April 2, 2021

Multisite study to examine the diverse and changing trajectories of children with autism and their families

After a diagnosis of autism, parents and caregivers often have the same question: *"What does my child's future look like?"*. This is a hard question to answer, as each child with autism is different. Our current research, clinical, and policy frameworks were not designed to address those differences. That is why our models of care often do not meet the complex and unique needs of children with autism and their families.

A cross-institutional team of autism researchers, clinicians, and community service providers are launching a multisite collaboration – the ***Pediatric Autism Research Cohort (PARC) study*** – to examine the diverse and changing trajectories of children with autism and their families.

The PARC study will recruit preschool children with a new autism diagnosis from 6 autism clinics in Hamilton/Ottawa/Kingston/Sudbury – Ontario, Edmonton – Alberta, and Jerusalem – Israel. The projected recruitment numbers of 1000 children across all sites means the PARC study can become one of the largest autism cohort studies in the world.

Dr. Stelios Georgiades, McMaster University

"The PARC study is an exciting opportunity to demonstrate the impact of collaborative efforts to bridge the research-to-practice gap," says Dr. Stelios Georgiades, founder and co-director of the McMaster Autism Research Team at McMaster University in Hamilton, Ontario. McMaster is the main coordinating site for the PARC study, and Dr. Georgiades is the Principal Investigator.

Dr. Melissa Carter, Children's Hospital of Eastern Ontario

Data will be collected via questionnaires sent to families every 6 months, from the time of diagnosis to the early school years. The PARC study will improve understanding about what influences the development of children with autism by asking about the child, their family, the services they receive, and their environment over time. This information will be synthesized in individualized research reports and shared back to families. This will be done through an online research platform. "We see this research as an important way to help enhance communication between clinicians and families as they work to develop and adapt intervention plans," says Dr. Melissa Carter, a co-investigator with the Children's Hospital of Eastern Ontario (CHEO) Research Institute in Ottawa, Ontario.

"The PARC research study is an essential part of our family's life," says Adam Senour, a parent who took part in the pilot phase of the PARC study at McMaster University. "Participation in the study allows us to objectively track our son's growth over time and celebrate his various achievements. It also allows us to contribute to the larger vision of autism research and practice, in Ontario and beyond."

Factors that are thought to influence the developmental outcomes of children with autism include socioeconomic status, family experiences, individual strengths, symptoms and behaviours, resource availability, and services and supports. The PARC investigators have a particular interest in examining how characteristics of services and interventions are associated with diversity in child and family functioning across time.

Terri Duncan, Children's Autism Services of Edmonton

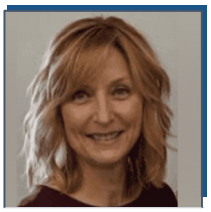
"We're excited to take part in research with such a focus on the interventions that children are receiving. This will allow us to monitor their outcomes and make any adjustments that are needed to the services we provide to families," says Terri Duncan, Executive Director of Children's Autism Services of Edmonton, a not-for-profit specialized service provider and PARC clinical site in Alberta. "This is a way research directly ties into our main goal of optimizing quality of life for families now and for the future."

Dr. Judah Koller, Hebrew University

"This research has the potential to inform better practices for intervention at a global scale," adds Dr. Judah Koller, a co-investigator with Hebrew University in Israel. "Our international team is excited to compare findings across our different settings to advance knowledge on how to effectively support autistic children and their families."

Dr. Elizabeth Kelley, Queen's University

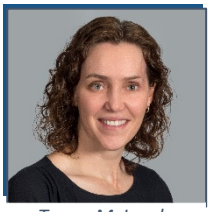
The PARC study is being embedded into clinical practice at all participating sites, using what the team calls a "pragmatic" research approach. "We appreciate the flexible design of this study, allowing us to adapt the study protocol to meet the way our local clinics operate," says Dr. Elizabeth Kelley, a co-investigator at Queen's University in Kingston, Ontario. "We are careful to make decisions about the study that are scientifically sound. We're also making these decisions together with our clinician partners in a way that makes sense with what is happening on the ground and will allow the research to succeed."



Sherry Fournier, Child & Community Resources

"The north is often not represented in autism research," says Sherry Fournier, Executive Director of Child & Community Resources, a service and community support provider and PARC clinical site in Sudbury, Ontario (representing the North Region). "We are pleased to be part of a collaborative team that understands our unique circumstances and facilitates our participation in the study. We are excited to provide this research opportunity to our families."

The PARC study is a partnership between academic research and clinical teams, but has also been closely informed by our work and collaborations with major autism advocacy organizations such as Autism Ontario, Autism Speaks Canada, the Sinneave Family Foundation, and the Canadian Autism Spectrum Disorder Alliance (CASDA) – each of which is supporting the new McMaster Children's Hospital Chair in Autism and Neurodevelopment, of which Dr. Georgiades has been named the inaugural chairholder. The PARC study will be one of the key projects supported by this Chair position.



Tanya McLeod, The Sinneave Family Foundation

"We applaud the PARC study co-investigators for advancing collaborative research and are encouraged by the intent to enhance communication to families and to share promising practices from this study with the broader community," says Tanya McLeod, President of the Sinneave Family Foundation.

"Crucial to our effort in moving forward a sustainable and comprehensive National Autism Strategy is an integrated knowledge translation pipeline from research to practice that is both rigorous in its study AND relevant to the community," says Dr. Deepa Singal, CASDA's Director of Scientific and Data Initiatives. "A learning health system approach that is embedded in the PARC study will bring together data, clinical practice, and evaluation to better inform care in Canada and internationally for Autistic people and their families."

Dr. Deepa Singal, Canadian Autism Spectrum Disorder Alliance

Margaret Spoelstra, Autism Ontario

Margaret Spoelstra, Executive Director of Autism Ontario adds, "The results of this international effort, led by an outstanding team of Canadian researchers, will be a source of encouragement to families who have been asking for this type of information for a very long time – results that help them to better understand their child's development and to make informed choices that will help their child live the best possible life."

Jill Farber, Autism Speaks Canada

"We are excited to share the launch of this important research project with such an impressive group of experts," says Jill Farber, Executive Director of Autism Speaks Canada. "This study is designed around families and their lived experiences which we believe will promote meaningful engagement and produce meaningful scientific evidence. Furthermore, our learnings will impact the ways in which we best support the unique needs of these children and families."

The PARC team is excited to be launching the study in the spirit of World Autism Awareness Day 2021, working collaboratively to help position each child with autism and their family on a positive developmental path toward optimal outcomes.