

## Family Advisory Committee – Meeting Notes

## June 2020

Location	Zoom
Guests	Karen Eisler, CEO

Strategic Area of Focus
Evolve Services
Nurture Relationships
Strengthen Capacities

No.	Area of Focus	Торіс	Discussion and Action Items
1.		Welcome and Introductions—sharing our talents!	Chair welcomed youth guest and Karen Eisler to the meeting
2.		Agenda – Any additional agenda items  Meeting Notes – approval of May 28, 2020 meeting notes	Agenda: Add AGM video and Youth Program Update to Agenda.  Meeting Notes approved by HG and seconded by MD.
3.		CTN Celebratory Video for 2020	Heather shared the CTN video of accomplishments over the 2019-20 year. The video was shared at the Annual General Meeting (AGM)
4.		Standing item: Successes and Challenges	Challenge: A member raised the challenge faced by many people with disabilities who are unable to participate in recent protests for Black Lives Matter due to COVID 19.  Success: Recent Youth Group and F-Words. Seeing two Youth members facilitate the group and act as role models was a very positive experience for all involved. CanChild is now looking at how they can support the two young adults to continue to support the engagement of youth. People with disabilities are often unable to collect together to raise their voice. Discussion followed re: the importance of compensation to youth and young adults for the work they do in order to demonstrate value and

	support advocacy work.
- Addressing Diversity –Discussion	Karen Eisler, CTN's CEO, led a discussion re: diversity. Points included:
	<ul> <li>Do not want to lose ability to access leadership team at CTN</li> <li>CTN has done many positive things to ensure the inclusion of the client/family voice including hiring family members raising a child with special needs. CTN has not however hired a person living with a disability.</li> <li>One FAC member stated that hearing from diverse membership at FAC has helped to broaden her understanding of what many of our families may be dealing with.</li> <li>Sharing stories is so important –being open and honest helps all of us learn</li> <li>Diversity training would be important for staff and volunteers</li> <li>Being curious is a positive step – how a question is asked is critical –being non-judgmental in our questions and our response</li> <li>Children/families need to see themselves reflected in the staff and therapists they are working with</li> <li>Issue of standardized tests was raised –need to ensure that these are inclusive of all experiences. Language of the test can cause challenges for families for whom English is a second language. Families may not always ask for clarification due to stigma. May not want to admit that they don't understand</li> <li>Issue of women and their right to choose. Women living with a disability do not necessarily have privacy in terms of their medical decisions and care.</li> <li>Need to listen to youth and treat them as individuals apart from their parents. Ensure their agency. Families cannot be the voice of individuals with disabilities. Let youth be alone with their therapist or health care provider.</li> <li>Accept that all people need a sense of self, time alone</li> </ul>

		<ul> <li>Male perspective is important. Continue to encourage voice of fathers as they have a unique perspective. Challenge to find male therapists in pediatrics.</li> <li>Continue discussion by adding diversity as standing item to various CTN agendas. How are we addressing? How are we progressing?</li> <li>Karen thanked the group for their discussion. The discussion will help to inform further work by CTN.</li> </ul>
	Updates: - Update from Youth Group and Graduation	<ul> <li>LT and Heather provided an update to the FAC re: the Youth group's discussion re: graduation. Heather shared some survey numbers. Grades for the youth participating ranged from grade 9 to 12+.</li> <li>Discussion followed:</li> <li>Pair graduation for CTN services with a transition tool kit—include therapist's recommendations, links to other services, how to connect with medical team</li> <li>For graduation—it would be important for therapists to attend</li> <li>Important to recognize that it would be important for the graduating youth to have family support. This may not be possible for all kids</li> <li>Graduation may not be important to all students or families — whatever we decide may only support a some clients</li> </ul>
5.	FAC – Chair positions and Terms of Reference, Membership list	Michelle shared that all members had responded to the on-line vote to have RC and LM continue in their roles of Chair and Vice Chair until June 2021. Michelle shared the terms of reference and reminded the Committee that a review is required with any suggested changes being made in September.  Michelle also let the Committee know that Karen Steele will be stepping down after 4 years on the Committee. Discussion as to what position the Committee would find beneficial —Local Team Facilitator, Service Navigator or School Based Rehabilitation service navigator? Discussion also included need to recruit family members versus staff members. It would also be good to hear a

9.	Next Meeting: September 17, 2020 meeting	Michelle asked the group if it would be possible to have a brief summer meeting to address some changes the Diagnostic Assessment Service would like to make.  Action: Michelle will survey the group for a meeting time when the DACS team is ready to present during the summer.  Next Regularly scheduled meeting: September 17, 2020 10am to noon by ZOOM
8.	Updates from Other Committees and Community Activities	No updates were shared at this time.
7.	<b>Feedback</b> – Frequently Asked Questions re: appointment at a CTN site during COVID.	Action: Michelle to send out email to group asking for questions that families may have related to COVID and CTN and services. CTN is looking at putting together a Frequently Asked Question section on the website for families.
6.	Supporting Self Advocacy in Children and Youth – Discussion re: next steps	and forward any suggested changes to Michelle. Michelle will bring all suggestions forward to September meeting. Heather to increase efforts over the summer to recruit other family members. All FAC members to share information with families to create interest.  Discussion led by R. re: doing some training as to how parents can help to build self-advocacy skills in their children. Possibly combine this with the F-words. And help children and youth communicate their dreams and needs.
		father's perspective on the Committee.  Action: All to review the current FAC Terms of Reference