

# The Family Voice

Special Edition: What your Research Family Advisory Committee is doing for you!

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VOLUME 4, ISSUE 1

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## VISION

Family will be integral members of the recovery process and will be embraced by and actively engaged at all levels of the organization.

## MISSION

The Family Advisory Committee (FAC) is a partnership between CAMH staff and family members affected by a family member's mental illness and/or addiction. The CAMH FAC will engage with families, patients, community members, and care providers to improve client care and enhance the experience of both patients and their families at CAMH.

## DEFINITION OF FAMILY

Any person or group of people someone identifies as belonging to their family or significant circle of support.



## Family Engagement in Research: “Nothing About Us Without Us”

At CAMH, there has been a great deal of family engagement activity in research. We are in the midst of a movement towards patient- and family-centred research that partners with clinician scientists, researchers and those with lived experience. Families and caregivers are vital for their unique insight into the lives of those they care for and the way research can be designed, framed and conducted. Family engagement in research ensures evidence is accurate, holistic, relevant, useful, and trusted by those that CAMH serves. It is also an ethical way to do research!

More and more, public funders of research are requiring caregiver and patient engagement from the start. CAMH's commitment to this work is allowing targeted efforts to build capacity between scientists and researchers and family members with the aim of building a culture of patients and families as partners on research teams. The knowledge and skills of the researcher *and* those who are at the core of what is being researched can link to produce enriching and relevant results.

## Families/Caregivers need to bring...

Engaging in research can inform and enlighten researchers and expose issues that they may not have considered. This is a place to be heard and have your contributions matter. For families, knowing and believing you are experts in your experience is key to contributing and having your voice heard. It will take time and energy, as well as an interest and curiosity to engage in research, which differs from other kinds of projects and processes. Engaging in research doesn't replace or give you access to care. While change can be slow, research can be the starting point to bigger systems of change and it starts with your involvement.

## Researchers need to know...

A good starting point for a researcher considering engaging with family partners is to reflect on the need for the caregiver voice in your project. Bringing caregivers in as research partners earlier (such as the problem identification or research question stage) can help support relevant research outcomes and helps to prevent tokenism. Tokenism can look like inviting patients and families to be involved in order to fulfill a requirement rather than meaningfully engage them. Caregiver voices and experiences are also diverse, complex and sometimes conflicting. While this can raise challenges, your flexibility, openness and adaptability will help keep the researcher-caregiver relationship meaningful for all. There are tools, supports, and a growing body of evidence to help you build authentic family engagement into your research.

## CAMH Family Engagement in Research

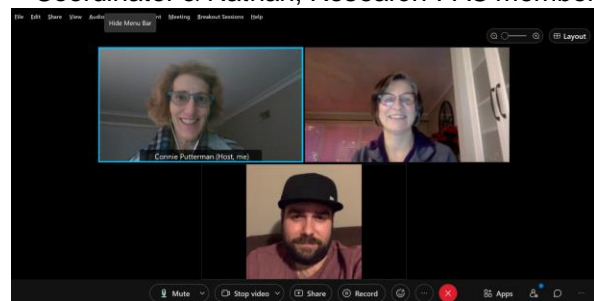
To date, we have created a structure to support this work for both researchers and family members. We have designed and co-developed training, on-boarding tools and processes as well as introductory workshops for family advisors and researchers. We also have a growing network of caregiver-experts actively involved at all stages of research across CAMH. With the support of a full time family engagement in research coordinator (Connie), caregivers are learning to recognize and share their needs while engaging in research.

## Future Directions

There is a lot of work to be done in Family Engagement in Research (FER) moving forward. We are working to encourage earlier partnerships with caregivers as this is the heart of meaningful and authentic family engagement in research. We continue to educate and partner with research divisions across the organization. We are actively working to diversify our group and expand our network of caregivers internally and externally.

While we approach this work with great enthusiasm and an innovative spirit, we must be careful to not repeat wrongs from the past. This requires a reflection on the history of power dynamics in research and its impact on those with lived experience. CAMH's commitment to patient and family engagement within the strategic plan is part of this process, including the commitment to principles of equity diversity and inclusion. The impact on care and experience require continuous engagement to bridge the gap between research results and clinical care. We need and want your involvement in research!

—Connie Putterman, CAMH Family Engagement Coordinator & Nathan, Research-FAC member



**The Research Family Advisory Committee Members who contributed to this issue of the Family Voice. Pictured: Connie Putterman, Shannon, and Nathan Not Pictured: Melanie**

## Message from the co-chairs

As we look forward into 2022, the FAC is excited to begin collaborating with partners at CAMH on the Family Voice Newsletter. This special edition is one example of upcoming partnerships. For Volume 4 Issue 1, we connected with the Research Family Advisory Committee (FAC) and the Azrieli Adult Neurodevelopmental Centre at CAMH in writing articles, being interviewed, and sharing their perspectives. The Research FAC is

made up of family members with lived experience supporting someone with a mental illness and/or addiction (much like the CAMH FAC). The primary difference between the two advisory groups is the focus of our work, while the CAMH FAC is focused on quality improvement, patient safety and experience in the clinical and corporate programs, Research FAC is focused on research at CAMH. Read on to learn more about the work they are doing and how they are making a difference for families in research!

In 2022, the Family Voice Newsletter will be exploring new ideas and seeking contributors. If you are a staff member at CAMH we would love to highlight the amazing work you are doing to support an excellent family experience. If you are a family member we want to hear your story and learn more about what information and features you would like to see in the Family Voice Newsletter. If you are a community organization supporting families we are keen to interview you and feature your work as a spotlight or in our resource section. Interested in collaborating with us? Email [ashley.bowe@camh.ca](mailto:ashley.bowe@camh.ca) to learn more.

We hope you enjoy this special edition! This is the first of many new collaborations as the CAMH FAC is committed to working together with patients, families, and staff towards the goal of improving communications with families at CAMH.

—Susan Conway, mother, CAMH FAC co-chair, & Ashley Bowe, sibling, CAMH FAC co-chair



*The CAMH FAC welcomes and thanks the Research Family Advisory Committee for their collaboration and partnership on this issue! CAMH-FAC member list, 2021–22*

*Top, from left: Susan Conway, John Im, Mara Jayenthiran, Pauline Lefebvre-Hinton, Miriam McCann, and Nicole Waldron. Front, from left: Vivien Cappe, Thanisa Sundaralingam, Mary Beth Odell, Ashley Bowe.*

## Meet the Family Advisor in Research: Nathan

### What drew you to Research?

Before becoming a father, I used to provide person-centred care for adults with developmental disabilities and in the DeafBlind community. Since then I have become a sociocultural anthropologist. This is a discipline that has a history of activism, community-led and participatory-action research, which includes communities as stakeholders in the research process. As a caregiver facing constant barriers to get my son's needs met, because complexity doesn't fit nicely into standardized boxes, I also have firsthand experience on what happens when research (and the policy and social services informed by this research) excludes the very people it impacts. As an Advisor in research I continue my critical advocacy work, this time by informing, shaping, guiding, and helping to create research that utilizes the diverse expertise of caregivers – and increase understanding and knowledge of the complexities of neurodiversity and mental health.

### What's been the most rewarding thing you've done as a research FAC member?

I find that by sharing my story and perspectives I often inspire others who then see the benefits of sharing their own. I also take pride in the ways I am giving greater visibility to queer and male caregivers – who are an underrepresented voice.

### How long have you been supporting your family member?

My husband and I adopted our son in 2006, coming to us with multiple diagnoses. He is now twenty-two, and these include a Developmental Disability, Autism, and mental health conditions.

### What types of work have you been involved in?

- Research Family Advisory Committee Member
- Azrieli Adult Neurodevelopmental Centre Family Caregiver Advisory Group (planning & subcommittee)
- Research Ethics Board Community Member
- Slight Centre, Specialty Care for Youth Wellness (SCY-Well) Complex Care Initiative



- Participated in studies via interviews, surveys, workshops
- Youth Suicide Prevention: [Let's start the conversation panelist](#)
- Onboarding for Project ECHO Ontario Adult Intellectual & Developmental Disabilities (AIDD)
- External to CAMH, I Completed "Teaching and Facilitation Course" for Family as Faculty from Holland Bloorview

Your favourite pearls of wisdom? This article "[To Institutions looking to 'transform'](#)".



**Pictured:** Azrieli Adult Neurodevelopmental Centre Advisory Members.

## Spotlight Research Centre: Azrieli Adult Neurodevelopmental Centre at CAMH

For this issue of the Family Voice, we are spotlighting the Azrieli Adult Neurodevelopmental Centre, the first research and education centre in Canada dedicated to improving care for adults with neurodevelopmental disabilities (e.g., autism, intellectual disability, and down syndrome) and mental health challenges.

### What does the Azrieli Adult Neurodevelopmental Centre do?

The Centre, led by Dr. Yona Lunsky, is one of several Centres of Innovation at CAMH with a focus on research excellence, clinical innovation, education and training, and knowledge exchange. The Centre works closely with people with neurodevelopmental disabilities and family caregivers to study and develop ways to improve the health and health care of this population. As

a team, we are committed to health equity and firmly believe that individuals with neurodevelopmental disabilities and their families should have access to the right care, at the right time, in the right place.

### What opportunities are there for families of someone with a neurodevelopmental disability to be involved?

Our Centre is committed to amplifying the voices of family caregivers in everything we do. As part of this commitment, our core team includes a family caregiver and several other family caregivers who advise on specific projects. The family advisory committee meets bi-monthly and provides input on research study design and knowledge translation. They also provide input on clinical innovations and family and professional education.

### What are some examples of ways families have been involved with the Centre to improve care and experiences for other families?

**Clinical Innovation:** Family caregivers co-facilitate clinical interventions including [Acceptance and Commitment Training \(ACT\)](#) workshops, mindfulness workshops, and [mindfulness podcasts for family caregivers](#). Importantly, these supports are designed and delivered by caregivers and clinicians working together in partnership. Research has shown the positive impact of these programs, including improved health and wellbeing among participating caregivers and their families.

**Knowledge Exchange, Education and Training:** Family caregivers play an important role in both creating and sharing ideas at our Centre. For example, families have been involved in the creation of accessible healthcare tools and resources for people with neurodevelopmental disabilities and their families (i.e., [Family Matters Toolkit](#), [COVID-19 Vaccine Information](#)). Similarly, caregivers are involved in education and training. For example, caregivers co-developed and [co-led virtual courses for other family caregivers](#) and health and social service

providers ([ECHO Ontario Mental Health](#)) targeting the mental health of adults with neurodevelopmental disabilities. Course participants have reported improvements in wellbeing and highlighted the value of family members as teachers. Family caregivers also have many opportunities to share their lived experience with a range of audiences (e.g., clinicians, researchers, other families) and in a variety of ways including [conferences](#) and [webinars](#).

**Research Excellence:** Family caregivers play a key role in all aspects of research at our Centre including providing input on research questions, developing grant applications, creating and refining research tools (e.g., consent forms, surveys, focus group/interview questions), analyzing data and sharing information through publications and presentations.

To learn more, please contact Azrieli Adult Neurodevelopmental Centre Family Advisor, Lee Steel: [lee.steel@camh.ca](mailto:lee.steel@camh.ca)



## Research Highlight: Toronto Adolescent and Youth Study

The Toronto Adolescent and Youth Study (TAY) is a five year, longitudinal study and the first of its kind at CAMH that tracks the development of children and youth aged 11 to 24. The study starts from the time they have a mental health concern. The main aims of the study are to find out who is at the highest risk of developing psychosis as well as the relationship between

## WHERE ARE YOUR RESEARCH FAMILY ADVISORY COMMITTEE MEMBERS?

### Research Projects at CAMH:

- Toronto Adolescent & Youth (TAY) CAMH Cohort Study
- Child Youth and Family Services Navigate Study / Epi-Set & Specialty Care for Youth Wellness (SCY-Well)
- ECHO Ontario Adult Intellectual & Developmental Disabilities (AIDD)
- Azrieli Centre- Acceptance and Commitment Therapy Workshops
- Cognitive Function in Addictions (CDiA) Study
- Opioid Addiction Management (OUDrx) Study
- BrainHealth Databank

psychosis and other factors, such as substance use or other diagnoses such as autism or ADHD.

The ultimate goals of the TAY study are to provide important information and evidence that will guide clinicians and empower families to positively influence youth mental health outcomes. It will also influence other studies in youth mental health research by revealing gaps and new areas of study. We connected with Melanie, a Research Family Advisory Committee member to learn more about her experiences engaging in the project.

### What is the role of Families on TAY?

I am a Research Family Advisor on a project group that focuses on recruiting participants to the study and on engaging and retaining them once they are in the study. Specific things I have provided input on are the consent process, how participants are compensated, and the communication products that participants and their caregivers receive about the study. I also recently joined the TAY Steering Committee, the leadership committee that makes decisions about the study.

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## Describe what made you interested in research engagement?

A few days after a friend suggested I get involved at CAMH as a Research Family Advisor, my social worker approached me as well. It felt it was meant to be.

## What are three highlights of participating as part of the research project team?

First and foremost, I find it very meaningful to use my experience in supporting my daughter to help others and to have a positive influence that other families can benefit from. Second, I enjoy being a part of the CAMH community and continuing to learn about mental health. I found out about several terrific resources and happenings at CAMH by being engaged. Lastly, I know my contribution is valued and have seen my input being incorporated into the study.

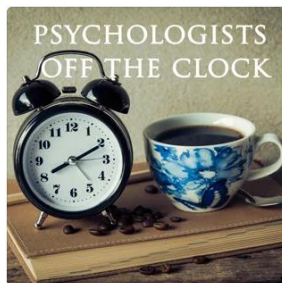
## What lessons have you learned along the way that you want to share with others?

The involvement of the CAMH family engagement coordinator in supporting advisors was very valuable. She took the time to find out what my skills and interests were and then recommended areas for me to be involved in and has provided guidance throughout. I would encourage anyone who wants to be involved and doesn't know where to start to simply reach out to the Family Engagement in Research Co-ordinator ([connie.putterman@camh.ca](mailto:connie.putterman@camh.ca)) to get started!

—Melanie, Research-FAC member

## Reviews:

### Podcasts, Apps and More



**Psychologists Off the Clock.** Dr. Debbie Sorensen, Dr. Diana Hill, Dr. Yael Schonbrun, and Dr. Jill Stoddard.

*Free on Spotify and Apple Podcasts.*

**The Gist:** This is a talk show style podcast hosted by four clinical psychologists that has a focus on

Acceptance Commitment Therapy (ACT). ACT is an action-oriented approach to psychotherapy that stems from traditional behavior therapy and cognitive behavioral therapy. The concepts of ACT are included throughout the podcasts, as each of the hosts uses ACT in their clinical practices. Despite this, ACT is not always the main focus of each episode. Episodes generally feature a guest expert in different fields and focus on relationships, parenting, health, and how to live your best life.

**The Good:** I find the podcast to be very informative and presented in an accessible way. The hosts are knowledgeable but at the same time relatable and human. With every episode I find I learn something or find it reinforces how I would like to be living my life. It is a great way to learn more about ACT but you don't need to know the concepts to understand the episodes.

**The Bad:** Personally I can't think of anything that I don't like about the podcast. It is hosted by four women, but they do often have male guests. It is out of the United States so some of what they talk about may not be as applicable in Canada.

— Shannon Pascoe, Research-FAC member



**The Skillful Podcast.** Bay Area DBT & Couples Counseling Center.

*Free on Spotify and Apple Podcasts.*

**The Gist:** This podcast is hosted by two

therapists in the San Francisco Bay Area and explores various Dialectical Behaviour Therapy (DBT) concepts and skills, including radical acceptance, mindfulness, distress tolerance, and opposite action. Some episodes cover topics of general interest, such as coping with the Covid-19 pandemic fatigue, and getting through the holidays stress free. The hosts also share how they apply DBT skills in their own lives.

I learned a lot from this podcast about supporting my daughter and myself. I also enjoy the format of listening to a podcast and find the hosts to be personable and relatable.

— Melanie, mother, Research-FAC member

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## Resources

**RESOURCE HIGHLIGHT: THE SASHBEAR FOUNDATION** offers Family Connections, an evidence-based 12-week group that meets weekly for education, skills training and support for people in a relationship with someone who has emotion dysregulation (e.g., borderline personality disorder). Groups are available across Canada.

### Access free webinars from Sashbear:

<https://sashbear.org/en/resources-main/webinar-series> the webinars feature experts in emotion dysregulation and Dialectical Behaviour Therapy (DBT). They explore various topics, including effective treatments, trauma, substance use, suicidality, and eating disorders. Visit the website to view past webinars and register for upcoming webinars, participants can also submit questions during the live session. Melanie a mother and Research-FAC member shared “*These webinars were very informative in explaining various concepts. They helped me to better understand my daughter and learn skills to support her.*”  
[info@sashbear.org](mailto:info@sashbear.org)  
[www.sashbear.org](http://www.sashbear.org)

**ACCESS CAMH** provides centralized information, intake and scheduling for most CAMH services, Access CAMH makes it easy to find the help and services you need with a single call. Access CAMH Family Line is **416 535-8501, press 2**, listen to the choices to the end, and you'll be connected.

For community resources on a wide range of topics, see: [www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets](http://www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets)

**CAMH FAMILY INFORMATION AND SUPPORT CENTRE** phone line is an information and support resource for CAMH families during COVID-19. It includes a recorded message on current CAMH policies and where to find more information on a variety of topics. Callers can also leave a message with questions about services and supports: **416-535-8501 ext. 33472**.

**FAMILY RESOURCE CENTRE (FRC) at CAMH** has materials on mental health and addiction, resources and information on community supports and family-focused events. It is now in the RBC Patient and Family Learning Space, McCain

Complex Care and Recovery building. Until COVID-19 restrictions lift, the FRC is open virtually 9:00 a.m. to 4:45 p.m., Monday to Friday.

**416 535-8501 ext. 33202**

Email: [family.engagement@camh.ca](mailto:family.engagement@camh.ca)

**CAMH VIRTUAL CAFÉ CONNECTION** is an informal gathering of CAMH friends and family members held the last Thursday of the month, 6:00–7:30 p.m.; call or e-mail for details to join virtually.

**416 535-8501 ext. 33202**

Email: [family.engagement@camh.ca](mailto:family.engagement@camh.ca)

[www.camh.ca/families](http://www.camh.ca/families)

**SUBSTANCE ABUSE PROGRAM FOR AFRICAN CANADIAN AND CARIBBEAN YOUTH (SAPACCY)** provides support and counselling to Black youth (ages 13–24) and their families who are dealing with substance use and/or mental health problems. Family members can self-refer for an assessment.

For more information, contact Access CAMH at **416 535-8501, press 2 or 1 800 463-6273**

**ACROSS BOUNDARIES** provides community mental health and addiction supports and services and in-house programs that include individual and family supports, as well as a peer support group, men's group, women's group, community kitchen and more. Services are available in Caribbean dialects, Shona, Amharic, Harare, Xhosa, Afrikaans, Urdu, Tsonga, Swahili, Somali, Twi, Dari, Pashto, Farsi (Persian), Punjabi, Hindi, Bengali, Tamil and Mandarin.

51 Clarkson Ave., York

**416 787-3007**

[www.acrossboundaries.ca/](http://www.acrossboundaries.ca/)

**RECONNECT FAME FAMILY & CAREGIVER SUPPORT SERVICES** offers families ongoing monthly support groups and one-on-one support across the GTA. The groups are drop-in format and are facilitated by family support worker. FAMEkids and FAMEyouth programming available.

**416 248-2050**

[www.reconnect.on.ca/](http://www.reconnect.on.ca/)

**FAMILY OUTREACH AND RESPONSE PROGRAM, CMHA** offers educational



information, programs, support services and referrals for friends and family of people recovering from serious mental illness.  
[toronto.cmha.ca/programsservices/family-support](http://toronto.cmha.ca/programsservices/family-support)

**MOOD DISORDERS ASSOCIATION OF ONTARIO (MDAO)** provides information, resources and support groups for people with depression, anxiety and bipolar disorder, and for their families and friends. Services include WRAP for Families; drop-in groups and short-term professional counselling for families.

**1 888 486-8236** or **416 486-8046**  
**416 486-8046 ext. 300** (line for family members of youth ages 14–35)  
[www.mooddorders.ca](http://www.mooddorders.ca) or [www.mdao.ca](http://www.mdao.ca)

**NATIVE CHILD AND FAMILY SERVICES OF TORONTO** offers children’s mental health assessments and treatment (0–6 years and 6+ years), transitional support for women in domestic violence situations, women’s and men’s healing, family work, group programs (including Strengthening Families). 9:00 a.m.–5:00 p.m.

**416 969-8510**  
<http://www.nativechild.org/>

**THE ONTARIO CAREGIVER ORGANIZATION** is an independent nonprofit dedicated to caregivers.

**1 833 416-2273** for 24/7 helpline  
Online chat 7:00 a.m. to 9:00 p.m., Mon. to Fri.  
[www.ontariocaregiver.ca](http://www.ontariocaregiver.ca)

## Family Resource

### e-Bulletin

The Family Resource Centre and Family Advisory Committee have partnered in launching a monthly Family Resource e-Bulletin.

**What to expect:** Family-focused resources and events, new issues of the Family Voice newsletter, Café Connection reminders, and more!

**Interested in subscribing?** Click [here](#) or email [family.engagement@camh.ca](mailto:family.engagement@camh.ca)

## Family matters

### We want to hear from you!

Family members—including relatives, partners, friends and co-workers—play an essential role in supporting the care and wellbeing of people living with mental illness and/or addiction.

Do you have an experience or story to share?

Do you have feedback about your experience at CAMH?

Your voice matters and we want to hear from you!

How to share feedback with CAMH’s Family Advisory Committee (FAC):

- Phone: 416 535-8501 ext. 33202
- Email: [family.engagement@camh.ca](mailto:family.engagement@camh.ca)
- In person when COVID-19 restrictions lift: Family Resource Centre, now in the RBC Patient and Family Learning Space, McCain Complex Care and Recovery building. Hours will be 9:00 a.m. to 4:45 p.m., Monday to Friday.

### Would you like to receive new issues of the Family Voice Newsletter to your email inbox?

Scan the QR Code below using your smart phone camera and click the [link](#) to subscribe to our Family Resource e-Bulletin.



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