

2022-23 Progress Report

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MacART is grateful for the support from the McMaster Children's Hospital Chair in Autism and Neurodevelopment, which is sustained by McMaster's Department of **Psychiatry and Behavioral Neurosciences and the Hamilton** Health Sciences Foundation.











Message from Co-Directors

The McMaster Autism Research Team (MacART) began as a way for academic researchers and clinical practitioners at McMaster Children's Hospital, Hamilton Health Sciences, and McMaster University to work together on different projects related to autism.

Now, eight years after the idea of MacART was first proposed, we continue to grow our membership and initiate new research studies. However, many of these projects have expanded beyond a local focus. Through collaboration with scientists, clinicians, policy makers, trainees, educators and community advocates, our members are leading and participating in a variety of projects with provincial, national, and global impacts.

We have been aligning our work with the assessment report on autism released by the Canadian Academy of Health Sciences in 2022, which aimed to inform development of a National Autism Strategy. The report outlined strategies for improving future autism research - including balancing research across disciplines, considering longitudinal designs about changes over the lifespan, and translating research to practice much of which MacART had already been striving to implement.

Our connection with the McMaster Children's Hospital Autism Program continues to support the provision of evidence-based care and generating practice-based evidence from research activities embedded within services. The broad range of programs and practices offered to individuals and families by our clinicians strive to meet a variety of needs, all while being supported by research evidence and also collecting research data to further improve those offerings.

This report is an update on the important and timely work being done by our MacART members and partners.

Stelios Georgiades, PhD

McMaster Children's Hospital Chair in Autism and Neurodevelopment

Associate Professor, Psychiatry & Behavioural Neurosciences, McMaster University

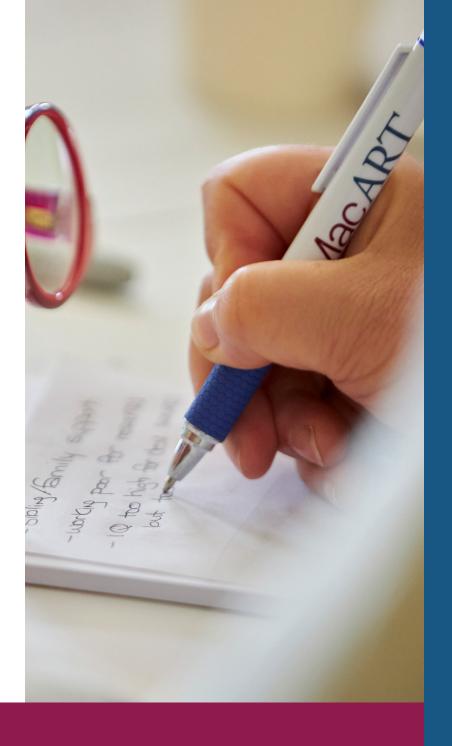
Founder & Co-Director, McMaster Autism Research Team (MacART) Director, Offord Centre for Child Studies

Caroline Roncadin, C.Psych.

Clinical Director, McMaster Children's Hospital Autism Program, Hamilton Health Sciences Co-Director, McMaster Autism Research Team (MacART)

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 researchto-practice gap in autism. MacART
is designed to foster collaboration
among the families, researchers,
clinicians, educators, and
policymakers whose lives and work
are touched by autism.

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 individuals, families, and communities affected by autism across the lifespan.



Research



Education



Community Engagement



Evidence-Based Policy

MacART Members

MacART is composed of a collaborative group of researchers, clinicians, and clinicianscientists who have come together to better understand how to support the strengths and challenges of Autistic children and their families. MacART has attracted the participation of more than 40 leading researchers from 13 departments and 4 research centres.

MacART members are engaged in autism research projects that range from the clinical, in which social communication skills are studied, to the biomedical, in which the gut/brain association is investigated, to the social/contextual, in which the relationship between child, family, school, and community are explored. MacART is also composed of top-level, experienced developmental pediatricians, psychiatrists, psychologists, and therapists at McMaster Children's Hospital. The various programs and services at McMaster Children's Hospital diagnose over 250 children per year and provide care to over 1,000 families in the greater Hamilton area.

The proximity of academic researchers, clinicians, and clinician-scientists makes McMaster a unique place in Canada with the capacity to advance autism care through meaningful research, using its combination of expertise and infrastructure.

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Over the last decades, Autism
Alliance of Canada has played a
key role in advocating and guiding
for a National Autism Strategy. It
is thanks to the active involvement
of key partners and members,
such as MacART, that we are
making change happen. As pivotal
developments are taking shape in
Canada's national autism landscape,
we are proud to strengthen our
collaboration with MacART to
engage in meaningful work in the
autism and disability sectors at the
national level."

Dr. Jonathan Lai, Executive Director, Autism Alliance of Canada

40+
Leading
Researchers

Research Centres

13
Departments

Magdalena Janus

Nick Kates

Trainees

Holly Augerman	Alina Kislenko	Claire (Yun-Ju) Chen
Ellen Badone	Olaf Kraus De Camargo	Irene O'Connor
Teresa Bennett	Stephanie Lavoie	Jeffrey Esteves
Joseph Beyene	Vivian Lee	Stephen Gentles
Kerry Boyd	Bill Mahoney	Rita Jezrawi
Katrina Choe	Karen Margallo	Linda Nguyen
John Connolly	Paul McNicholas	Diana Parvinchi
Briano DiRezze	Ronit Mesterman	Mackenzie Salt
Irene Drmic	Olivia Ng	Areeba Sharafuddin
Eric Duku	Caroline Roncadin	Ayesha Siddiqua
Manual Calmanta als	Datas Daganhassa	

Elisabetta Trinari

Mohammad Zubairi

Margaret Fahnestock Peter Rosenbaum Jane Foster Rebecca Shine Julia Frei **Karun Singh Stelios Georgiades** Noam Soreni **Kathy Georgiades** Peter Szatmari **Geoff Hall** Jean-Eric Tarride

The McMaster Autism Research Team is an important member of the McMaster **Children's Hospital** family. Our hospital strives to provide effective and evidence-based autism services to families, and MacART's research is a vital part of

Bruce Squires, President, McMaster Children's Hospital

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that."

MacART Leadership Group

The MacART Leadership group is comprised of nominated individuals who each represent the key 'pillars' that make up the foundation of MacART. Each representative brings their expertise to the Leadership Team, which is tasked with determining the strategic priorities of MacART as a whole.



Policy Engagement:

at the core of what we do as a team, the foundation to all of our work is for the evidence generated by our research to be taken up by groups, organizations, and government to inform their policies in meaningful ways.

Community Engagement: connecting and collaborating with individuals, families, and organizations to increase participation and involvement, and have more meaningful impact.

Translational Models of Care:

exchanging information in collaborative ways to improve the integration of research and evidence into practice.

Population Health Research: considering individual, group, and area-level factors, and social, geographical, and policy contexts, and how they intersect to impact health.

Training & Education: enhancing learning, collaboration, and interdisciplinary experiences for students and trainees.

Biomedical & Basic Research: exploring the relationship between fundamental biology, genetic makeup.

Clinical Research:

incorporating and integrating research and evaluation into the clinical care provided to patients and families.

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Impact

MacART members have been consistently successful in obtaining research funding and grants, publishing papers in top-tier academic journals, and presenting their findings at local and international conferences. In 2022-2023...



Publications

MacART members published 89 articles related to the topic of autism.



Presentations

MacART members were invited to give 3 keynote lectures and invited to give 97 oral presentations or posters at conferences around the world related to the topic of autism.



MacART members held active funded research grants related to autism (on which they were a Principal Investigator, Co-Investigator or Collaborator) totaling \$45,784,280.

42 individual research grants



1,562Twitter/X Followers

From Jan 2022-Dec 2023 MacART's Twitter/X account has had 60,294 tweet impressions and 2,541 tweet engagements.



55,000 Page Views

MacART's website was viewed ~55k+ times by ~10k+ visitors in 80 countries.



Chair Holders

Dr. Stelios Georgiades: McMaster Children's Hospital Chair in Autism & Neurodevelopment Dr. Teresa (Terry) Bennett: Jack Laidlaw

Chair in Patient-Centred Health

Dr. Paul McNicholas: Tier 1 Canada Research **Chair in Computational Statistics**

Dr. Peter Szatmari: Patsy & Jamie Anderson Chair in Child and Youth Mental Health

Dr. Kathy Georgiades: David R. (Dan) Offord

Chair in Child Studies

Dr. Magdalena Janus: Ontario Children's Secretariat Chair in Early Childhood Development

MacART Collaborators

MacART is proud to work together with the following organizations:

























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MacART is an excellent example of how research can change care and practice and also impact policies. At **Hamilton Health Sciences we are not** only able to offer opportunities to the children and families we serve to participate in research, but we then have the advantage of being able to benefit from using research evidence to improve our services. With MacART, we can also work with partners to influence policy change in order to ensure that services across Ontario and Canada are based on thorough and up-to-date scientific evidence."

Dr. Marc Jeschke, VP of Research, **Hamilton Health Sciences**



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Research and Project Highlights

MacART aims to conduct research that is meaningful to those who will benefit from it: parents, Autistic people, practitioners, clinicians, educators, and policymakers. Our members are involved in numerous research projects and studies – in the laboratory, in the clinic, in the community, and everywhere in-between. Here are just a few of our ongoing initiatives and recently completed projects.

2023 Pandemic Canadian Autism Needs Assessment

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In 2020, MacART partnered with Autism Speaks Canada and Autism Alliance of Canada to develop, implement, and analyze the Pandemic Canadian Autism Needs Assessment – a survey where respondents shared their experiences to help inform on the impacts of the COVID-19 pandemic. (The results of that work can be viewed here.)

With support from the Public Health Agency of Canada, these three organizations have collaborated together again to release a new iteration of this survey in the fall of 2023. The survey will ask both caregivers of Autistic children and Autistic adults about the impact of COVID-19 on their services and supports.

The 2023 Pandemic Canadian Autism Needs Assessment is led by Dr. Stephen Gentles.

The Family Check-Up Program

Research has consistently found that Autistic children and youth and their caregivers and family members experience higher than average levels of life stressors. However, to date there are no programs that systematically assess child, caregiver and family well-being within the context of risk and protective factors. A team at McMaster University and McMaster Children's Hospital is working to develop a family-centered program that is tailored to the strengths and needs of Autistic children and youth and their families. The FAIR study is a hybrid implementation-effectiveness study of the Family Check-Up® in the McMaster Children's Hospital Autism Program. The Family Check-Up (FCU) is an evidence-based, family centred intervention aimed at identifying and leveraging child and family strengths and addressing risk factors to reduce child emotional and behaviour problems. Past research has demonstrated positive effects of the FCU on child emotional and behavioural problems, but it has never been evaluated in families of Autistic children and youth. In order to determine the effectiveness of the FCU in this population, a randomized control trial with 80 Autistic children/youth and their caregivers is underway. Additionally, the study team is using mixed methods to understand the barriers to and facilitators of FCU implementation within a clinical program for Autistic children and youth and their families.

This work is co-led by Drs. Terry Bennett and Irene Drmic.

The Canadian Journal of Autism Equity

The Canadian Journal of Autism Equity is an open-access e-journal focused on critically engaging with a variety of equity discussions within the autism community and public policy. Established in December 2020, it is published by McMaster University Library Press and supported by Autism Alliance of Canada. Seeking authorship primarily by first-voice Autistic people or people with lived experience with autism and intersectionality, the Journal seeks to offer a platform to amplify marginalized voices and share these perspectives with decision-makers and Canadians alike. Issues have thus far been published on employment, equity, and Autistics in decision making; an upcoming issue will be on housing. The CJAE has recently grown, bringing on 3 new editors (to a total of 8), and the editorial board was awarded the awarded The Gerry Bloomfield Professional Award in September 2022 for their "important contribution" to the elevation of Autistic voices and lived experience in the area of autism research and public policy".

The current Editor-in-Chief of the CJAE is Dr. Mackenzie Salt.



Evaluation of Virtual Care Services for Children in Ontario

In partnership with Empowered Kids Ontario (EKO), a team from McMaster University - led by Dr. Stelios Georgiades and Dr. Elyse Rosa – completed an evaluation focusing on the processes and outcomes of a variety of virtual care services provided to children across Ontario. This included a variety of services, including autism services, psychology services, behavioural services, and more. The results of this evaluation address a key knowledge gap in our understanding of the provision of virtual care services for children and their families. It was consistently revealed that virtual care for children is not one-size fits all. Findings of this evaluation provide consensus on the types of services, and aspects of care, that are not as compatible with a virtual setting compared to others. Further, the evaluation summarizes barriers circumvented by virtual care and those that remain, highlighting agreement between those providing care and those receiving it, that a hybrid approach to future care for children is optimal.

This evaluation is led by Dr. Stelios Georgiades and Dr. Elyse Rosa.

The PARC Study

The Pediatric Autism Research Cohort (PARC) study is a multi-site longitudinal cohort study recruiting preschool children with a new autism diagnosis. The team recently received CIHR funding in 2022, which has allowed the study to expand beyond just sites in Ontario (in Hamilton, Kingston, Ottawa, and Sudbury) - now to Edmonton and Winnipeg. The projected recruitment numbers of 1000 children across all sites could make this one of the largest autism cohort studies in the world. Our colleagues in Jerusalem, Israel have also received funding, allowing for a site to get underway there and facilitating an international component. The study aims to improve the understanding of what influences the development of Autistic children by asking about the child, their family, the services they receive, and their environment. The investigators have a particular interest in examining how characteristics of services and interventions are associated with diversity in child and family functioning over time.

The PARC study is led by Dr. Stelios Georgiades.



Having worked in the autism space for a long time, I know the importance of collaboration - but importantly, this collaboration is more successful when it is with knowledgeable, passionate, and committed individuals. **MacART** fits this description, and I know that our goals align as we work together in **striving to support Autistic** individuals and families."

Marg Spoelstra, Chief Executive Officer, Autism Ontario

Investigating Regional Differences in **Developmental and Service Use Pathways**

MacART trainee Rita Jezrawi received a Canada Graduate Scholarship-Doctoral award for her project titled "Multi-modal investigation of regional differences in developmental and service use pathways for young children with neurodevelopmental disorders (NDDs)". Her dissertation focuses on education and health outcomes for Autistic children and other neurodevelopmental disorders. Rita will be working on several studies spanning academic trajectories for young Autistic children and/or children with NDDs, as well as looking at past provincial policy choices and perspectives from providers and families of how those policies were translated into action. She aims to contribute to a better understanding of policy choices that impact children's developmental and educational trajectories and how we can facilitate more equitable outcomes within social, education, and health systems.

This work is led by trainee member Rita Jezrawi under the supervision of Dr. Magdalena Janus.

The Canadian Academy of Health Sciences Autism Assessment

The Canadian Academy of Health Sciences (CAHS) was selected by the Public Health Agency of Canada to conduct an autism assessment, meant to inform the government ahead of the creation of the National Autism Strategy. This process involved significant engagement and participation from Autistic individuals, families, stakeholders and key national, local and grassroots organizations to support consultation on a wide range of issues (including economic inclusion, social inclusion, and evidence-based intervention and therapies). An Oversight Panel and three Working Groups were convened to provide leadership for this assessment, made up of Autistic adults, parents, clinicians, and researchers - this included representatives from McMaster (with Dr. Stelios Georgiades as Vice-Chair the Diagnosis-Supports-Services working group). The assessment report was released in May 2022, and various versions can be found here.



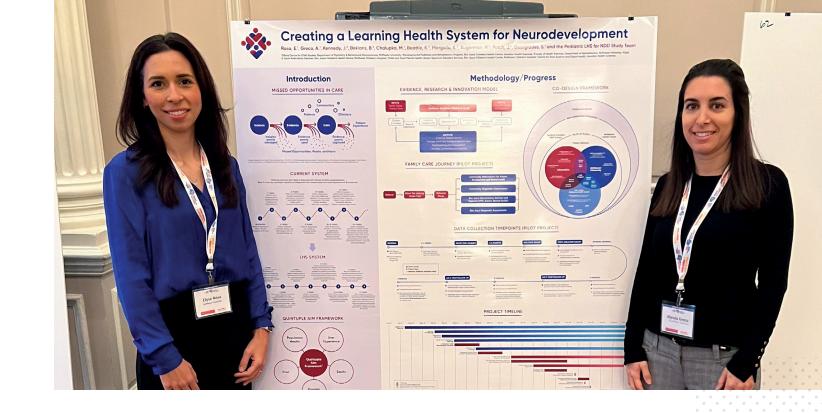
Canadian Autistic Adult Needs Assessment Survey

MacART member and Autistic researcher Dr. Mackenzie Salt is leading a Canadawide needs assessment survey of Autistic adults over 30 years of age. This project is being conducted in partnership with Autism Alliance of Canada and is being funded by the Public Health Agency of Canada. This survey seeks to help inform the National Autism Strategy currently being developed by the federal government through learning about the quality of life, needs, and priorities of Autistic adults in many areas of daily life. This survey was codesigned with the help of 10 other Autistic adults of various genders, ages, and abilities. The survey (live during summer 2023) is the first in a multiphase project. A second phase, involving running focus groups of Autistic adults to discuss, qualify, and prioritize the survey results for government and research action, is already planned and will be funded by the Sinneave Family Foundation. This phase of the project is expected to conclude in the summer of 2024. The data from the survey and focus groups will be de-identified and made publicly available in a data repository after the projects are completed.

2023 CHSCY Follow-Up

The 2023 Canadian Health Survey on Children and Youth (CHSCY) is a follow-up survey being done with the children and families who took part in the 2019 CHSCY in partnership with Statistics Canada. In 2023 a nationally representative sample of close to 42,000 children and families from across Canada were invited to take part again in order to explore the impact that COVID-19 has had on child and youth health and functioning (such as mental health needs, sleep, use of electronic devices, physical activity, and more). The 2019 CHSCY was conducted by Statistics Canada immediately before the COVID-19 pandemic and provides important baseline information that allows the study team to examine changes that occurred after the pandemic. The study team is also interested in examining whether the impact of the stressors stemming from the pandemic (economic, social and psychosocial) will disproportionately affect children and families with pre-existing physical, mental, and neurodevelopmental conditions, including Autistic children and youth. Information from this survey will be used to develop programs and policies to help improve the lives of Canadian children and youth.





Creation of Pediatric Learning Health Systems for Neurodevelopmental Disorders

The Pediatric Learning Health System (LHS) for Neurodevelopmental Disorders (NDDs) is a collaborative co-design project initiated as a pilot at the Ron Joyce Children's Health Centre (RJCHC) in Hamilton, to inform the creation of a Pan-Canadian Pediatric LHS for Neurodevelopment. The purpose of this work is ultimately to break down the many silos that currently exist and hinder optimal healthcare for children with diverse needs. The pilot will focus on children/youth 0-12 years receiving care at RJCHC, and will emphasize collaboration, co-design, and concurrent evaluation throughout its development. A concurrent evaluation of the developed system will promote continuous improvement in an adaptable and scalable system that is patient centred. This work has the capacity to inform a significant change to the healthcare of children and their families across Canada, particularly those with NDDs. This work aims to generate a system that drives positive patient outcomes and delivers high-quality healthcare services that are rooted in the child and family experience. The collaborative, co-design approach, along with utilization of and improvement of existing healthcare infrastructure, will effectively break down siloed care.

This work is led by Drs. Stelios Georgiades, Jeremy Petch, Holly Augerman, and Karen Margallo.



Examining Criminal Justice with Autistic Adults in Canada

MacART member and Autistic researcher Dr. Mackenzie Salt is co-investigator on a SSHRC-funded project led by Dr. Stephanie Ehret, a criminology professor at Trent University, in partnership with Autism Alliance of Canada. This project seeks to understand how Autistic adults interact with and experience the criminal justice system as well as what they believe should be changed to make the justice system more equitable for Autistic people. This project involves a survey of the Autistic population across Canada as well as focus groups, facilitated by Dr. Salt, to examine the results of the survey and further qualify the results. The goal is to use the results of this project to inform future policy.

This work is led by Dr. Mackenzie Salt.

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MacART makes community engagement a priority. **The Research Stakeholder Symposium on Autism and Mental Health in May 2023** demonstrated that care is taken to ensure research is relevant to community needs and members are committed to bridging the research-to-practice gap. As an organization that coordinates, invests in, and conducts direct service delivery to Autistic youth and adults, The Sinneave Family **Foundation appreciates that MacART strives to keep Autistic individuals and their** families at the forefront."

Tanya McLeod, President, Sinneave Foundation











The Martha and Vincent Wagar **Intellectual Disability and Autism Research Fund**

Established in 2021 from the estate of Vincent Wagar, the Martha and Vincent Wagar Intellectual Disability and Autism Research Fund was endowed to provide support for intellectual disability and/or autism research within the Faculty of Health Sciences at McMaster University.

The call for applications for the 2023 Martha and Vincent Wagar Intellectual Disability and Autism Research Fund Graduate Student Award was put out in May 2023. Applicants had to be pursuing graduate/post-doctoral work related to autism and/or intellectual disability in the Faculty of Health Sciences at McMaster University. The successful applicants were those demonstrating strong research skills, academic excellence and productivity, and proposing projects with strong scientific merit and potential impact.

We were thrilled to award \$20,000 each in support to:

Dr. Pegah Firouzeh - Postdoctoral fellow, Faculty of Health Sciences Supervisor: Dr. Briano DiRezze, CanChild Centre for Childhood **Disability Research, McMaster University**

Pegah will be using the Wagar Research funds toward research on meaningful participation, inclusion, and transition of children with disabilities to adulthood. They are interested in understanding how contextual factors affect the use of orthotics and mobility devices and the adaptations that would be required to facilitate inclusive environments for children and youth with disabilities.

> Dr. Krysta Andrews - Postdoctoral fellow, Dept of Psychiatry and Behavioural Neurosciences | Supervisor: Dr. Terry Bennett, Offord Centre for Child Studies, McMaster University

Krysta will be using the Wagar Research funds toward expanding their research to explore parenting interventions, parent-child interactions, and observational measure development with Autistic children. Further, their research will explore studies evaluating parent-

child interactions with Autistic children via observational measures, particularly for children with co-occurring intellectual disability and autism. With these explorations, they aim to provide important theoretical and empirical insights to guide a familycentered research agenda that includes groups of neurodivergent children and families who are most often excluded from both research and mental healthcare.

Dr. Monika Novak Pavlic - Postdoctoral fellow, School of Rehabilitation Science | Supervisor: Dr. Gillian King, School of **Rehabilitation Science, McMaster University**

standardized research tool.

Monika will be using the Wagar Research funds toward developing a self-report measure of child engagement, the Pediatric Rehabilitation Intervention Measure of Engagement-Child version (PRIME-C), which can be used to assess children's engagement for both clinical and research purposes. They aim to address a knowledge gap around evaluating children and youth satisfaction with pediatric rehabilitation services, developing a sustainable solution for evaluation engagement in therapy for Autistic children and children with intellectual disability that can be used to inform clinical practice and serve as a

Selected News, Events, and Accomplishments

MacART trainee Dr. Claire (Yun-Ju) Chen was a recipient of the **Society for Research** in Childhood Development (SRSD) 2023 Early Career **Interdisciplinary Scholars** Fellowship Program. The fellowship, established and organized by SRSD's Interdisciplinary Committee, aims to connect interdisciplinary and psychology/human development scholars for the purposes of sharing research and scientific methods. Dr. Chen is connecting with and learning from various scholars in the field of developmental psychology to refine her conceptual and methodological lens.

Dr. Stelios Georgiades and Dr. Olaf Kraus de Camargo, part of the Brighter Path group, received \$1.175 million in funding from the Juravinski Research Institute towards the **Towards a Brighter Path** for Every Child in Hamilton project. This project aims to create a collaborative network across research centres and academic departments at Hamilton Health Sciences/ McMaster Children's Hospital, McMaster University, and St. Joseph's Healthcare Hamilton, along with family and community partners.

Dr. Paul McNicholas was a recipient of the 2023 Dorothy Killam Fellowship for his research on identifying Autistic children's developmental trajectories. The **Dorothy Killam Fellowship**, run by the National Research Council of Canada, recognizes inclusive collaborators, research leaders, and barrier breakers who are driving the future of Canada. Dr. McNicholas will continue to work with his graduate student team to develop sophisticated models that will have important realworld applications. He will continue to investigate factors that contribute to why certain Autistic children shift between developmental trajectories/paths.



MacART trainee Dr. Mackenzie Salt and team received \$214,883 in funding from the Public Health Agency of Canada towards a research project to develop a national survey that includes questions about factors affecting quality of life such as employment, social relationships, health, and daily living, with the aim to help inform a national autism strategy. The project is co-led by Dr. Salt and Autism Alliance of Canada, and in partnership with the Sinneave Family Foundation, the Canadian Institutes of Health Research, the Azrieli Foundation, as well as MacART and the Canadian Journal of Autism Equity.

MacART members gathered at the International Society for Autism Research (INSAR) annual meeting in Stockholm, Sweden, where scientists, researchers, clinicians, policy-makers, and self-advocates came together to share and learn about the latest scientific developments in autism research. MacART members contributed to 26 posters, 2 oral presentations, and 2 panel sessions.

The **2023 MacART Research**

Symposium brought together selfadvocates, researchers, clinicians, service providers, educators, policy makers, and students to engage in group activities and innovation sessions around the theme of "Autism and Mental Health: Towards an Ecological Lifespan Approach". A lifespan approach coupled with a focus on the ecological/contextual model was used to generate new potential directions in the intersections of autism and mental health. MacART Trainee Awards were awarded to seven recipients.

The Kids Brain Health Network (KBHN) recently hosted their 14th annual conference in Ottawa, Ontario. This year's theme was "Celebrating 14 years of helping kids live their best lives" and aimed to bring together attendees interested in neurodevelopmental disabilities. From October 21st to 24th, MacART members contributed to 8 oral presentations and various poster presentations. Dr. Peter Rosenbaum delivered a keynote, the Fraser Mustard Lecture, titled "Childhood Disability in the 21st Century: Can We Create a Canadian Model for the World?".

Thank you!

Thank you to all of the MacART members and staff who helped with the creation of this report.

An extra special and sincere thank you to all of our research participants, community partners, and collaborators – the work we do would not be possible without you.



LET'S CONNECT

@macautism

macautism.ca

The information in this report is current as of December 2023. Please see our website for the most updated content, research, and our latest activities.

The McMaster Autism Research Team is based at McMaster University and McMaster Children's Hospital, which are situated on the traditional territories of the Erie, Neutral, Huron-Wendat, Haudenosaunee and Mississaugas nations, protected by the "Dish with One Spoon" wampum agreement. We recognize and respect the presence and stewardship of all Indigenous peoples as keepers of this land.







