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Message from Co-Directors

The McMaster Autism Research Team (MacART) is a partnership between McMaster Children's Hospital, Hamilton Health Sciences, and McMaster University.

Five years after its creation, MacART now has over 40 members from multiple academic departments and research centres, bringing together a diversity of knowledge and perspectives related to Autism.

But MacART is more than a group of academic researchers working together on different projects – it represents a **new way of collaborating for collective impact**.

MacART serves as a **platform** for scientists, clinicians, policy makers, trainees, educators and community advocates to come together with Autistics and their families to conduct meaningful research.

By integrating research, education, community engagement, and evidence-based policy, MacART generates scientific knowledge that leads to better clinical practices, programs, and policies to support individuals, families, and communities touched by Autism across the lifespan.

Our work usually starts with a local focus. Using collaboration as a vehicle, our members lead and participate in research projects with **provincial**, **national**, and **global impact**.

This report serves as an update on the important work 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)

Scientist, 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)

About 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 research-to-practice gap in Autism Spectrum Disorder (ASD), or Autism.

MacART is designed to foster collaboration among the individuals, families, researchers, clinicians, educators, and policymakers whose lives and work are touched by Autism.

MacART is grateful to the following sponsors for their financial support:











Research





Education





Community Engagement





Evidence-Based Policy

MacART Members

MacART members are engaged in Autism research projects that range from clinical, in which social communication skills are studied, to the biomedical, in which gut/brain association is investigated, to social/contextual, in which the relationship between child, family, school, and community are explored. MacART also includes top-level, experienced developmental pediatricians, psychiatrists, psychologists, therapists, and trainees at McMaster Children's Hospital, who diagnose over 100 children per year and provide care to approximately 1000 families with a child/youth diagnosed with Autism in the greater Hamilton area.

The collaboration between 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.

"We have a real opportunity to translate challenges into research, and research into practice that will help families living with autism."

Rob MacIsaac, President & CEO, Hamilton Health Sciences



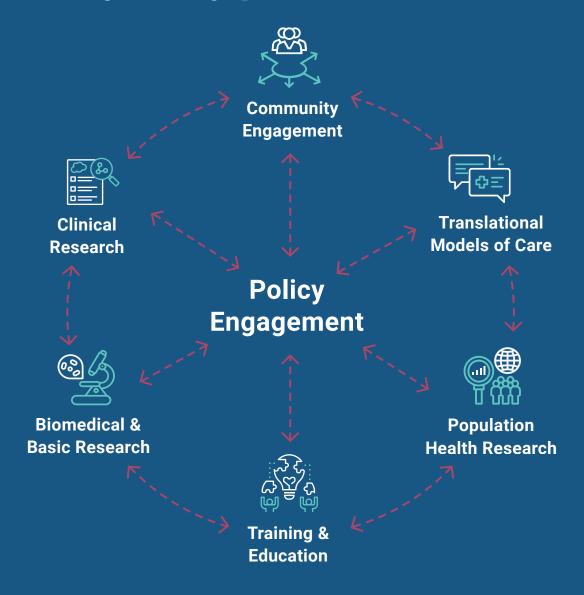


Members

Colleen Anderson	Geoff Hall	Karun Singh
Holly Augerman	Lorraine Hoult	Noam Soreni
Ellen Badone	Magdalena Janus	Peter Szatmari
Teresa Bennett	- Nick Kates	Jean-Eric Tarride
Kerry Boyd	Alina Kislenko	Mohammad Zubairi
Katrina Choe	Olaf Kraus De Camargo	
John Connolly	Stephanie Lavoie	
Irene O'Connor	Vivian Lee	Trainees
Briano Di Rezze	Bill Mahoney	Yun- Ju (Claire) Chen
Irene Drmic	Paul McNicholas	Stephen Gentles
Eric Duku	Ronit Mesterman	Rita Jezrawi
Margaret Fahnestock	Olivia Ng	Linda Nguyen
Jane Foster	Jo-Ann Reitzel	Diana Parvinchi
Julia Frei	Caroline Roncadin	Mackenzie Salt
Stelios Georgiades	Peter Rosenbaum	Areeba Sharafuddin
Kathy Georgiades	Florence Roullet	Ayesha Siddiqua

MacART Leadership

The MacART Leadership Team 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

Stelios Georgiades & Caroline Roncadin

The vision statement of MacART is "advancing autism care through meaningful research," but what does it mean for research to be meaningful? How can we, as researchers, design studies that will answer questions seen as important to a broader audience beyond other researchers? How can we ensure that the evidence we generate does not just remain in an academic paper, but instead is actually used to improve care and has more immediate impact on people's lives?

We see the need for policy engagement to be at the centre of all we do as a team, where it can interact with and anchor all of the other pillars. Our members conduct a wide variety of research – everything from lab-based work on stem cells and genomics, to interacting with families for research assessments or direct intervention services, to exploring population-level trends – but the goal is for the evidence generated from that work to then be taken up by groups, organizations, and governments to inform their policies.

We are extremely proud of the presence MacART members have had recently in various large-scale policy-related initiatives – such as working to redesign provincial autism programs and inform the development of the National Autism Strategy – that will have tangible impacts on the lives of individuals with Autism and their families. We look forward to continuing this important work and ensuring that the McMaster Autism Research Team remains a group that both generates and provides rigorous and credible research-based evidence that can be harnessed to inform policy-making.

"MacART continues to play a leading role in bringing meaningful research to impact practice and policy. CASDA is delighted to be a collaborator and partner as we navigate the complexity of the push and pull of evidence into communities."

Dr. Jonathan Lai, Executive Director, Canadian Autism Spectrum Disorder Alliance (CASDA)



Stelios Georgiades Associate Professor Psychiatry & Behavioural Neurosciences McMaster University



Caroline Roncadin Clinical Director McMaster Children's Hospital Autism Program Hamilton Health Sciences

Translational Models of Care

Teresa (Terry) Bennett

As a child and adolescent psychiatrist and researcher, I am interested in studying how children and youth grow up - specifically, how their unique developmental and mental health profiles interact with their experience of family, friends and participation in their world over time. Longitudinal cohort studies, which involve tracking the development of children over time, are important tools to help identify child mental health risk and protective factors. This knowledge can help us develop, deliver and evaluate research, focusing on how to best deliver programs of prevention and care that are provided more effectively in the right place and at the right time, to help children's mental health and development get back on track.

This leads to the key question of how we can apply our research knowledge and findings in order to enhance and innovate new approaches to child- and family-centred care. There is a great deal of research evidence being generated – but how can we best translate the important work others are doing into innovative models of care?

Translation science aims to apply what we know from observational and experimental research to identify how to best target treatments that support child development and mental health – what works most effectively, and for whom, and in which types of settings. This is a dynamic process that requires constantly synthesizing, disseminating, and exchanging knowledge from scientific discovery to clinical trials to implementation and policy studies.

In this way I see this pillar as working together with all the other pillars of MacART, being used to both inform their areas of focus as well as exchanging information between them. This collaborative, backand-forth approach can work to improve the integration of research and evidence into practice, with the overall goal of more effectively delivering care and improving health outcomes. That overarching goal is something that I think we at MacART already have in common, and so that doesn't require any sort of 'translation' at all.



Terry Bennett
Associate Professor
Jack Laidlaw Chair in Patient-Centered Care
Psychiatry & Behavioural Neurosciences
McMaster University

Biomedical and Basic Research

Jane Foster

Basic science research provides fundamental knowledge to help us understand the molecular and biological processes that contribute to health and disease. The MacART biomedical/basic science research team includes neuroscientists, psychologists, psychiatrists, and other healthcare professionals. MacART researchers are advancing bench-to-bedside-to-community research — utilizing state of the art tools in genomics, immunology, microbiology, medicine, population health, health policy,

and biostatistics to characterize the relationship between neurodevelopment and our fundamental biology, genetic makeup, environmental exposures, and social conditions.

We use an analytical and creative approach to connect previously independent lines of thinking to behaviour and neurobiological processes.

As lead of the Biomedical/basic research pillar, I have created a strong research program to understand how biological regulation of innate and adaptive immunity, and the microbiome, contributes to brain development and to the development of conditions including Autism and other neurodevelopmental disorders. In these efforts, I apply a multidisciplinary, holistic approach from molecular mechanisms to behaviour. Current research in the

Foster Lab aims to identify microbe-host mechanisms that influence brain function and behaviour. In the past decade, we have studied the role of microbiota-immune-brain communication on behaviour in mouse models using germ-free mice, raised in a sterile micro-isolator and lacking all microbiota, mice exposed to antibiotics, immune challenge, and stressors (genetically-modified and wild type mice). The host's relationship with bacteria during early postnatal life is influenced by genetics,

diet, drug and stress exposure, among others. Understanding how these environmental factors influence microbiota to brain communication may provide new insights into the heterogeneity that we see in neurodevelopmental conditions. With strength in neuroscience and immunology, we use an analytical

and creative approach to discover how the peripheral immune system influences neurodevelopment in novel ways and to connect previously independent lines of thinking to behaviour and neurobiological process and disease.



Jane Foster Professor Psychiatry & Behavioural Neurosciences McMaster University

Clinical Research

Irene Drmic

Through clinical practice at McMaster
Children's Hospital Autism Program, our team
of clinicians and service providers takes great
pride in the care we offer to the children and
families we serve. The activities, assessments,
and interventions conducted with families are
based upon solid bodies of research evidence
– but there is a commonly-cited statistic that



it takes approximately 17 years for newly-generated research knowledge to be incorporated into practice. This research-to-practice gap was one of the reasons MacART was formed, to try and bridge that gap between the research being done at McMaster University and the implementation of that knowledge at McMaster Children's Hospital.

Our researchers and clinicians have taken advantage of existing university and hospital infrastructure and cross-appointments, working to better integrate research into the clinical setting. Over the past few years, our Autism Program has successfully implemented a number of clinical research trials with very positive results – to the extent that we have already started offering some of the interventions as regular clinical services. Through reducing barriers to implementing research within our clinical practice, we are actually increasing the opportunities not only for our clinicians to be trained in new intervention models, but also the opportunities available for families to contribute to and benefit from our research.

As lead of the Clinical Research Pillar, I hope to continue to facilitate these important collaborations and moving research into clinical practice faster at McMaster Children's Hospital and beyond. While we work to plan the future of our Autism Program and adapt to various changes in the service sector, we have been careful to incorporate evaluation and research components into our processes that allow us to track our work and gauge our successes. This has demonstrated the importance of measurement and research to our staff, and we are confident that further team engagement will only set the stage for continued integration of research and clinical practice in the future.



Irene Drmic Clinical Psychologist McMaster Children's Hospital Autism Program Hamilton Health Sciences

Population-Health Research

Magdalena Janus

Taking a population-health approach in the research on children with neurodiversities ultimately aims to reduce inequities in children and families' health and well-being. To do so, we attempt to understand what are the factors that meaningfully influence their well-being, especially those that may not be immediately obvious, such as where a child lives, or who is their primary health care provider. We also consider a whole range of both individual and group or area-level factors and try to understand how they intersect with each other. This approach is effective for addressing public health and policy issues, and useful in understanding the impact of interventions in the context of social determinants of health.

As a non-clinician, I cannot help children in the same way that my amazing clinician friends and colleagues at MacART can. As a researcher with a long-standing desire to understand how social determinants of health impact children's health, development and learning, I have been pursuing a program of research to extend and modify that understanding for children whose development does not follow a typical path. My vision for the role of the Population Health pillar in MacART is to provide a broad picture that complements the biological and clinical research and helps to put the cell- and child-level findings in social, geographical, and policy context to optimize health and well-being for children with neurodiversities and their families everywhere.

"Population health is an approach to health that aims to improve the health of the entire population and to reduce health inequities among population groups. In order to reach these objectives, it looks at and acts upon the broad range of factors and conditions that have a strong influence on our health."

Source: Public Health Agency of Canada



Magdalena Janus Professor Psychiatry & Behavioural Neurosciences McMaster University



Community Engagement

Briano Di Rezze

At MacART, our research questions are guided by the needs of children and families with Autism. This pillar of community engagement aims to connect with individuals with ASD, their families, community agencies and other stakeholders to examine in community-based participatory research. Engaging stakeholders within the research process and integrating them as partners is at the core of MacART's collaborative nature. MacART aims to place children with Autism and their families at the centre of all that we do so that we can improve services, supports, and increase the opportunities available to them. More specifically, our team's research expertise in evaluation and measurement, and developing inter-disciplinary interventions, hopes to be utilized in supporting community efforts that focus on improving participation of children/youth in services and everyday activities. This helps us address the real day-to-day challenges faced by children/youth and the families we serve, as well as the clinicians and professionals supporting them.

Ultimately, through the Community Engagement pillar, we aim to increase participation and involvement of members of the McMaster and Hamilton communities in the research process. It is through engagement with individuals, families, and organizations that we gain valuable insights into what matters the most for those impacted by our research – ultimately, we hope they will be partners in our research rather than just the subjects.



Briano Di Rezze Associate Professor Rehabilitation Science McMaster University

Training and Education

Mohammad Zubairi

This pillar takes into consideration how we can support and continually enhance the training and education experience of students and practitioners working with members of MacART. These members supervise numerous research and clinical trainees at the undergraduate, graduate, and postgraduate levels, and are engaged in the mentoring of junior and intermediate faculty members. By training and mentoring emerging researchers and practitioners, we aim to help to solidify their understanding of and commitment to formulating and addressing academic questions that span the continuum of research and practice, from basic science to clinical activities.

It is our belief that involving these learners in MacART educational activities will promote their use of collaborative approaches that advance Autism care through meaningful research. Most importantly, this is a well-suited time to rethink Autism training given ongoing opportunity to learn with, from and through the lived experiences of Autistics. In my faculty role as a Scholar with the McMaster Education Research, Innovation, and Theory (MERIT) program and as Medical Director of the McMaster Children's



Hospital Autism Program, I have experience and interest in exploring opportunities to enhance learning and collaboration in the health professions. My goal is to use these opportunities to build infrastructure and capacity for interdisciplinary training, as well as incorporating a diversity of personal experiences, in order to connect those from different disciplines, backgrounds, and perspectives in their common goal of producing meaningful Autism research.



Mohammad Zubairi Developmental Pediatrician McMaster Children's Hospital

Research and Project Highlights

MacART aims to conduct research in a way that is meaningful to those who will benefit from it: parents, Autistics, 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 inbetween. Here are some examples of just a few of our ongoing initiatives.

The Pandemic Canadian Autism Needs Assessment

MacART partnered with Autism Speaks Canada and the Canadian Autism Spectrum Disorder Alliance (CASDA) 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. This was the first survey of the COVID-19 pandemic capturing the unique impact on the Autism community in Canada. The information shared by respondents is being used to inform organizations of what services and supports are most needed and helpful for Autistics and their families during this time, and to inform government of the need for increased supports for the Autism community in response to the COVID-19 pandemic and future emergency situations. The results of the report can be viewed here.

The Pandemic Canadian Autism Needs Assessment was led by Dr. Mackenzie Salt (McMaster University).





The PARC Study

The Pediatric Autism Research Cohort (PARC) study is a multi-site longitudinal cohort study that will recruit preschool children with a new Autism diagnosis. The current sites are in Hamilton, Kingston, Ottawa, and Sudbury, Ontario, in Edmonton, Alberta, and in Jerusalem, Israel. The projected recruitment of 1000 children across sites means the PARC study could become one of the largest Autism cohort studies in the world. The study aims to improve the understanding of what influences the development of children with Autism by asking about the child, their family, the services they receive, and their environmental context. The study 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 (McMaster University).

Mobile Developmental Outreach Clinic (M-DOC) Project

The M-DOC is a mobile screening clinic developed to provide assessments to underserved populations with the hopes of decreasing the age at diagnosis and allowing access to early interventions more quickly. The mobile aspect of the clinic allows the clinical team to deliver community-based point of care service to low-income, racially diverse urban populations. An iteration of the M-DOC was conducted by the SAAAC Autism Centre in 2018, and they partnered with McMaster University to evaluate the project; the results were positive (showing good cultural responsiveness to participants and a shorter time to diagnosis compared with other diagnostic pathways), and a new iteration of the M-DOC is currently ongoing.

The M-DOC is led by the SAAAC Autism Centre, with the evaluation component being led by Dr. Stelios Georgiades (McMaster University) and Dr. Mohammad Zubairi (McMaster University).

The DASCA Study

McMaster University/Children's Hospital is the only Canadian site for a study funded by the National Institutes of Health (NIH) in the United States, which is creating and testing a new questionnaire that measures socialcommunication abilities in children with neurodevelopmental disabilities. Social-communication deficits are commonly observed in children with a range of intellectual and developmental disabilities, including Autism, and are therefore a primary target of intervention for these children. However, existing measures of social-communication were not designed to provide fine-grained distinction in level of impairment. This project will result in a measure of social-communication that is standardized according to age and developmental level, thus making it sensitive to incremental changes that occur over development or in response to treatment.

The new measure – called the Developmental Assessment of Social-Communication Abilities, or the DASCA – will be better able to detect smaller changes that occur over a child's development or in response to interventions they receive. The DASCA study aims to recruit families from the Ron Joyce Children's Health Centre who have a developmental concern about their child.

The DASCA study is led by Dr. Somer Bishop (University of California, San Francisco), with Dr. Stelios Georgiades (McMaster University) as the local site lead.





External Evaluation of Autism Ontario's Service Navigation Program

To support timely and equitable family access to the Ontario Autism Program (OAP), provincial funding was allocated to **Autism Ontario** for the Service Navigation Program (SNP). Service Navigators provided information about the OAP to families to help them find qualified service providers and connect them with local resources. MacART conducted an external review of the SNP based on administrative data collected by Autism Ontario as well as surveys conducted with the Service Navigators. The evaluation suggested that the SNP was very successful in its first year of existence, applying a family-centred approach that provided immediate and practical access to families and resulted in high event/program attendance and high satisfaction levels. With the SNP continuing into 2021, MacART is also continuing its role as an external evaluator.

The SNP navigation is led by Irene O'Connor (McMaster University), with support from MacART members and members of the Centre for Health Economics and Policy Analysis (CHEPA, McMaster University). "We are thrilled to work with the McMaster Autism Research Team, whose research helps to inform public policy and programs locally and provincially for the families of children with autism and neurodevelopmental disorders."

Marg Spoelstra, Executive Director, Autism Ontario

Evaluation of Virtual Care Services

In partnership with Empowered Kids Ontario (EKO), our team from McMaster University is conducting an external evaluation of virtual care and foundational services offered by Children's Treatment Centres (CTCs) across Ontario. This project will evaluate how the delivery and outcomes of virtual care provided by CTCs can inform future provision of services for children and their families. An evaluation will focus both on the processes and outcomes of a variety of services and will importantly identify potential ways to enhance both program and service delivery, as well as a measurement of the resulting impact of these services.

This evaluation is led by Dr. Stelios Georgiades and Dr. Elyse Rosa (McMaster University).

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. It was established in 2020, published by McMaster University Library Press and is supported by the Canadian Autism Spectrum Disorder Alliance. 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.

The current Editor-in-Chief of the CJAE is Dr. Mackenzie Salt (McMaster University).

"This journal is an excellent way to highlight the voices and works of Autistics across the country. Given that the journal accepts a wide variety of types of submissions (personal essays, poetry, videos, and more), this represents an unparalleled possibility to increase the diversity of perspectives being heard."

Dr. Mackenzie Salt

Supporting the creation of Learning Health Systems for neurodevelopmental disorders

Policymakers, healthcare workers, stakeholders and researchers across Canada are increasingly aware of the importance of ensuring comprehensive and integrated care and supports are available to individuals with neurodevelopmental disorders (and their families) across the lifespan. However, there is a gap between what is being learned and achieved in the research community and the actions being taken to improve patient care and experiences. To explore this issue and work to bridge these gaps, the Azrieli Foundation provided funding support for a partnership with the McMaster Health Forum to facilitate a comprehensive stakeholder dialogue, working to combine the interests of key stakeholders and bring forth actionable outcomes working towards developing a Learning Health System for neurodevelopmental disabilities.

This work is led by Dr. Stelios Georgiades (McMaster University).



The ARBA Study: A randomized placebo-controlled trial of ARBaclofen vs. placebo in the treatment of children and adolescents with ASD

The ARBA study is an international multisite Randomized Controlled Trial of ARBaclofen for treatment of social function in children and adolescents aged 5-17 years with Autism Spectrum Disorders. Participating Canadian sites include Kingston, Toronto, London, and Hamilton. McMaster University's involvement as an ARBA Study site is made possible through infrastructure developed because of years of successful collaborations in clinical trials research with MacART investigators Dr. Peter Szatmari and Dr. Terry Bennett, whose work also focused on pharmacologic treatments for core symptoms of Autism. This study will investigate the effect of Arbaclofen on social function, global function, social withdrawal and social communication, and explore biological markers (e.g. genetics, epigenetics, functional MRI, EEG) as predictors of medication safety and treatment response.

The ARBA Study is led by Site Qualified Investigator Dr. Julia Frei and supported by Treating Clinicians Dr. Olaf Kraus de Camargo and Dr. Mohammad Zubairi (McMaster University).

2022 CHSCY Follow-up

The 2022 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. A nationally representative sample of close to 27,000 children and families from across Canada will be invited to take part again in order to explore the impact that COVID-19 has had on the physical and mental health of children and youth, such as sleep, use of electronic devices, schooling during the pandemic, and physical activity – among many others. The 2019 CHSCY was conducted Statistics Canada immediately before the COVID-19 pandemic and provides important baseline information allowing 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 children and youth with Autism. Information from this survey will be used to develop programs and policies to help improve the lives of Canadian children and youth.

Working Towards a National Autism Strategy

MacART has been working with

the Canadian Autism Spectrum

Disorder Alliance (CASDA) on numerous initiatives, all of which keep in mind the overarching goal of supporting the development of a National Autism Strategy (NAS). In September 2020 we held a virtual meeting with MacART and CASDA members to highlight our research and how various projects can support and inform CASDA and their goals. This has led to continued collaboration between MacART and CASDA, including co-supervision of students and the use of our research evidence in the creation of various policy briefs. MacART members are also working with the Canadian Academy of Health Sciences (CAHS) on the Autism Assessment, conducted to inform the government on the creation of the National Autism Strategy.

MacART Collaborators

MacART is proud to work together with organizations that share our vision/mission, including:



























"Through our partnership with the MacART, we are able to collaborate on meaningful research that can be used to inform the day to day clinical practice that supports children, youth, and families."

Dr. Bruce Squires, President, McMaster Children's Hospital

MacART by the Numbers

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.

Progress between January 2020 - August 2021:



70Publications

MacART members published 70 articles related to the topic of Autism.



107
Presentations

MacART members were invited to give 107 oral presentations or posters at conferences around the world related to the topic of Autism. This included 3 keynote lectures.



MacART members held active funded research grants related to Autism (on which they were a Principal Investigator, Co-Investigator or Collaborator) totaling \$36,819,163.

40 individual research grants



1,420
Twitter followers



21,108 Page views

MacART's website was viewed 21,108 times by 7,111 visitors in 80 countries.

"MacART goes well above and beyond what is expected of them as a research team. As one of Hamilton's trusted autism community partners, they work with families to develop, conduct, and disseminate the results of studies to ensure that their research efforts provide the maximum possible benefit to families of Autistic people."

