly be themselves, reaping the rewards of independence, true inclusion, self- determination, and endless possibilities.**

