



# Healthy Trajectories

A Child and Youth Disability Research Hub



## Welcome to our Healthy Trajectories December Newsletter!

### *A message from our Director, Christine*

As we reach the end of 2023, it is a time to reflect on what we have been doing and also to plan for what is to come in 2024. In this newsletter you will read about many of the activities of the team, including news of travel and presentations around the globe, of success in project grants, and other activities to which the team has contributed.

In the last couple of weeks, we listened and read with great interest the findings of [the NDIS review](#), which have been announced by the Minister, discussed in the media, and shared via Town Hall meetings across the country. I want to thank all those associated with Healthy Trajectories for their contributions and submissions through the review period. The report outlines the recommendations going forward and now is the time for us to keep looking for how we can inform and contribute to the proposed changes, and measure impacts of those changes, so that continuous quality improvement occurs.

After a period of rest, recovery, relaxation and (hopefully) a bit of sunshine, we will welcome in 2024 and continue our work together across the programs of research.

I wish you all a joyous festive season and a very happy New Year.

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## ***News to celebrate from Healthy Trajectories!***

Christine takes a trip to Orebro...

In October this year, I was able to travel to Orebro in Sweden to meet with the team who are undertaking a 5-year study about the relations between participation and mental health in young people with disability and chronic health conditions. The research program includes a longitudinal study of participation and mental health outcomes, and several smaller studies based in Swedish children's treatment centres that explore ways to enhance children and parents/caregivers involvement in the processes of therapy. We used these few days together to plan the work of the next year or so, and I look forward to sharing outcomes as they become available.



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## **Celebrating International Day of People with Disability**

The team hosted a joyful celebration of International Day of People with Disability earlier this month at the Royal Children's Hospital, Melbourne. Healthy Trajectories' Ambassador [Eliza Hull](#) joined us on Main Street to read her award-winning picture book [Come Over to My House](#) to an excited audience of children, sharing stories of kids and families with a diverse range of abilities. Eliza then filled the hospital with music by performing [Running Under Water](#), which showcased her incredible voice in a song with a powerful meaning.

Associate Professor Adrienne Harvey from the Healthy Trajectories team then led a chat with Sienna, who lives with cerebral palsy, and Dr Giuliana Antolovich, a paediatrician at The RCH. Sienna shared messages about what she likes about her cerebral palsy, and her love of the ParaMatildas with the crowd – which contained many soccer fans!

The morning wrapped-up with a special screening of Eliza’s moving short film *And Then Something Changed*, which shows how we need to change the world, not the person.

We would like to say a **big thank you** to everyone who came to help us celebrate, particularly Eliza and Sienna, along with our campus partners at The RCH and MCRI. It was a delightful, inspiring morning.



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## Healthy Trajectories Seed Funding Recipients 2023

We are excited to announce the recipients of our 2023 Healthy Trajectories seed funding round!

- Dads And Disability: Co-designing Assistance and Research to Empower (DAD-CARE) led by [Professor Nathan Grills](#)
- CP-Pathfinding: Your health; co-design of a lifestyle module to empower young adults with cerebral palsy in their health literacy knowledge and participation led by [Dr Stacey Cleary](#)

- A school-based program to build genetic literacy in students and teachers: A pilot to assess feasibility, acceptability and impact led by [Hollie Feller](#) and [Dr Simone Darling](#).
- Customer-directed mealtime services for people with cerebral palsy across the lifespan: What do they need and when do they need it? led by [Associate Professor Kelly Weir](#)

These exciting projects have been selected to receive funding of up to \$30,000 each and we are looking forward to seeing the important work that will develop from them.

**You can read more about these four brilliant projects in [the announcement on our website](#).**

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## Family Engagement in Research Training Program

McMaster University, CanChild, and Kids Brain Health Network in partnership with the Healthy Trajectories team have been running the Family Engagement in Research Training Program. This program has been developed for researchers and people with lived experience and their families to work together on research projects. The 8-week program includes a range of sessions covering why family engagement in research is important, how to engage and partner in research, and tools to support engagement. The program started in October 2023 and ran until early December 2023. There were 20 participants in the program. We have both Canadian and Australian colleagues facilitating the program, including Sam Micsinszki, Kristina McGuire, Bridget O'Connor, Heather Renton, Frances Hunter, Sevastine Katsakis and Elise Davis. The participants are working on developing a knowledge translation tool to support family engagement in research. Previous student projects can be viewed [on the CanChild website](#).

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## Healthy Trajectories' Research Themes and Programs

The research work of Healthy Trajectories builds on a long-standing interest in improving the lives of those growing up with disability and their families.

Our research falls into four programs of work:

- **Family Wellbeing**
- **Early Childhood Initiatives**
- **Optimising Health Outcomes**
- **Learning and Belonging**

The programs and projects within them have arisen from our work on the National Disability Research Agenda. In addition, all our programs are guided by two core themes: **Participation Across the Life Course** and **Consumer Research Partnerships**.

You can read more about the research we do by visiting our website.

[Click to read about our research](#)

## Family Wellbeing

It has been a busy couple of months for the Family Wellbeing theme as we prepared to deliver the ENVISAGE for Service Providers program, [ENVISAGE-SP](#). Our research assistants in Australia (Miriam Yates) and in Canada (Debra Hughes) have done an amazing job registering and enrolling health care providers to get the pilot evaluation of the workshops underway.

The five workshops are co-facilitated online by a parent peer and researcher/clinician. The ENVISAGE-SP program was developed in response to parents asking for a version of [ENVISAGE- Families](#) to be developed specifically for service providers. This was so families and service providers have a common language and tools to talk with each other about disability and development. The workshops will continue over summer in Australia and winter in Canada. We will then evaluate the impact of the workshops on service providers.

We are recruiting into the pilot study of effects of ENVISAGE-SP, please [click here find out more and register your interest in ENVISAGE-SP](#).



[ENVISAGE-First Peoples](#) is now being delivered as part of the DSS implementation of ENVISAGE in Australia. [Have a look at the amazing artwork](#) that has been incorporated into the program by Wiradjuri women Jordana Angus. Also take a moment to read [this article](#) by a parent who shares her insights into the [ENVISAGE-Families](#) program and what can be learned through doing the program.

[ENVISAGE-Families](#) is a national program for caregivers of children with a disability or developmental concerns that aims to empower caregivers to feel confident in their parenting. ENVISAGE-Families provides support, knowledge and connections for caregivers. The implementation of ENVISAGE-Families is underway. The team have now trained 47 service provider facilitators and 41 parent peer facilitators, and 378 caregivers have enrolled to participate in the program. 70 programs will have been completed by the end of the year. Evaluation is underway to capture the experiences and impact of the program for caregivers.

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## Travel scholarship success

ENVISAGE-Families State Project Administrator (Victoria and Tasmania) and PhD student, Kerry Britt received the Henry and Rachel Ackman Travel Scholarship & CP-Achieve Travel Scholarship to support her recent travels to the [European Academy of Childhood Disability \(EACD\)](#) Conference, Ljubljana, Slovenia, the [Child Bright Conference](#), Toronto, Canada, and the opportunity to spend several weeks in Canada meeting and working with the research team at [CanChild, McMaster](#)



## A prize-winning essay

We are delighted to say that Dr Nicole Merrick has been awarded the [Spinal Research Institute](#)'s SCI Research Writing Prize. Nicole works as a Post-Doctoral Research Fellow at Healthy Trajectories and researches spinal cord injuries. You can read Nicole's prize-winning essay 'Fallen warriors: lessons from rugby-related spinal cord injury in Australia' on pages 32-33 of [Why Research Matters 2023](#).

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## Connections

Along with providing Healthy Trajectories with counsel, several Consumer and Family Council members have been busy producing disability-related podcasts that are well worth listening to.

- [Accessible travel podcast](#) with Nicholas Lapsley. Nicholas has new guests on every week who share their experiences with traveling with a disability.
- [Accessed that](#) with Oliver Hunter and Karni Liddell. Oliver and Karni talk with guests about travelling in Queensland with a disability, complete with reviews and feedback on the places they visit.
- [Dad-Ability](#) with Rob Hale. Rob's podcast covers a huge range of topics all about being a dad with a child with disability, to help share stories of success, struggles, and everything in between.
- [Loop Me In](#) with Dr. Lisa Interligi and Kristine Christopolous. Lisa and Kristine draw on their own experiences as parents of children with disabilities to discuss topics of interest to other parents and carers.

You can listen wherever you get your podcasts! To learn more about our councils, including how to get involved, please visit [our lived experience council page](#).

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*The Healthy Trajectories Child and Youth Disability Research Hub acknowledges the Traditional Owners of the lands and waterways on which we work, and pays respect to the Elders, past and present.*

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