

Peer support best practice toolkit

A resource for individuals developing and providing peer support programs
for families of children with medical complexity and other lifelong disabilities

SECTION 2.0

Current programs
in Ontario:
Case studies



Evidence to Care (EtC) at Holland Bloorview Kids Rehabilitation Hospital is a specialized team of knowledge translation experts supporting the hospital in its commitment to transform care through evidence, knowledge generation, and translation. Through collaborative efforts, EtC strives to make research evidence accessible in promoting evidence-based care in the field of childhood disability.

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CONFLICT OF INTEREST DECLARATION

The contributing committee members have no conflict of interest to declare.

ACKNOWLEDGEMENTS

Evidence to Care would like to acknowledge participants of the peer support focus groups for their feedback and insight and Hilary Edelstein for her support with the overall project. Evidence to Care would also like to acknowledge working group members, and Kate Robson and Jessica Van Wyk for providing case studies for this Toolkit.

FUNDING

The Peer Support Toolkit was developed with funding support from the Government of Ontario and the Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) Foundation. Evidence to Care would also like to recognize the Holland Bloorview Teaching and Learning Institute and the Bloorview Research Institute for their continued support.

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Updated: May 2016

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HOW TO CITE THIS DOCUMENT

Providenza, C., Schippke, J., Townley, A., & Kingsnorth, S. (2015). *Peer support best practice toolkit: Section 2.0 Current programs in Ontario: Case studies*. Toronto, Ontario: Evidence to Care, Holland Bloorview Kids Rehabilitation Hospital.

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SECTION 2.0

Current programs in Ontario: Case studies

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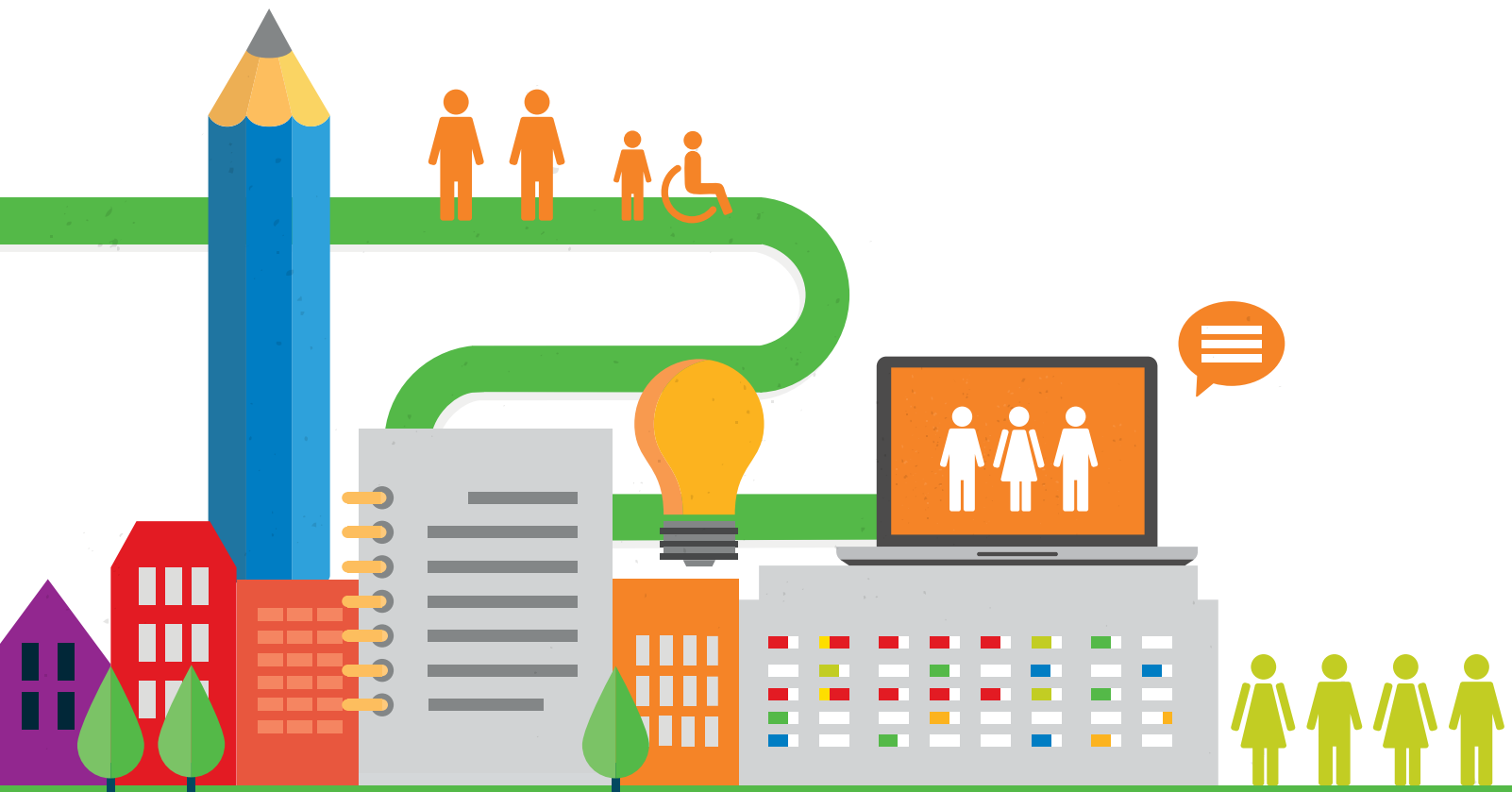
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Introduction

This section showcases examples of in-person, online, and parent matching peer support programs across Ontario. Program leaders provide an overview of each program, successes and challenges, key learnings and recommendations. Contact information for each program is provided.



In-person support groups



Complex Needs, Complex Parenting – A Therapeutic Support Group, Grandview Children’s Centre

Program description

Families of children with complex diagnoses express a unique need for therapeutic social work intervention and support. A specialized parent support group was developed to provide family/client focused care and support caregivers of children with complex needs. Program components include: parent networking, empowerment, resource navigation, therapeutic counselling, and emotional/informational support. This program has been offered three times (comprised of four to six sessions). Peer support was a key attribute and was facilitated by a registered social worker. Often a ‘take home’ was built into the group. For example, in the most recent group, each session contributed to reconstructing a flower plant, decorating and planting the flower. This was used as a metaphor and to connect each session.

Do not be discouraged if the program does not work out the way it was imagined. Start small and be open to it growing, changing or evolving

Successes

- Gathering feedback (evaluation) from parents/caregivers to support the need for the program
- Majority of the families in attendance that have children with a rare diagnosis expressed an appreciation for other families who “get it” and who they can relate to
- Engaging caregivers involved in past groups to mentor newer participants

Challenges

- Ability to offer childcare during meetings (currently being explored)
- Expanding opportunities for parents to attend using various technologies (e.g. Skype, telephone)

Recommendations

- Enhance accessibility (i.e. incorporating other ways for families to attend – online, Skype, phone)
- Provide flexibility (i.e. working with families who are attending so their experience is maximized)
- Do not be discouraged if the program does not work out the way it was imagined. Start small and be open to it growing, changing or evolving

Other programs

- Grandview Children’s Centre – Facebook Group: <http://grandviewkids.ca/programs/family-resources/family-networking>
- Extend-a-Family Waterloo Region: <http://www.eafwr.on.ca/how-can-we-help/medically-fragiletechnologically-dependant/>

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Parent Talk, Holland Bloorview Kids Rehabilitation Hospital

Program description

Peer support programs can have a profound impact on parents and have been found to reduce stress, enhance life satisfaction, and create learning opportunities for dealing with difficult situations. At Holland Bloorview, “Parent Talk” was launched in Fall 2014 following the success of a pilot project* to support parents of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). The program was co-designed with families, ensuring relevancy, meaningfulness, and accessibility were the primary objectives. Topics for the ASD program included: resiliency, support and coping, and building a network. Topics for the CP program included: sleep challenges and strategies, hypertonia, and transitions. All talks are facilitated by a topic expert, a family-centred care specialist, who is also a parent of a child with ASD, and a family mentor.

Successes

- High attendance across various ASD and CP topic areas indicates the value and need among families
- Highest attendance rates were for topics relating to younger children
- Demographic information will continue to be tracked to understand the participant population in more depth so that programming can be tailored
- Marketing materials are tailored with frequent marketing opportunities both onsite, on the hospital’s website and through all social media channels
- Onsite childcare is provided free of charge to enhance participation

Challenges

- Coordination can be time intensive
- Families have requested longer sessions (increase to 2 hours)
- Difficult to find a date and time that works for everyone
- Location and setting: Increased attendance requires a larger space, reducing the intimacy of the program

Recommendations

- Advertise and send a lot of reminders; collect email addresses to send flyers directly to families
- Have topic experts, mentors, and facilitators who are experienced
- Greet people as they arrive and make sure they are comfortable
- Offer refreshments
- Be organized: It will not instill confidence in you if you are scrambling to put out material or equipment as people arrive
- As a facilitator, make or encourage parent-to-parent connections where appropriate
- Ensure your guest speaker allows time for and encourages parents to share their thoughts
- Evaluate the program (formally or informally) and adjust your program when possible to accommodate this feedback

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*This pilot project was initiated and led by parents Philippa Howell and Brenda Relf of the Autism Speaks Autism Treatment Network/Autism Intervention Research Network on Physical Health’s Family Advisory Board.

Parent Coffee Break, Algoma Public Health

Program description

Parent Coffee Break (PCB) is a parent support/education group for parents of children with any exceptionality in Sault Ste. Marie. It runs one evening each month from October to May from 6:30 to 8:00 pm. There is a brief topic and sometimes a guest speaker, as well as time for more casual discussions. The topics are chosen by the parents but usually include: parent stress and coping; the education system; respite; funding and paperwork; behaviour, etc. The group is run jointly between the Children's Treatment Centre and the Infant and Child Development Program, and is offered at a downtown Best Start Hub family centre.

Successes

- Providing childcare
- Agency facilitation
- Including guest speakers
- Downtown location
- Paid facilitators
- Very good attendance on nights when a speaker is attending

Challenges

- Diagnosis specific groups were not as successful (with the exception of autism spectrum disorder) in the community, likely due to the small overall population (e.g. a session on equipment might be better attended by parents of a child with cerebral palsy, but sensory issues will draw parents of children with autism. Overall, 'regulars' come to all of the sessions and this is very supportive)

- Weather
- Some sessions have been offered through Ontario Telemedicine Network (OTN) to connect with district families, but generally families have reported they prefer to attend in-person

Recommendations

- Provide food/coffee
- Provide childcare
- Provide funding for transportation
- Include paid facilitators to keep the amount of work involved for the parents to a minimum
- Address issues/services specific to the population (e.g. Aboriginal population)

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Neonatal Intensive Care Unit Parent Support Program, Sunnybrook Health Sciences Centre

Program description

In 2010, the Neonatal Intensive Care Unit (NICU) at Sunnybrook Health Sciences Centre created the Parent Coordinator role to offer peer support to NICU families. The Parent Coordinator is a graduate of the NICU. The kind of peer support provided depends on the needs of the particular family; activities include, but are not limited to, one-to-one support, social events, support groups, craft sessions, and phone/online support. The Parent Coordinator is responsible for designing and creating educational materials for parents and families, working with outside agencies (i.e. public health) to offer expanded support to NICU families, and visiting (peer support) with parents-to-be in the High Risk Pregnancy Unit. Educating staff about patient and family centred care, representing the unit at conferences, and working with unit staff to ensure family perspectives are considered when creating new policies and procedures.

Successes

- The role has been very successful overall, as parents report high levels of satisfaction with their interactions with the Parent Coordinator
- Since the role began, the unit has implemented many new programs to help support families. Examples include: weekly peer support groups, weekly education programs, outreach newsletter, new family centred Welcome Book, family welcome bags, parking support program, calendar of social events, monthly Dad Night

Challenges

- Finding funding for materials and food for social events. These activities are donor-supported and it is hard to sustain the same levels of service throughout the year without guaranteed funding
- Burn out. The role is wonderful, but also exhausting. It is a part time role, and so it can be extremely challenging to keep the work confined to the hours scheduled

Success AND Challenge

- The role was intentionally designed to be very flexible and the tasks of the Parent Coordinator vary widely from day to day. This can be immensely rewarding and interesting, but also overwhelming

Recommendations

- If a parent is brought into the unit in a paid role, identify champions for the parent to connect with. Staff members should offer support on an ongoing basis and give the parent opportunities to debrief regularly
- Ensure the parent isn't being asked to do things that are not within the job description, and help champion the role with other staff members
- Ensure adequate funding is in place for related programs, like events or support groups
- Check in regularly to make sure the scope of the role is not growing more than it should
- Make sure the parent receives appropriate training and support for all elements of the job (e.g. bereavement, public speaking, conflict resolution, communication training)
- Before asking the parent representative to take on a task, determine if the task is an appropriate use of this person's time. How would this task have previously been handled? Not all situations involving parents or family members should fall to the Parent Representative to solve. The Parent Representative is there to help everyone become better at patient and family centred care ... not to do everything family-related by her- or himself

Contact information

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Ancaster Parent Support Group, Community Living Toronto

Program description

This is a Parent Support Group for parents who have children (all ages) with Autism Spectrum Disorder (ASD). The group is a place for parents to share the successes and challenges of raising a child with ASD. Parents offer/gain support, resources, and build relationships that extend beyond the sessions.

Successes

- Creating a warm, safe environment where parents feel free to share their feelings is essential
- Having parents contact/check in with another parent when they have been absent from the group for a while is also beneficial (this promotes circle of support away from the group)

Challenges

- Parents would like to meet more often (difficult due to space availability and staff time)
- Group dynamics (e.g. it can be challenging when parents' views conflict or when a parent takes up all the time and other parents do not get to speak or have limited time)

Creating a warm, safe environment where parents feel free to share their feelings is essential

Recommendations

- Ensure there is a balance within the group so that everyone has a voice
- Have facilitators who work well together
- Create a balance between offering information/support and allowing parents to connect and support each other
- Know the characteristics of the target group (e.g. age of children, community resources)

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Youth Sibling Support Group, Extend-A-Family

Program description

Extend-A-Family's Youth Sibling Support Group (YSG) has been meeting since 2011. There was a recognized need for support for siblings (who have brothers/sisters with a developmental disability) going through transitional stages of their teen years, and that's how the YSG was born. The YSG is a safe space where siblings (age 10-15 years) can meet, connect, discuss what family life is all about, share their celebrations and challenges, and find support and friendship with other siblings who truly understand. The YSG meets several times a year and gathers in different locations around the city. There is always a conversational component to the time together, as well as interactive activities. The activities and outings come from the group members' interests. Siblings are encouraged to connect between gatherings to continue to grow that trust and friendship.

Successes

- Having YSG members contribute questions, conversations, and activities of interest
- Regular members attending
- Seeing relationships deepen and grow
- Rotating gatherings to different locations/events
- Even with ebbs in flow of attendance, the siblings who are there really benefit from connections and conversations

Challenges

- Finding a day or evening that suits everyone's schedule
- Identify an age group that can relate to each other in conversation (originally had 10–17 year olds with a vast difference in experiences and ability to connect)

Recommendations

- Ensure there are facilitators to help guide conversations
- Provide a listening ear to the needs and desires of the group
- Foster an environment where siblings are committed and empowered to support each other

Contact information

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Online peer support



Ability Online

Program description

Ability Online is a supportive online community for kids, teens, and young adults with all kinds of disabilities or chronic illnesses. There is also a separate section for parents and professionals. Membership is free and the online experience is safe, secure, and monitored. Ability Online helps members build confidence and skills by connecting them to a supportive community of role models and peer mentors, linking them to great learning resources, and providing them with a safe and nurturing platform to receive assistance tailored to their specific learning needs. It allows any member (child, teen or parent) to connect with others for friendship, support, and information in a secure, bully-free environment where the goal is to help members accomplish great things! Connections tend to be informal in nature, but networking can be facilitated if needed.

Successes

- The online environment is socially and physically accessible
- Being available 24 hours, seven days a week from anywhere there is internet access allows members to connect when and where it is most convenient
- Program has been incident-free for 25 years and has expanded to include parents and professionals
- Skill development modules, games, and online library of books can be used by parents/ caregivers with their children

- Siblings are welcome and there are volunteer opportunities for those in high school to earn community service hours
- Secured funding for a separate equipment grant program for families who are active members of Ability Online
- National program

Challenges

- Fear parents have about allowing their more vulnerable children to participate online
- Meeting needs of parents for whom English is not a first language

Recommendations

- Rather than reinvent the wheel, look to partner with existing programs like Ability Online. Community partners can set up private pages and forums within the site to be accessed just by those client groups
- The online community can be a wonderful compliment to offline activities, and helps to keep the conversation going long after offline groups have finished meeting

Contact information

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Parent Advocacy Link (PAL), THREE TO BE

Program description

An online support group was created through Facebook for parents, families, and caregivers of children with neurological disorders. This closed space is one where they can share struggles, successes, concerns, hopes, experiences, helpful hints, questions, and inspiration with others. Parents can access information, tools, resources, and peer support, which helps them become the greatest advocates they can be for their children. Partnerships with community organizations across Ontario and Canada have been formed to ensure that what is provided is the most relevant for families' needs and to make collective voices heard. Everything done through PAL is aimed at making all aspects of special needs parenting better, easier, and supported. Every day, more families are receiving a diagnosis of cerebral palsy, autism spectrum disorder, epilepsy, and other neurological disorders.

Successes

- Over 750 members with new members joining daily. Membership includes individuals from the Greater Toronto Area, Ontario and across Canada, the United States, and overseas
- Sharing commonalities across families with different diagnoses
- Newly diagnosed families benefit from connecting with other families further along on their journey, giving these supportive parents a sense of purpose and belonging
- Safe place to vent, cheer, worry, share, and inquire
- No pressure to participate; can be a silent observer
- Easy to log on (access using mobile technology) and ask questions regardless of time or location
- Responses to questions and support is easily available
- Allows for easy sharing of tips and resources
- Expanding social networks and interactions (e.g. meet ups)

Challenges

- Ensuring privacy – once something is on the internet, it stays there forever even with a 'closed' group
- As a moderator (i.e. administrators), knowing when to jump in and when to let things play out
- Sometimes things can be misinterpreted when not being said in-person
- Differing personalities/views can be a blessing and challenge depending on the person and the topic

Recommendations

- Provide clear rules and guidelines early on (e.g. exercise caution when sharing sensitive and personal information about yourself/family)
- Engage a strong and confident moderator who can stay neutral
- Provide follow-up documents from discussions that are of interest to the group
- Make valuable resources available online
- Engage group members to be positive champions who can motivate other members and foster an environment for sharing. Having champions can set up the support group for success
- Find out what people want and do not assume to know. Let the audience dictate what matters to them and what they want to share

Related Resources

PAL Pathway Kit for newly diagnosed families
<http://www.threetobe.org/pal/>

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Program description

Connected Families is a social media tool that has some privacy but also allows opportunities to meet new people who have similar concerns and interests. It is built into the ConnectABILITY.ca community of people with a developmental disability and their support networks. Connected Families is a meeting place for families to connect with others. This is a place to talk about and connect about everything from the little stuff to the really big stuff, how to solve problems, find resources, and find ways to make dreams happen. Families can tell stories, share ideas, successes, and even frustrations.

Challenges

- May be limiting for families who do not have access to a computer or have English as a second language

Contact information

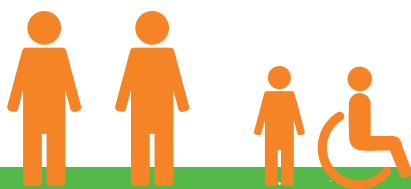
ConnectABILITY.ca

Click on: *Register/Login*

<http://connectability.ca/login/>

Find out what people want and do not assume to know. Let the audience dictate what matters to them and what they want to share

– Parent Advocacy Link (PAL), THREE TO BE



Online Support Network for Families Caring for Medically Complex Children, The Hospital for Sick Children

Program description

This online support network is an asynchronous, peer information, and support group for parental caregivers of children with complex health needs, moderated by staff from the hospital. The group was developed using the most stringent guidelines to ensure privacy of information. The project was designed as a research study and required development of consent forms that explicitly outlined both benefits and risks associated with the group. Plans also included using quantitative measures, qualitative interviews, and content analysis of postings made by participants to evaluate the group intervention.

Successes

- Receiving research funds for the project
- Developing a well-encrypted website
- Recruiting over 30 families

Challenges

Participation was minimal to none. While formal feedback from the recruited families has not yet been received, the program developers have some thoughts about why this did not work:

- Details in consent forms, particularly related to access by research monitors, may have put off the participation by some families
- In order to properly safeguard online information the online site was well-encrypted and required a number of steps to log on. This may have created time and convenience barriers for parents
- The site was developed by a hospital web-team and had to fit a template for hospital sites. It was not particularly aesthetically pleasing and was difficult to maneuver

- The group was targeted to families with children with a broad range of conditions – perhaps families prefer to join condition specific groups

**Stay tuned for findings from interviews with the recruited families to learn more*

Conducting a feasibility trial first to determine whether the selected approach is attractive to families

Recommendations

- Conducting a feasibility trial first to determine whether the selected approach is attractive to families
- Ensure groups are easily accessed and run with flexibility
- Provide prompts for parents to participate

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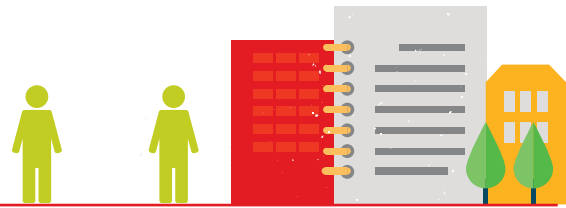
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Parent matching



Family Mentor Program, Children's Treatment Network (CTN)

Program description

Thanks to funding by the Ontario Trillium Foundation, the new Family Mentor Program is launching fall 2015 at the Children's Treatment Network (CTN). In this program, volunteer mentors with lived experience caring for a child or youth with special needs are matched with another family within Simcoe County or York Region. The mentors are overseen by Regional Coaches who facilitate all recruitment and training. The goal of the program is to offer resources and support for families through phone calls, emails, and face-to-face meetings at local sites.

Successes

- Support from internal team and external partners
- Initiative spearheaded by Family Engagement Council
- Secured grant funding for three years
- Flexible and responsive model
- Program will be utilized by network partners
- Value and recognize lived experience as a key resource among families
- All key stakeholders have been asked for feedback along the way

Challenges

- Building a program that supports and reaches out to diverse communities across both Simcoe County and York Region (this is a huge geographic catchment area and includes various diverse cultural and socio-economic groups that the mentor program must support)

Dedicate time to training and recognition of all peer support workers/mentors

- Future challenge will be finding funding for the program after the grant is completed

Recommendations

- Consider a model that is both flexible and responsive to the needs of those you support. CTN has built a three-tier program with a part time coordinator, two part time Regional Coaches (one in Simcoe and one in York), and volunteer mentors, to respond quickly to families at a local level
- Get feedback from partners and stakeholders in all programs to have their support and input from the very beginning. It allows you to be partners in the truest sense and make sure you respond to any questions or concerns before launch
- Dedicate time to training and recognition of all peer support workers/mentors

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