



Welcome to our Healthy Trajectories December Newsletter!

A message from Christine

As another year draws to a close, we think about what we have done and learned over the year, and we make plans for next year. In 2022, Healthy Trajectories grew from an idea to a working program bringing together multiple teams and projects. We have appointed staff, developed a website, provided seed funds to researchers, attended training, and applied for grants to keep our priority research moving forward. You will read about some of these activities in the newsletter below. 2023 is already shaping up to be busy and we look forward to working and connecting with you all.

On behalf of the Healthy Trajectories team, we wish you a safe and happy holiday season, and hope you enjoy some fun, as well as some rest and relaxation.

\$6.9 million of the Federal Government's National Early Childhood Program grant to deliver ENVISAGE!

The Healthy Trajectories team at the University of Melbourne are pleased to be key partners in The Australian Catholic University (ACU) team that will deliver a peer support program, through the Federal Government's National Early Childhood Program. The peer support program is called ENVISAGE-

Families, and aims to empower, support, and connect caregivers early in their experience of raising a child with disability or developmental concerns.

Funded by the DSS \$13.8 million to support children with disability or emerging developmental concerns | Department of Social Services Ministers (dss.gov.au) - this program is one of two that aim to support young children and families across Australia.

ENVISAGE stands for ENabling VISions And Growing Expectations, and was co-designed with Australian and Canadian parents, carers, service providers and researchers, and includes a dedicated co-designed First Peoples program. Our international research shows that ENVISAGE-Families empowered parent/caregivers to take strengths-based approaches to their situation. It increased parent/caregivers confidence in parenting children with a disability and provided them with tools to support connection, collaboration, and wellbeing.

As we roll out our National Early Childhood Program, there will be positions for parent partners and early childhood professionals to support the implementation of ENVISAGE across Australia. If you are interested in being informed about these opportunities, please let the team know at envisage@acu.edu.au



Healthy Trajectories Seed Funding Recipients

Loneliness, social isolation and mental health for young people with disability. This project is led by <u>Dr Zoe Aitken</u> in partnership with <u>Children and Young People with Disability</u>
<u>Australia</u> (CYDA). It aims to advance understanding of loneliness and social isolation experienced by young people with child-onset disability and its impact on their mental health.

Feasibility of goal sharing digital interface to empower children with disability and their families and improve collaboration: A qualitative, pre-implementation study. This study led by Dr Sarah Knight in partnership with Sameview aims to identify facilitators and barriers to implementing a goal sharing interface between hospitals and health care programs, and community systems like NDIS providers, to enable families to share their goals with their service providers.

Consumer preferences and early life predictors of physical activity for children born very preterm: A mixed methods study. In this project <u>Dr Tara Fitzgerald</u> will address important knowledge gaps which are crucial to effectively promote physical activity participation for children born very preterm (less than 32 weeks' gestation).

Music technologies for people with disabilities: Creating a framework to assess suitability for individual students. In this project, <u>Dr Anthea Skinner</u> and her team aim to create a framework to evaluate adaptive musical instruments and accessible music technology, so that musicians with disability and their teachers can choose the equipment that best suits their individual needs.

Consumer Involvement

The Healthy Trajectories team views consumer involvement as empowering and that consumers have an important role.

Consumer involvement is when children, adolescents and young adults with a disability and their families, partner with researchers in all aspects of research. We believe that our research is better with consumer involvement and our findings better meet the needs of people with a lived experience of disability and their families.

Consumers can be involved by participating in advisory groups, providing expert opinion on important issues, being collaborators and/or co-investigators of research.

We aim to:

 Involve consumers from the beginning to decide what to research; how to carry out the research; how to interpret

- the findings and how to translate the research to ensure that the outcomes reach the people that need to know.
- Find creative, engaging, and effective ways of involving children, adolescents, young adults, and families, with a diverse range of disabilities. From both city and rural areas; whether they can access services easily or not. Whether they need support to communicate or assistance to communicate themselves. Whatever their background or ability to speak English or not.
- We need all these voices! People with lived experience are the best people to inform and answer research questions.

Consumer Engagement enquiries. Email: <u>healthy-trajectories@unimelb.edu.au</u>



Welcome to our Healthy Trajectories Young People's Consumer Council

We are delighted to have welcomed sixteen team members on to our Young People's Consumer Council as research advisors. Thank you all for your contribution to date and we look forward to continuing work together in 2023!

Coming soon!

A Families Consumer Council

- Are you a parent, grandparent, guardian, or carer who has valuable knowledge and experience to share within disability research?
- Are you interested in partnering with us and influencing the field of disability research?
- Do you enjoy working in a supportive team?
- Are you willing to contribute 2 to 4 paid hours per month?

Expressions of interest coming out in January 2023!

Family Engagement in Research Training from Canada to Australia



The Healthy Trajectories team have recently completed a 10-week Family Engagement in Research (FER) course developed and delivered in partnership with parents and researchers. The FER course was delivered by CanChild Centre for Childhood Disability Research and Kids Brain Health Network in partnership with McMaster Continuing Education.

The course was delivered through online facilitators, and it involved study partnerships between researchers, clinicians, and people with lived experience of disability. The topics covered included:

- How to engage families throughout the research process
- · Barriers, facilitators, and ethics surrounding engagement
- Available FER resources both here and in Canada

One aim of the course was to design new tools to expand family engagement in child health research. Many wonderful resources were created, including:

- an infographic on how to engage families in paediatric research, from the start
- a <u>podcast</u> to discuss the opportunity for consumer engagement in lab-based research
- tool kits and protocols for FER partnering and budgeting including Easy-to-Read versions
- and tools to bring researchers, clinicians, and families together now and into the future.

The course certainly equipped the group with pathways, networks, and tools in readiness for further family-centred research projects. While most of the resources from our cohort are not yet online, you may wish to check out those created by previous participants by clicking on the icon below.

Click here to access FER tools

Healthy Trajectories is offering a Doctoral Scholarship!

Are you interested in research to promote well-being and quality of life for those with child-onset disability and their families? This scholarship might be for you.

This doctoral scholarship is available for those interested in research that focuses on either of the following areas of need:

- reducing co-morbidities associated with disability to improve wellbeing and quality of life
- understanding the complex and intersecting needs of those experiencing multiple disadvantages that compound the experience of disability

We hope to recruit a high-quality student into this PhD position and are open to those with varying discipline backgrounds. Experience in disability is desirable. Interested applicants should <a href="mailto:emailt

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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.