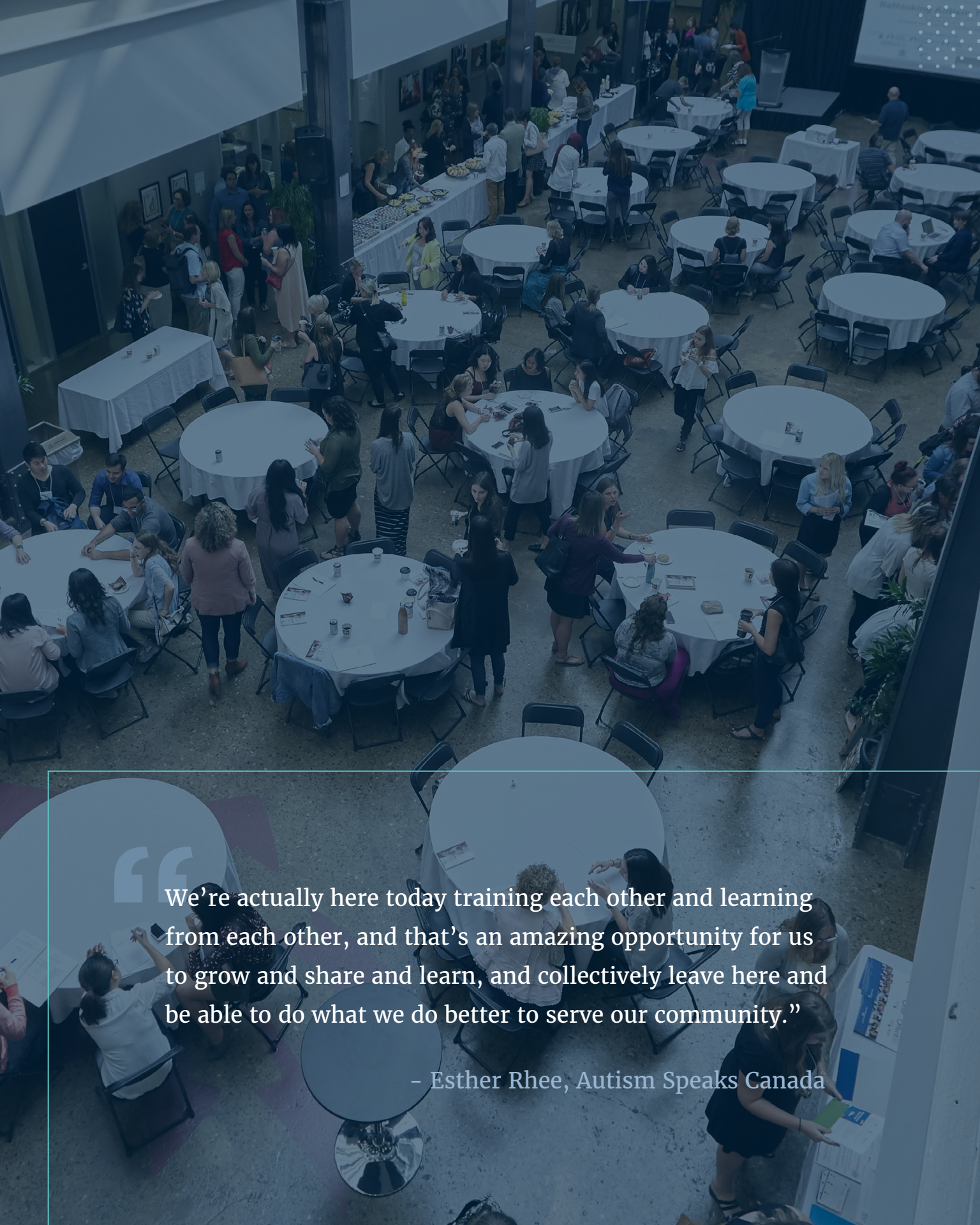


2017

MacART AUTISM RESEARCH
STAKEHOLDER SYMPOSIUM

Rethinking Autism Training



“We’re actually here today training each other and learning from each other, and that’s an amazing opportunity for us to grow and share and learn, and collectively leave here and be able to do what we do better to serve our community.”

- Esther Rhee, Autism Speaks Canada

WELCOME MESSAGE FROM CO-DIRECTORS



On September 15th 2017, the **McMaster Autism Research Team (MacART)** held its second [Autism Research Stakeholder Symposium](#). The theme of this year's symposium was 'Rethinking Autism Training', a topic that is linked to one of our foundational pillars - **Education**.

Once again, there was strong support from the ASD community as 250 participants (representing the full spectrum of stakeholders: families, autistic advocates, educators, clinicians, researchers, policy makers, students, and trainees) came together to **help identify stakeholder priorities related to autism training**.



This report provides an overview of the symposium; it includes information about existing training opportunities in ASD, as well as a **synthesis of stakeholder priorities to help shape training collaborations moving forward**.

Improving autism training is a fundamental step towards achieving our larger vision of *advancing autism care through meaningful research*.

Thank you for joining us on this journey!

Sincerely,

A handwritten signature in black ink, appearing to read 'Stelios'.

Dr. Stelios Georgiades
MacART Founder & Co-Director
georgis@mcmaster.ca

A handwritten signature in black ink, appearing to read 'Terry Bennett'.

Dr. Terry Bennett
MacART Co-Director
bennett@hhsc.ca

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ABOUT MacART

MacART is a partnership between McMaster Children’s Hospital, Hamilton Health Sciences, and McMaster University aiming to bridge the research-to-practice gap in Autism Spectrum Disorder (ASD). This research collaborative was founded in 2014, when co-Director Dr. Stelios Georgiades set an ambitious objective: to link scientific research on ASD at McMaster University to clinical practice at McMaster Children’s Hospital.

Canvassing the McMaster University community, he found faculty members and their students across many different departments who were all conducting ASD research but working in ‘silos’. He also recognized that at McMaster Children’s Hospital, hundreds of children are diagnosed and treated by highly qualified and skilled clinicians, some of whom are also researchers. Through consultation with these researchers and clinicians, the [McMaster Autism Research Team \(MacART\)](#) was formed. MacART has since grown to include over 40 leading researchers from 14 departments and 5 research centres - including a number of trainee members.

By integrating research, education, community engagement, and evidence-based policy, MacART aims to contribute scientific knowledge that will lead to better clinical practices, programs, and policies to support those living with ASD across the lifespan.



RESEARCH



EDUCATION



COMMUNITY



POLICY

SYMPOSIUM OVERVIEW

On September 15th, 2017, MacART hosted its second Autism Research Stakeholder Symposium, themed 'Rethinking Autism Training'. Over 250 stakeholders participated, with strong representation by autistic advocates, family members, community organizations, clinicians, service providers, researchers, educators, policy-makers, students, and trainees.

Our keynote speaker was Dr. Lonnie Zwaigenbaum, Co-Director of the Autism Research Centre in Edmonton, Alberta and leader of the national [Autism Research Training Program](#).

The morning also included talks by clinicians, researchers, representatives from the Hamilton-Wentworth Catholic and Public school boards, Ontario Ministry of Children and Youth Services representatives, and community stakeholders. A panel discussion also brought together various perspectives on knowledge-building and autism training.

During lunch, MacART was pleased to present travel awards to 8 student and trainee researchers. Brief messages of support were also provided from some special guests and local leaders.

In the afternoon, attendees engaged in small-group breakout sessions in a reflection and dialogue activity led by Dr. Sean Park of McMaster's [Health Leadership Academy](#). Participants explored what inspired them to begin working with those living with ASD, what challenges they face, and how those challenges might be addressed in order to build a better future (see 'Rethinking Autism Training' on page 15).



This is the kind of space we want to be in, and that we want to be a participant in – the opportunity to collaborate with parents, with professionals, people on the spectrum, researchers. To have a rich dialogue with that kind of group matters – autism training for researchers and their training as researchers is critically important.”

– Marg Spoelstra, Autism Ontario



AUTISTIC ADVOCATES: 4

CLINICIANS: 9

COMMUNITY ORGANIZATIONS: 20

EDUCATORS: 22

FAMILY MEMBERS: 13

MCMASTER & HHS LEADERSHIP: 4

POLICY MAKERS: 3

RESEARCHERS: 32

SERVICE PROVIDERS: 86

STUDENTS & TRAINEES: 42

250+ stakeholders attended the 2017 symposium.

The second MacART Symposium brought together a diverse array of stakeholders to discuss and plan collaborations to help **rethink autism training.**

SYMPOSIUM HIGHLIGHTS



KEYNOTE PRESENTATION

Perspectives on Training and Application to Autism Care and Research

DR. LONNIE ZWAIGENBAUM, UNIVERSITY OF ALBERTA

Dr. Lonnie Zwaigenbaum introduced a training paradigm to help people build the skills needed to approach complex problems in the autism field, and explained how those skills could be applied to enhance ASD care and research. Dr. Zwaigenbaum highlighted his experience as a trainee at McMaster University, in an interdisciplinary environment with mentorship and encouragement, as well as his experience leading the Autism Research Training Program. A key lesson learned from these experiences is the need to embed partnerships into training initiatives, to provide a sense of shared ownership and responsibility.

Dr. Zwaigenbaum noted that training is an essential component to system advancement, and cannot be limited to teaching technical skills. Effective instructional techniques are essential but not sufficient – impactful training benefits from partnerships, collaborations, and strong relationships.

“We need to think about leadership training, think of interdisciplinary ways to be effective partners and collaborators. We need to embed these ideas into training programs to develop our disciplinary and real-world competencies.”

Training, like learning, is a lifelong process. By empowering learners and colleagues through knowledge, challenges can be tackled and ultimately achieve improvements in care, better collaboration and inclusion, and increased quality of life for those living with ASD. Importantly, establishing a system of care would require broader collaborations and support from various disciplines.

View the full presentation: macautism.ca/videos



“ We saw a need, and we saw opportunity, to bring people with lived experiences together with some of our students and learners.”

- Dr. Kerry Boyd,
McMaster Children’s Hospital

Curriculum of Caring

**DR. KERRY BOYD & GUEST WITH LIVED EXPERIENCE,
MCMASTER CHILDREN’S HOSPITAL AND BETHESDA SERVICES**

The Curriculum of Caring (CoC) is a program aimed at helping healthcare professionals effectively care for people living with developmental disabilities. The program brings empathy into the core of healthcare delivery through experiential learning, allowing medical students to connect with patients in social and clinical settings. The program has seen great success as reported by both medical students and patients who have participated in the program.

View the full presentation: macautism.ca/videos

Training in Schools

**MICHELLE TORSNEY, MANAGER OF SPEECH,
LANGUAGE, AND HEARING SERVICES - HAMILTON-
WENTWORTH CATHOLIC DISTRICT SCHOOL BOARD**

**ANNA DIFAZIO, MANAGER OF INTENSIVE SUPPORT
SERVICES - HAMILTON-WENTWORTH DISTRICT
SCHOOL BOARD**



Representatives from both Hamilton-Wentworth school boards presented on the services and training initiatives on supporting children with special needs that are available to their staff. The aim of the training is to help educators build their skills and confidence in addressing the broad range of abilities and needs of children in their classrooms. These projects bring together professionals from different disciplines to work towards the same goal.



Discussion Panel: Lived Experiences and Autism Training

DR. BRIANO DI REZZE, MCMASTER UNIVERSITY, MODERATOR
DR. ELLEN BADONE, MCMASTER UNIVERSITY, RESEARCHER AND PARENT
KAITLYN HENRY, AUTISTIC ADVOCATE
BLAIR ROSE, AUTISTIC ADVOCATE
MARGARET GILLRIE-FRASER, EDUCATOR AND AUTHOR

A discussion panel made up of autistic advocates, an educator, and a researcher and parent shared their lived experiences. The panelists provided valuable insights on what they believe is crucial for effective ASD training, education, and practice.

“

We need to include autistic people, not just through studies, but include us in teaching people how to learn when they're being trained, teaching people in the community how to react to people on the spectrum, by talking to people on the spectrum.”

- Blair Rose, Autistic Advocate

“

We're starting to make some really big changes in autism services here in Ontario. As we start to do that, we really need to think about what training is necessary to support some of these big, big changes that we're making."

- Sarah Hardy,

Ontario Autism Program Project Team

Ontario Autism Program (OAP)

SARAH HARDY, DIRECTOR OF THE ONTARIO AUTISM PROGRAM PROJECT TEAM AT THE MINISTRY OF CHILDREN AND YOUTH SERVICES AND EVANGELO BOUTSIS, SENIOR POLICY ANALYST, ONTARIO AUTISM PROGRAM PROJECT TEAM

The new Ontario Autism Program (OAP) plans to combine previous intervention programs into one program that is flexible and specialized to address individual needs. Developed with input from parents and ASD clinical experts, the new OAP aims to make it easier for families to access services and to be engaged in the clinical decision-making process. The OAP emphasizes a collaborative approach to services between families and professionals. The Ministry of Children and Youth Services is interested in creating a provincial training strategy, and intends to determine priority areas and methods for delivering training.

Messages from Community Stakeholders

Esther Rhee, Autism Speaks Canada

Autism Speaks Canada has proudly provided over \$8 million in research funding for both pre- and post-doctoral trainees conducting ASD research. Some outcomes of this research include the ability to diagnose autism and flag symptoms earlier, better understanding of sensory processing challenges, and realizing the importance of including females in ASD research.



Cynthia Carroll, Canadian Autism Spectrum Disorders Alliance (CASDA)

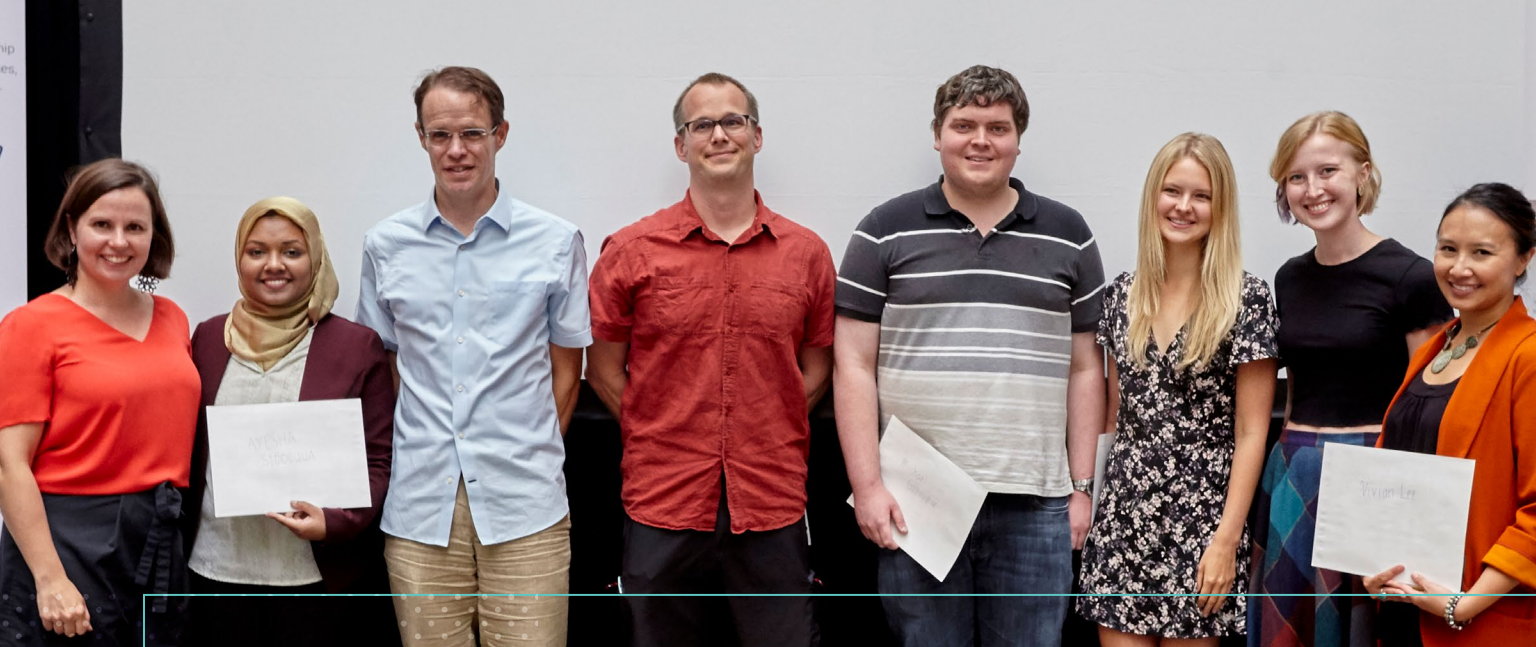
CASDA is a collaboration of autism organizations and individuals across Canada, now with over 100 members, working at the government level toward a national autism strategy. CASDA recognizes the importance of accessible training, involving a variety of occupations, to allow for capacity building.



Marg Spoelstra, Autism Ontario

Autism Ontario stresses the importance of emphasizing the family perspective in research and training. Autism Ontario encourages researchers to persist and go on to contribute, work on knowledge translation, and promote acceptance and opportunities for individuals living with ASD.





Travel Awards

MacART was pleased to present MacART Trainee Travel Awards to 8 successful applicants. This competition provides support to trainees working in ASD to travel to events that will enhance their research training experience.

Ayesha Siddiqua

PhD student
Health Research Methodology

Michael Gallagher

PhD student
Mathematics

Dr. Vivian Lee

Postdoctoral fellow
Psychiatry and Behavioural
Neurosciences

Dr. Stephen Gentles

Lawson fellow
Offord Centre and MacART

Vanessa Bierling

Undergraduate student
Honours Mathematics
and Statistics

Katia Jitlina

ASD track psychology resident
Hamilton Health Sciences
and doctoral student
University of British Columbia

Peter Tait

PhD student
Computational Science
and Engineering

Grace Teskey

Master's student
Medical Sciences

From L to R in the photo is: Terry, Ayesha, Stephen, Peter, Michael, Vanessa, Grace, and Vivian. (Katia not pictured.)

Messages from Collaborators and Supporters

During the lunch hour we heard brief messages from some of our local leaders and collaborators:

Filomena Tassi

Member of Parliament,
Hamilton West—Ancaster—Dundas

Dr. Paul McNicholas

Director,
MacDATA Institute

Dr. Ellen Lipman

Director,
Offord Centre for Child Studies

Rob MacIsaac

President & CEO,
Hamilton Health Sciences

Dr. Olaf Kraus De Camargo

Developmental Pediatrician,
CanChild Centre for Childhood
Disability Research

Dr. Caroline Roncadin

Clinical Director of ASD Services,
McMaster Children's Hospital

Dr. Ted Scott

Acting Vice President Research
& Chief Innovation Officer,
Hamilton Health Sciences



I have had the distinct pleasure of learning about the incredible work of MacART. I am proud to be a Member of Parliament in a community that is on the leading edge – at a provincial and national level – of research and care in this very important area. The work you do gives hope to the many individuals and families impacted daily by autism.”

- Filomena Tassi, Member of Parliament
Hamilton West—Ancaster—Dundas

MacART

McMaster Autism
Research Team

The McMaster Autism Research Team (MacART) is a partnership between McMaster Children's Hospital, Hamilton Health Sciences and McMaster University that aims to bridge the research-to-practice gap in Autism Spectrum Disorder (ASD).

Advancing autism care through meaningful research."



MacART aims to generate scientific evidence, better sharing and uptake of effective clinical practice and policies to support individuals, families and communities affected by autism.

“

What is significant about the approach being taken here is the fact that it is so collaborative. The fact that researchers, clinicians, teachers, and people with lived experience with autism, are coming together to share ideas and plan the next steps.”

– Rob MacIsaac, President & CEO,
Hamilton Health Sciences

RETHINKING AUTISM TRAINING

BREAKOUT SESSION

Dr. Sean Park, an instructor with McMaster’s Health Leadership Academy, led the symposium attendees in exploratory activity inspired by Design Thinking methodology. Participants explored what inspired them, what helped them grow in their work, what challenges them, and what they believe a better future might look like.

1. Inspiration - What event or experience started you on your journey? What inspired you to learn and do more?

Participants shared that a personal connection to those living with ASD was the main inspiration and motivation that started them on their path to learn and do more within the ASD community.

- Researchers identified that the dynamic field of ASD motivates them to chase expertise and continue to search for effective intervention strategies.
- Service providers are especially inspired by the strength and perseverance they witness from families living with ASD.
- Autistic advocates are searching for opportunities to be heard by others.

“Lack of knowledge breeds fear - in my early days I think I was fearful of what I didn't understand. Any opportunity to learn assists us as a whole, connecting to come together as partners in compassion and understanding.”

“There is no reflection without action, no action without reflection.”



2. Big Impacts - What's had the biggest impact on your journey of learning more about ASD? What was so valuable about it?

Participants indicated that the biggest impact on their growth was meaningful support and guidance by mentors in their field.

- The gratitude of families and resilience of children motivates clinicians, researchers, and service providers to learn more and continue their work.
- At the same time parents are encouraged by the commitment of therapists and support workers assisting their children in overcoming barriers.
- Therapists and service providers are especially encouraged by training opportunities that would allow them to integrate new research into practice.

“Collaborating with parents and caregivers, being able to offer help and knowledge to those families, helps their children reach their full potential.”

3. Current Challenge - Describe a current challenge you're working on, something that feels stuck and you don't know the way forward, or some situation that needs to change.

A number of challenges can impact the quality of care and support provided to those living with ASD:

- Across disciplines, participants indicate that the biggest challenge is finding time to learn more about ASD.
- Service providers find it difficult to keep pace with evidence-based research and training in order to implement intervention programs effectively.
- Participants emphasized that collaboration between multidisciplinary teams has proven to be difficult because of the lack of time and capacity to facilitate these connections.

“(One big challenge has been) trying to find the time to stay up to date on the current research and then translating it into useful strategies to use with families.”



4. Better Future - Describe what the future would look like if the above situation was somehow resolved or different. Imagine what would be happening if there was a solution at work.

- Attendees were optimistic that taking part in events such as this symposium are an important step forward towards rethinking autism training.
- Participants are looking for more supports and resources on education, therapies, and research in ASD.
- Attendees are seeking greater collaboration across multidisciplinary teams in order to increase the quality of care children and families living with ASD.

“Respectful conversation can happen where all partners can look at common challenges and be in a better position to problem-solve successes, all to ultimately support kids and families.”

5. Action - look back through your worksheets and circle 3 words that are clues and potential resources for getting to the better future. Create at least 3 action statements that use one or more of the words above.

Part of the afternoon’s session was to reflect upon people’s journeys, but also to take what was brought to the surface and do something with it. We asked participants to pick three words that stood out to them as key clues and resources to a better future. These words were used to develop action statements committing them to doing small things to change their situation.

The word cloud on the next page shows the most common words identified by participants - these ideas are a way to launch us forward towards our better future.



Families
 Motivate
 Individualized
 Interdisciplinary
 Leadership
 Advocate
 Training
 Acceptance
 Relationships
 Consistency
 Education
 Believable
 Multidisciplinary
 Innovation
 Work
 Time
 Passion
 Impact
 Learning
 Translation
 Initiative
 Coordination
 Experience
 Opportunities
 Include
 Vision
 Improve
 Experience
 Difference
 Value Lived
 Compassion
 Development
 Understanding
 Freedom
 Social
 Mentorship
 Community
 Communicate
 Research
 Care
 Knowledge
 Collaborate
 Contribute
 Change
 Willingness
 Flexible
 Sustainability
 Encouragement
 Success
 Team
 Progression
 Creative
 Respect
 Support

KEY MESSAGES FROM THE 'RETHINKING AUTISM TRAINING' SYMPOSIUM

Below are the top 3 training priorities identified by stakeholders:

Embedding Stakeholder Collaboration into Training Programs

The concept mentioned most often was 'collaboration' - between autistic advocates, families, schools, service providers, organizations, researchers, and the community at large. Stakeholder collaboration must begin early, and be integrated at the training level, in order to foster lasting relationships. To ensure success, parameters and principles for meaningful collaboration must be identified and evaluated.

Building Infrastructure & Capacity for Interdisciplinary Training

Stakeholders noted that their potential for meaningful contributions to those living with ASD is not always met due to the lack of resources and supports for interdisciplinary training. There is a need to develop infrastructure for accessible evidence-based training connecting those coming from diverse disciplines, backgrounds, and perspectives.

Using Diversity in Personal Experiences to Advance Training

Even though autism stakeholders come from diverse backgrounds, we all share a common vision of supporting those living with ASD. Drawing from motivational training approaches can create opportunities to utilize and embrace this diversity to advance interdisciplinary training models and initiatives.

The inaugural MacART Autism Research Stakeholder Symposium in 2016 focused on the *Research* pillar of MacART, and has since led to the development of numerous relevant [research projects](#).

With this year's focus on the *Education* pillar, MacART recognizes the importance of training and mentoring autism experts as part of the larger vision of advancing autism care through meaningful research.

The top 3 training priorities identified by the stakeholders will serve as starting points for new and meaningful training collaborations in our autism community.

Acknowledgements

Thank you to Drew Duffy, Nikita Patel, Polly Chiu, Kara Hannah, and Aliana Weavers for their contributions to this report. Thank you to symposium planning committee - Vivian Lee, Anna Kata, Cameron Henry, Steve Gentles, Navita Dyal, Sandra Lee, Sean Park, and Amanda Calzolaio - for their help in making the event come together. Thank you to Jim and Annette Ray for their generous, ongoing support of MacART. Thank you to Blair Rose for her input on this report. Finally, thank you to all the symposium participants for the invaluable contributions!

Collaborators



Sponsors



250+ stakeholders attended the 2017 symposium.

The second MacART Symposium brought together a diverse array of stakeholders to discuss and plan collaborations to help **rethink autism training.**

