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Transforming Autism Care Consortium

Uniting minds, improving lives

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Transforming Autism Care Consortium

Fonds de recherche Québec

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1. Introduction

1.1 Network Overview

The Transforming Autism Care Consortium's (TACC) **mission** is to connect and mobilize research strengths in Quebec to improve quality of life for autistic individuals and people with neurodevelopmental conditions (NDCs).

Our **vision** is of a connected ecosystem that bridges science, practice, and living and lived experience, ensuring that research translates into tangible impact for individuals, families, and communities.

Our **strategic plan, TACC 2.0**, is guided by the perspectives of autistic people, people with other NDCs, and their families and by numerous local and international policy frameworks. All converge on the urgent need to address the unmet needs identified by autistic people, people with other NDCs, and their families.

These unmet needs span areas of health, well-being, and experiences of stigma, discrimination, and social exclusion throughout the lifespan. These preventable negative experiences come at a high cost to society, not only in terms of healthcare costs but also in negative impacts on quality of life for those affected and their families.

Our new strategic plan builds on the network's experience and successes while setting a new goal: to continue to support high-impact scientific discoveries while strengthening our collective capacity to address unmet needs.

TACC's research axes reflect scientific expertise in our field. To date, TACC has leveraged its international leadership in key areas (e.g., genomics, cellular and animal models, neuroscience, cognition, and behavior) to deepen our understanding of the underlying causes of NDCs, including their complexity and variability.

TACC is now well-positioned to advance underrepresented but high-impact research areas in NDCs: implementation science, social determinants, learning health systems, and living labs.

We are harnessing these strengths to achieve five strategic objectives:

1) Develop open science common resources through the Quebec 1,000 Families (Q1K) platform
2) Train the next generation of leaders
3) Enhance excellence in multidisciplinary research
4) Develop innovative models of cross-sectoral partnerships, and
5) Implement a knowledge mobilization strategy that expands the network's reach and fosters social innovation.

1.2 Highlights of the Year

Since the beginning of the new funding cycle, our communications strategy has showcased over 15 impact stories highlighting major achievements related to the TACC 2.0 plan. Many of these stories illustrate the expansion of our inclusive governance model.

With rapidly growing membership and increased diversity in expertise, interests, and aspirations, TACC is entering a new phase grounded in collaboration and inclusion, exemplified in key significant achievements this year:



Our leadership now includes 17 members on the Scientific Committee, an expanded Community Engagement Committee representing key players in our provincial ecosystem, and a new group of Trainee Co-Leads.



A highlight this year was a public event held alongside our Annual Member Assembly in the format of an open forum ("an unconference"): participants set the agenda, self-organized into thematic groups, and used the discussions to gain knowledge and connections relevant to their own environments.



A new Living Lab at Giant Steps, an innovative school and service centre for autistic people, has expanded rapidly and started to produce co-designed research with the school community.

2. Activities and Impact in Numbers

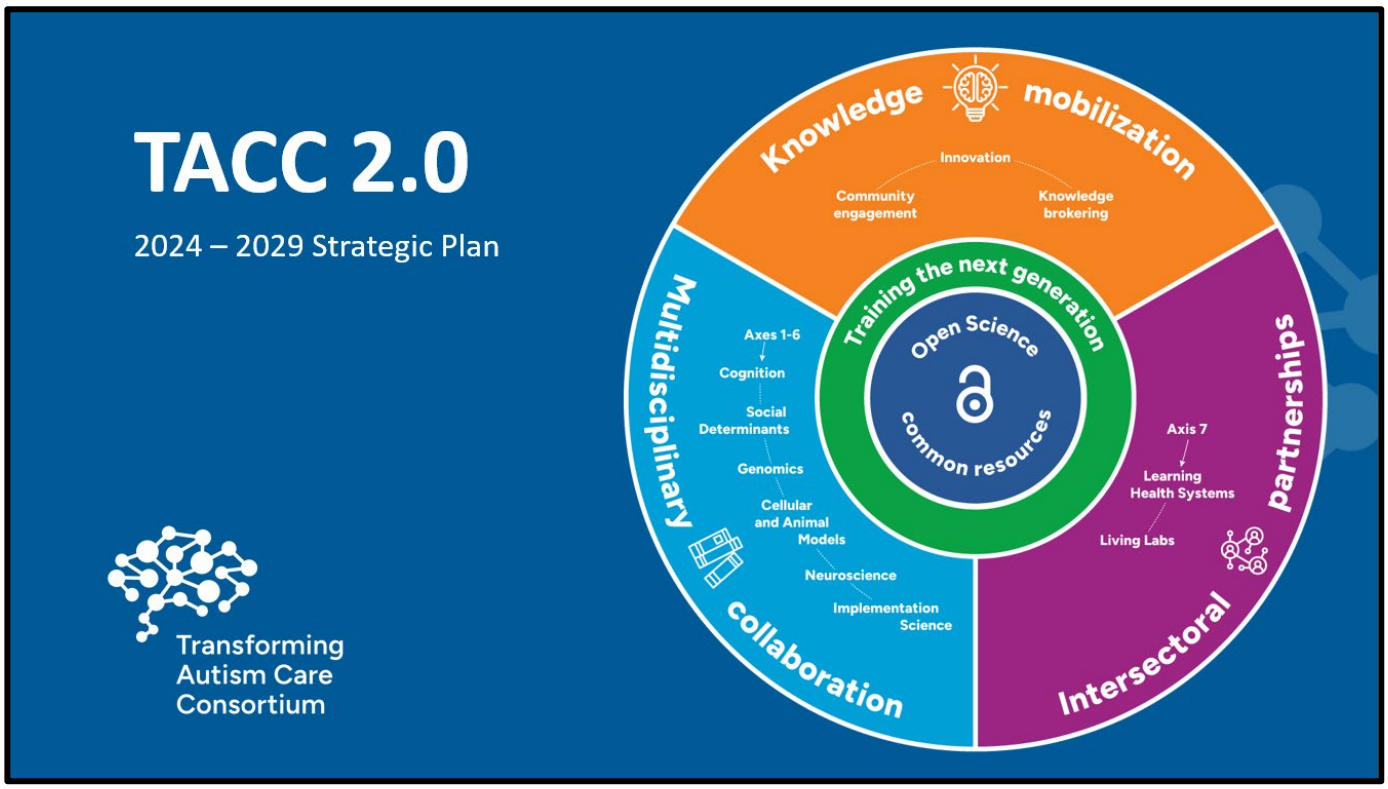


Fig. 1 *2024 – 2029 TACC Strategic Plan*

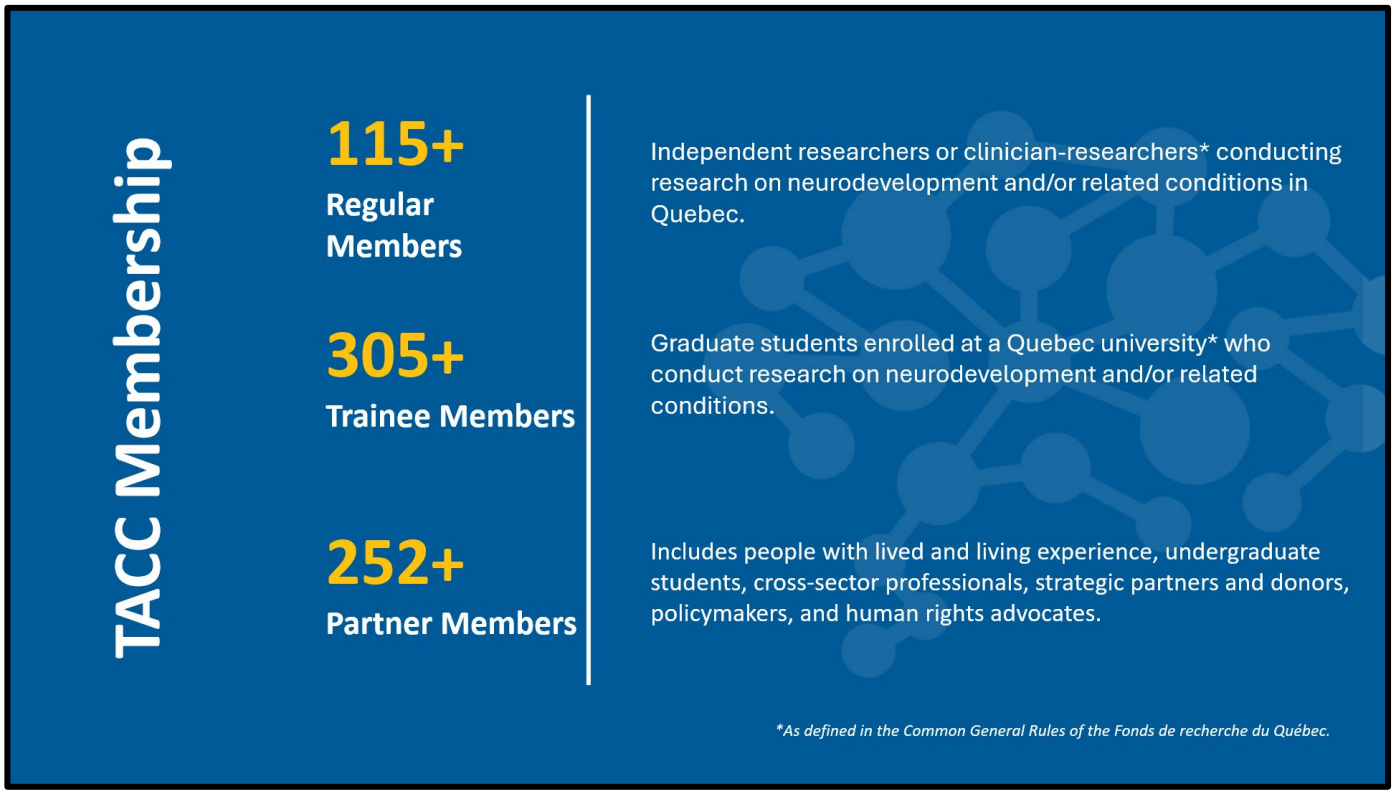


Fig. 2 *TACC Membership (Sep. 2025)*

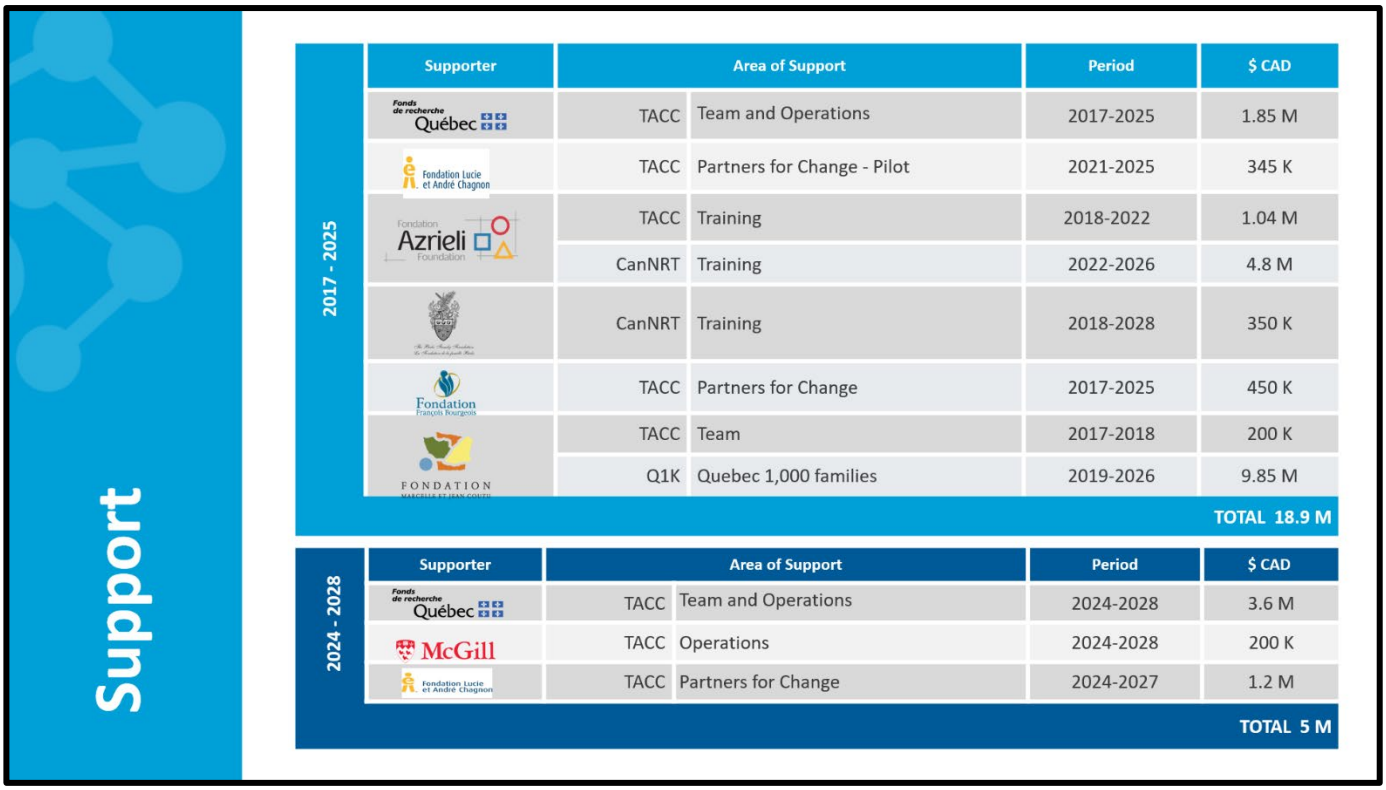


Fig. 3 *Support*



Fig. 4 *TACC Activities*

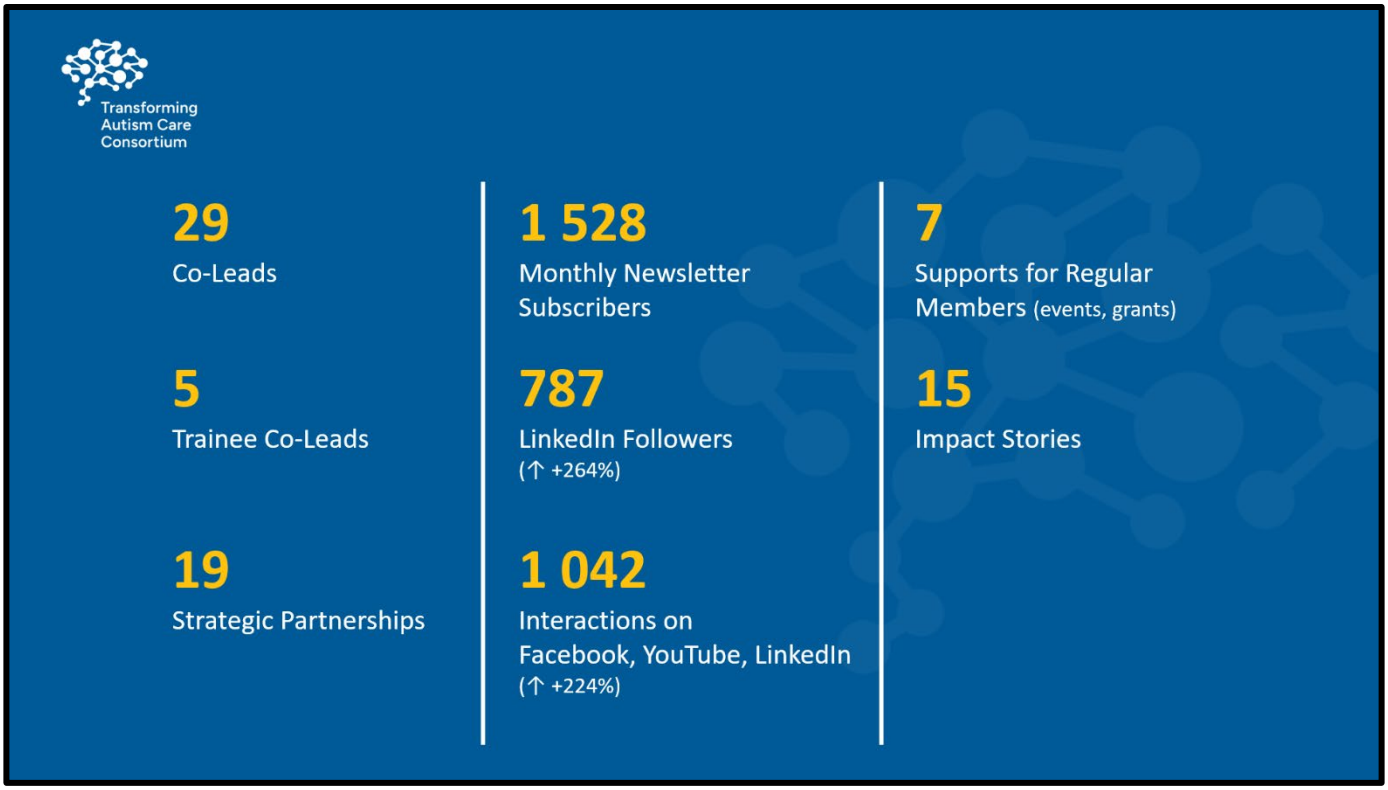


Fig. 5 *TACC Governance, Engagement and Partnerships*



Fig. 6 *Canadian Neurodevelopmental Research Training (CanNRT) Platform*

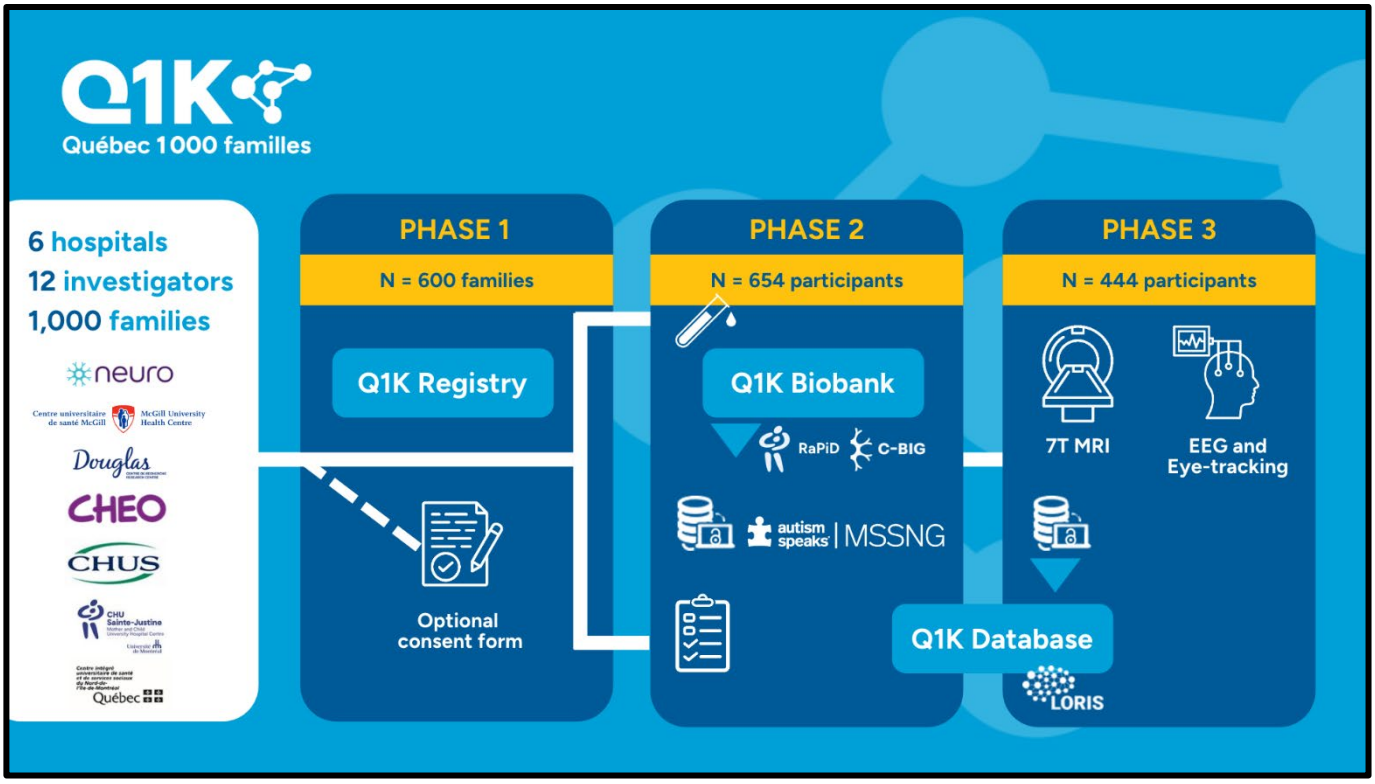


Fig. 7 *Quebec 1,000 Families (Q1K)*



Fig. 8 *Partners for Change, Giant Steps Living Lab, and Autism Festival*

3. Network Structure and Partnerships

The implementation of the TACC 2.0 plan relies on a group of initiatives, common resources, and strategies to structure and strengthen the research ecosystem. In addition to our expanded leadership, the TACC team now includes expertise in network management (J. Popic); open science (E. Kirby); training (E. Minogianis); knowledge mobilization (M. Habra); and communications (V. Tamburro), ensuring effective rollout of planned activities.



Jelena **Popic**



Emily **Kirby**



Martine **Habra**



Ellie-Anna **Minogianis**



Vanessa **Tamburro**

Each activity is guided by concrete objectives and incorporates participation and engagement mechanisms:

3.1 Member Engagement Strategy

This strategy aims to foster trust and active engagement in network activities. Efforts focus on consolidating and unifying the member registry, facilitating knowledge sharing and exchange, and amplifying the impact of TACC 2.0 through various communication channels.

3.2 Partnership Strategy

TACC contributes to building a robust and interconnected NDC research ecosystem in Quebec and beyond. Partnerships aim to expand and coordinate investments; connect multiple networks/platforms; and involve diverse communities, including those with lived experience, in leadership roles.

3.3 Quebec 1 000 families (Q1K)

Q1K grew out of TACC and is supported by a $10 million donation from the Coutu Foundation. Now in its fourth year, this major initiative brings together families, clinicians and researchers to develop a province-wide open science resource. It aims to strengthen collaboration among Quebec hospitals and research centres, engage 1,000 families in research, and build a next-generation multimodal dataset to support research and practice.

3.4 Canadian Neurodevelopmental Research Training (CanNRT) Platform

CanNRT grew out of TACC's former Quebec Autism Research Training (QART) Program and has expanded it across Canada. Now in its third year, the platform offers graduate trainees and clinical fellows a collaborative learning environment that supports research excellence, career development, mentorship and cross-sector collaboration.

3.5 TACC Trainee Co-Leadership Award

This new award enables trainees to develop leadership skills, supports their inclusion in network governance, contributes to the strategic plan, and fosters collaboration with experts and community partners. In 2024–2025, five trainees received this award and are actively involved in network governance.

3.6 Partners for Change

This initiative leverages research as a catalyst for social innovation through activities that connect the ecosystem, support partnered research and promote knowledge mobilization. Activities focus on unmet needs identified by communities.

3.7 Giant Steps Living Lab

We established a new living lab physically integrated into the new Giant Steps building—a school and service centre for autistic children and youth. The living lab bridges research and lived experience by co-designing, testing, and sharing inclusive practices. This is being achieved by fostering a research-oriented culture, generating evidence-based data, and implementing innovations.

3.8 Autism Festival

The Autism Festival is an initiative celebrating the intersections of science and society through participatory activities that engage the public. The festival promotes research advancements through creative expression and fostering dialogue between researchers and the community.

4. Knowledge Translation and Mobilization

4.1 Research Infrastructure and Shared Resources

The Quebec 1,000 Families (Q1K) project is a cornerstone initiative for the network, generating knowledge and research infrastructure across six affiliated hospitals and centres. Participants are invited to enroll in the project during their clinical visits. The Q1K protocol consists of three phases of participation and the creation of permanent shared resources (see Section 2 for the number of enrolled participants):

Q1K Registry

The Q1K Registry collects minimal data to identify and match enrolled participants with a wide range of studies. Several strategies have been implemented to increase the visibility of the Registry, including information sessions for internal (CISSS/CIUSSS clinicians) and external partners.

Q1K Biobank

The light phenotyping of the second phase involves data collection through questionnaires and blood samples. DNA and neural cell analyses derived from iPSCs are stored in the Q1K Biobank, another shared network resource.

Q1K Database

An in-depth phenotyping of a subset of participants is conducted in the third phase, with data recorded in the Q1K Database.



Q1K collects genomic, cellular, behavioral, and brain imaging data (MRI, EEG, eye-tracking), which will be accessible to the scientific community following open science guidelines (see Section 8.2). Notably, the use of 7T MRI in a pediatric and/or children and participants with specific support needs represents a significant innovation of Q1K.

Adaptive and flexible behavioral strategies have been developed, including:



- Visual stories illustrating different aspects of the protocol for participants, parents, or caregivers to review before their lab visit;
- Illustrations and audio recordings of various protocol aspects;
- Videos demonstrating a mock run-through of the protocol, including brain imaging;
- Sensory tools tailored to participants' specific needs (e.g., weighted blankets, noise-canceling headphones, fidget objects, quiet spaces).

4.2 Partners for Change

During the pilot phase of Partners for Change, TACC funded six research-community partnership projects focused on housing and employment support, early childhood parenting, accessibility to services and cultural programs, and school inclusion.

In 2025, TACC formalized a partnership with Société Inclusive, a platform bringing together Quebec research networks and centres interested in social inclusion for individuals with disabilities related to mobility, sensory capacity, and physical challenges.

Mélanie Couture, TACC Co-Director, and Martine Habra, responsible for partnerships and knowledge mobilization, joined Société Inclusive's Partner Committee and continue to contribute to its governance and activities.

This partnership enables TACC researchers and non-profit organizations to submit proposals for participatory research funding competitions. It has already expanded Société Inclusive's reach into autism and NDCs, increasing the number of funded projects in this field.

Together, these projects have emerged as a powerful driver for addressing major challenges related to sustainable health goals (see Section 7).

4.3 Giant Steps Living Lab

A major achievement in 2024–2025 was the launch of the new Giant Steps Living Lab. The lab aims to facilitate research centred on education and community approaches by creating a bridge between traditional labs and real-world settings. It is a key partnership for TACC, as the living lab seeks to foster multidisciplinary and cross-sectoral knowledge development while addressing community needs.

Key developments include:

- Establishing an Advisory Committee with a wide range of intersectoral stakeholders
- Structuring a Working Group to oversee the implementation and deployment of the platform
- Finalizing a policy for managing research project requests submitted to the living lab
- Approving 15 research projects focused on generating knowledge for students, parents, and educational practices (e.g., multilingualism, child cognitive development, teaching practices, outdoor play)
- Facilitating the co-creation of projects by TACC researchers and Giant Steps leadership, targeting the center's strategic priorities.

4.4 Learning Community

TACC continued to expand its training offerings for professionals to support their clinical practice. These trainings fostered collaboration and knowledge sharing among healthcare professionals, researchers, experts from various sectors, and individuals with lived experience.

This initiative is a critical step in developing inclusive healthcare systems that meet the needs of those directly affected. In 2024–2025, nine training sessions were organized, reaching 260 professionals. These sessions enhanced skills and confidence in early identification and intervention practices—areas where wait times are long in the community and one-size-fits-all services are common.

The trainings ensured that practices are evidence-based and that research findings are directly applied to care and support, creating a lasting positive impact on the lives of individuals with NDCs and their families. (Additional knowledge mobilization activities strongly linked to participatory and inclusive research are described in Section 8.)

5. Network Impact and Added Value

TACC began as a collaboration among researchers and philanthropic organizations to unite partners in the autism research ecosystem. Over the years, TACC has solidified its position as a key player in Quebec's and the international neurodevelopmental conditions (NDC) ecosystem.

This year's efforts have transformed a vision into tangible achievements across three impact areas:

5.1 Breaking Down Silos

The global neurodevelopmental research ecosystem is a complex network of partners from diverse sectors (e.g., research, practice, community, and policy). In 2024–2025, we continued to build and strengthen bridges to bring partners together and enable them to define and implement innovative solutions by:

- Establishing a new governance structure that systematically integrates researchers, clinicians and professionals, trainees, and individuals with living and lived experience, ensuring broader representation and more inclusive decision-making (see Section 8.1);
- Launching committees and revising the Charter, which clarified roles and responsibilities and laid a strong foundation for the network's next growth phase;
- Implementing a new communication strategy that expanded the network's reach in knowledge dissemination and events, highlighting member profiles across Quebec, and opened bidirectional channels for exchange (e.g., Facebook, LinkedIn, YouTube). Our metrics show that this new communication infrastructure has significantly increased our reach and engagement (see Section 2).

5.2 Advancing Research

To date, we have leveraged Quebec's international leadership in genomics and neuroscience to launch Q1K, the first large-scale platform of its kind in the province. The past year has confirmed TACC's added value as a catalyst for interdisciplinary and cross-sectoral collaboration, serving a more equitable and inclusive society:

- TACC maintained the engagement of founding philanthropic partners ($5M in active funding) to support a range of research activities managed by the network.
- Q1K is already making a tangible impact on advancing open science by contributing innovative data and tools (see Section 8.2).
- Our Partners for Change program and the new Living Lab have facilitated the launch of numerous real-world research projects led by our members, producing knowledge and outcomes that directly address community needs (see Section 7).

5.3 Building Capacity

TACC will build on its training programs, knowledge mobilization activities, structuring initiatives, and participatory approach to strengthen and energize the NDC research ecosystem while connecting it to other networks to address urgent societal challenges. The 19 partnerships established or consolidated over the past year have also enhanced TACC's ability to serve as a unifying force and create synergies within the ecosystem, providing leverage. For example, these partnerships have enabled:

- Integration of ecosystem partners into TACC governance (FQA, SQDI, RNETSA, IU-DI-TSA);
- Translation of participatory research training modules into French to facilitate the involvement of individuals with NDCs and their families in citizen science (CHILD-BRIGHT, ODISÉ);
- Optimization of resources and reduction of costs associated with shared research and training infrastructure (Société Inclusive, IMPaCT, Canadian Autism Alliance);

6. Empowering the Next Generation of Leaders

In addition to our new Trainee Co-Leadership Award, TACC has been recognized for its innovative training programs since its inception. In 2022, the transition from the Quebec Autism Research Training (QART) Program to the Canadian Neurodevelopmental Research Training (CanNRT) Platform was completed,

thanks to a $4.8M donation by the Azrieli Foundation. This new platform aims to provide a pan-Canadian collaborative training environment that supports research excellence and sustainable, equitable career paths for early-career researchers in neurodevelopment and related conditions. Through intersectoral and multidisciplinary learning, mentorship, and connectivity, CanNRT prepares the next generation of leaders.

With the involvement of 29 co-lead researchers and stakeholders, the program offers:



Entry Awards

The most recent selection competition for the 2025 CanNRT Training Program concluded in recent months. Over 160 applications were submitted—more than double the number received in 2022—demonstrating TACC's growing influence in Quebec and Canada's research ecosystem. CanNRT has partnered with IMPaCT (Increasing capacity for Maternal and Paediatric Clinical Trials), a CIHR-funded health research training platform focused on advancing perinatal and pediatric clinical trials, as well as the Autism Alliance of Canada on public policy. These partnerships co-funded two trainees.



Training Passport

CanNRT trainees can apply for flexible support (up to $2,000/year) through the Training Passport to maximize their engagement in career development activities, such as conference presentations, training events, and workshops tailored to their interests and needs. Since January 2023, over $80,000 has been awarded to program trainees for such opportunities.



Annual Summer School

The CanNRT Summer School has been held annually in August in Montreal (2023–2025). This week-long immersive learning experience brings together 29+ trainees and 40+ mentors from diverse sectors and disciplines to explore topics like equity-based co-creation, inclusive research methods, and media relations. Post-event surveys highlight high participant satisfaction, with praise for organization (84%), thematic content (95%), interactivity (96%), perceived impact (88%), and overall experience (98%).



Curriculum

The CanNRT curriculum is developed through two expert committees: Priority Area Leads (PALs), who strengthen future capacities in essential priority areas addressing identified training gaps (e.g., scientific communication and writing, policy, clinical studies); The Curriculum Co-Design Committee, which designs a dynamic, adaptable, and accessible program for CanNRT members using a high-quality co-design process with diverse stakeholders, including individuals with lived experience.



Thematic Retreat

From March 24–26, 2024, in St-Sauveur, the first annual thematic retreat brought together 22 CanNRT leaders and partners, including trainees and faculty from across Canada, to discuss progress on specific neurodevelopmental research training themes. Sessions focused on student leadership, curriculum co-design, and community building. Participants emphasized the value of the discussions and collaborative environment.

7. Sustainable Health Research

A key driver of investment in sustainable health is our Partners for Change program, which fosters cross-sectoral collaborations and positions research as a catalyst for social innovation. The program directly addresses issues related to autism and neurodevelopmental conditions, which are growing public health priorities. As illustrated below, Partners for Change has established concrete mechanisms to support several priority areas identified by the Fonds de recherche du Québec (FRQ) in sustainable health,

including real-world research, citizen engagement, and the involvement of new health stakeholders. In many cases, research supported by the program has also touched on other FRQ priorities, such as personalized health (including public health and population health), mental health, and axes focused on social participation and inclusion.

Lasting Impact

Projects funded under the Partners for Change program continued to make an impact in 2024–2025:

- The Orchestre Symphonique de Montréal (OSM) team, recipients of a Partners for Change grant with researchers Quentin and Sim (McGill) for their project on inclusive symphonic music concerts, received the prestigious Prix Opus and an award from Quebec's Ministry of Culture and Communications.
- Courcy (Université de Montréal) and Hervé (Maison de l'autisme) transformed their project results into bilingual video capsules launched in 2024, sensitively and accurately depicting the housing realities of autistic adults.
- Findings from Soulières (UQAM), Buissières (UQTR), and Cuzzi (Autisme sans limites) were highlighted in a webinar on Neuroinclusion in the workspace (Neuroinclusion en milieu de travail), attracting over 180 registrations and sparking engaged discussion.
- The event on the built environment for autistic individuals, featuring the work of Lasalle (Université de Montréal), was showcased in a multimedia narrative highlighting TACC members' contributions. The innovative event format, presenting cross-perspectives, was so well received that we plan to repeat it annually.

Continuing the momentum, seven new projects were funded in 2024 through our partnership with Société Inclusive. These projects target major challenges for sustainable health, such as access to care and services, inclusive and secure housing, successful youth transitions to adulthood, and healthy aging for autistic and neurodivergent individuals. They also address cross-cutting issues like healthy affective and sexual relationships, reducing social inequalities, and supporting families as key partners in well-being:

- Flanagan (McGill), Couture (U Sherbrooke), Giant Steps Centre, *Espace pour la vie*: Co-creation of an accessibility and neuroinclusion assessment tool.
- Argumedes-Charles (Sherbrooke), Nader (U de Montréal), Coopérative de solidarité l'Envolée: Social housing for autistic adults seeking autonomy.
- Courcy (U de Montréal), Rodriguez del Barrio (U de Montréal), *Maison des jeunes Bordeaux-Cartierville*: Transition toward inclusion.
- Argumedes-Charles (U Sherbrooke), Lord (UQAT), Fédération québécoise de l'autisme: Autism and aging—analysis of health and well-being indicators.
- Higgins (UQ-Abitibi Témiscamingue), Gilbert (UQAR), Autisme sans limites: Connexion Spectrum—sexuality and healthy relationships.
- Rezzonico (U de Montréal), Desmarais (U Laval), Dysphasie+: Co-development of workshops to promote self-awareness and communication for adolescents with DLD (Developmental Language Disorder).
- Guillaume Ouellet (UQAM), Coralie Sarrazin (HADéPAS, UCLille), Société québécoise de la déficience intellectuelle: Valuing the daily practices of parents of children with developmental particularities—parental creativity as a driver of social inclusion.

8. Contributions to Open Science and Inclusive Research

8.1 New Inclusive Organizational Structure for TACC

Support from the Fonds de recherche du Québec (FRQ) enabled us to implement a new organizational structure, integrating several new partners interested in research in autism and other neurodevelopmental conditions. This structure introduces two key actions to ensure TACC activities align with community needs.

First, the Scientific Committee has been expanded to include researchers with expertise in education, policy, human rights, intervention, and other fields.

Second, the mandate and composition of the Community Engagement Committee (CEC) have been revised. CEC meetings serve as a bidirectional forum to foster communication between academic and community settings.

CEC members represent the Fédération québécoise de l'autisme, Société québécoise de la déficience intellectuelle, Institut universitaire en déficience intellectuelle et en trouble du spectre de l'autisme (IU-DI-TSA), and Réseau national d'expertise en trouble du spectre de l'autisme (RNETSA). IU-DI-TSA and RNETSA are mandated by the Ministries of Health and Education to develop best practices and knowledge transfer, respectively. Their presence on the CEC strengthens ties between these organizations.

8.2 Shared Q1K Resources

A major network goal is to promote resource sharing, such as data generated by the Q1K project, to enhance cohesion and collaboration among partners.

The Q1K Registry offers significant opportunities to accelerate NDC research in Quebec by connecting families and researchers. In 2024, efforts to engage clinicians and families in Q1K included:

1) Hosting information sessions
2) Distributing customized promotional materials to various sites
3) Maintaining regular contact with clinicians
4) Engaging external associations.

Participation in light and deep phenotyping phases includes returning research results to families via their treating physicians, facilitating access to care. The Q1K Biobank and Database centralize data collected across sites, eventually enabling open science access.

Recently, a collaboration and data access process was established, and a Researcher Committee was formed to review requests. Additionally, a centralized data access platform for behavioral, electrophysiological, brain imaging, and genetic profile data is being developed via the C-BIG Platform (The Neuro), simplifying access through a single portal.

8.3 Autism Festival

Three public events were organized as part of the Autism Festival:



Tisser des liens: This inclusive event at the Musée des Beaux-Arts de Montréal brought together autistic adults and TACC trainee members, offering a unique platform to explore art in ways adapted to diverse neurotypes and linguistic abilities.



La neuroinclusion en milieu de travail (Neuroinclusion in the workplace)*:* In March 2024, TACC and Société Inclusive co-hosted a webinar sharing findings from partnered research on employment inclusion for neurodivergent people. More than 180 people registered to discuss barriers and opportunities related to employment.



Construire l'inclusion: Perspectives sur l'environnement bâti pour les personnes autistes: This event aimed to share knowledge and stimulate discussion on designing accessible spaces for autistic people. Approximately 110 people registered to attend in an interactive panel offering diverse insights on inclusive design.