



Healthy Trajectories

A Child and Youth Disability Research Hub

Welcome to our Healthy Trajectories July Newsletter!

A message from Christine

Hello everyone!

If you are in chilly Melbourne, I hope you have your warm socks on, and good scarf! For those further afield, and perhaps in warmer climates - enjoy! This month's newsletter is full of news of our activities. In March I said we were busy, and in July you will see some of the fruits of our labours.

...again, we invite your involvement with us - below you will see several opportunities to have your say or to partner with us in our research and advocacy. Together, we can make a difference.

News to celebrate from Healthy Trajectories!

- **Designing Leaning Spaces for Diversity, Inclusion and Participation: Australian Research Council Linkage Project Grant Success**

Healthy Trajectories is thrilled to part of the team, led by Associate Professor Ben Cleveland of the University of Melbourne, that was successful in receiving grant funding for this important work.

This project aims to provide evidence-based guidance on how to design and/or modify mainstream schools to make it easier for students with disabilities to participate. We aim to inform architects, educators, and policy makers about disabled students' space requirements (what should our schools and classrooms look and be like) and to develop strategies and

tools to help us co-design schools with people with lived experience of disability. The outcomes will include an inclusive learning spaces design framework.

We look forward to keeping you updated, including where there are opportunities for you to build knowledge with us, on this important topic.

The investigators are Ben Cleveland, Christine Imms, Wes Imms, Janet Clinton, Lorraine Graham, Ruth Aston, Christina Candido, Kate Tregoan, Paul Loh, Laurence Robinson and Judy Connell. Partners include architect firms, education departments, the Association for Children with a Disability and Heads Together for ABI.

- **An opportunity to visit mainland China and talk about participation-focused practice**



This month, Christine had the opportunity to join several hundred paediatric rehabilitation colleagues at their annual

conference in Chengdu in Sichuan Province of China. The National Conference, hosted by several organisations, including the Chinese Academy of Rehabilitation Medicine Pediatric Rehabilitation Committee (CARM-PRC), provided an opportunity to share knowledge, and to meet a few giant Panda's!

Christine was captivated by the 2-day rehabilitation competition, where rehabilitation physicians and teams of therapists demonstrated their skills in working with children with cerebral palsy or autism - in front of an audience and a set of judges. Impressive to see that around 600 individuals took part. The teams of therapists - a physiotherapist, occupational therapist and speech pathologist - worked together to plan and provide a 20 minute combined therapy session for a child they had just met. They had to choose their approach, select toys and other objects from those available on the stage, engage and work directly with the child, and then tell the judges and audience why they did what they did.

The conference followed on the next 2 days, and Christine spoke about the importance of doing therapy in natural contexts - in children's homes, schools and the community. This provided opportunity to talk about what a typical day looks like for children in Chengdu, and how rehabilitation is organised. She gained a lot of food for thought!

Website now live!



A Child and Youth Disability Research Hub

A healthy trajectory means taking your best path in life! Our aim is to make it possible for children and youth whose lives are complicated by disability to reach their full potential for health and participation across the life span. Healthy Trajectories for all!

 Healthy Trajectories /

- **2023 Seed Funding Opportunity – Coming Soon!**

The Healthy Trajectories research hub is focused on building consumer-partnered/led, interdisciplinary and inter-sectoral research to address the needs of those with child-onset disability and their families. Our research aims to progress the vision that all children and youth, whose lives are complicated by disability, have the best chance of reaching their full potential for health and participation across the life span.

Healthy Trajectories is excited to be offering seed funding again this year with grants of up to **\$30,000 on offer**. We are particularly interested in funding projects driven by and with people with disability and their families, that are likely to have practical outcomes and a clear pathway to sustainable funding.

Further details will be on our website mid-July.

Shortlisted for Awards in the Judges Showcase at the Sports Medicine Australia Conference

Congratulations to Nicole Merrick - a new researcher in our team, who has had two of her papers accepted for presentation, and nominated for awards in the up-coming Sports Medicine Australia conference.

Paper 1: You pretty much know straight away: Lessons learned from player experiences of rugby-related spinal cord injuries in Australian rugby union.

For this study we interviewed people who had sustained spinal cord injuries (SCI) playing rugby. We wanted to learn more about the experience of injury and what happens on-field when one of these injuries occurs.

What we found:

- Most clubs, coaches and referees teach players how to play safely and also give regular reminders to players
- The people who are at the ground when there is an injury don't always know what to do but they provide supportive care until an ambulance arrives
- People experience a range of feelings and symptoms after injury which can help those around know when a player might have had a spinal injury

Why is this important?

- It is important that the injured player reaches a spinal hospital as soon as possible after injury
- The findings from this research can help people at the ground to know when a spinal injury might have occurred and get the right medical attention quickly

Paper 2: You never stop adjusting: understanding player experiences of rugby-related spinal cord injury in Australia and opportunities to improve support.

This study aimed to understand more about quality of life and participation for people who sustained a spinal cord injury (SCI) playing rugby. We also wanted to see if there were gaps in support for these injured players and identify ways those gaps could be addressed. We conducted interviews with injured players to discuss a range of topics they felt were important for us to know about.

What we found:

- Taking care of your health and staying socially connected can both be harder after SCI
- When their connection to sport changes it can affect how people feel about themselves
- Having opportunities to work and study are important after SCI
- Learning from other people with SCI can help with adjusting to life after injury
- The rugby community provide a lot of social support and connection, as well as fundraising

Why is this important?

- Understanding the things that are important for people with SCI can help us provide better support
 - Organisations (such as Rugby clubs, fundraising and wheelchair sport organisations) can work together to provide specific support for rugby players who sustain a SCI
-

Roundtable updates - Family Wellbeing

Thank you to the 40+ people who attended the Family Wellbeing Roundtable. At this Roundtable, we drew on the diverse expertise and perspectives of attendees about how to build knowledge and capacity to enhance family wellbeing for families raising children and youth with disability. Discussions explored strategies and initiatives to improve the lives of children and youth with disabilities and their families.

As part of our summary of discussions we asked for One Main Point in response to our questions. This is what we heard:

1. What is needed to address what families tell us they need? Families need **quality coordinated services** and clinicians who are willing to hear and learn, and who **consider people in the context of their family and community**.

2. What do we already know that is ready to be widely communicated and/or implemented?

- Connecting with **peer support**
- Adoption of a **hopeful stance**
- **Family centred** services and systems
- Support through **transitions**
- Provision of **culturally safe** care
- Valuing and drawing on **lived experience**.

3. What don't we know that needs research now - to impact family, services, community, and policy? We don't know how to shift systems and policies so that the NDIS and healthcare for people with a disability puts the family in the centre instead of being client/patient-centred; it is equitable for minority groups such as families whose children need complex medical care, families with a social disadvantage, and families with culturally and linguistically diverse backgrounds; and takes a life-course approach.

4. What and who will be needed to build our research connections to ensure impact on family wellbeing? A **communication strategy** and agency to ensure **plain language** summaries of all research are **disseminated to diverse groups**, associations and families so they may understand more thoroughly the research that is being conducted.

We have sent a summary to participants, and are planning our next steps, but if you'd like to know more, please email us.



- **Next Roundtable - Coming soon!**

We are pleased to announce that our second Healthy Trajectories Round Table will be held on Wednesday November 22nd, 2023. This will be a hybrid meeting.

The round table will focus on our theme **“Optimising Health in Disability”**. Research in this theme focuses on minimising the impact that multiple health issues have on the everyday lives of children and their families. Current studies include:

1. How chronic pain impacts children with cerebral palsy,
2. Use of long-term rigid-wrist hand orthoses to managing and prevent muscle contractures, and
3. Improving delivery and access to health care for those with medically complex cerebral palsy.

Our goal is to broaden and strengthen the research within this theme and we look forward to working with others to achieve this.

Watch this space for more details coming soon!

Consumer Involvement

We Invite You



Dear Family Member,

We would like to invite fathers, mothers, and grandparents of children and young adults with a disability to join us to make a difference.

About Healthy Trajectories

We are the Healthy Trajectories Child and Youth Disability Research Hub - which is a team of researchers who work with child-onset disability.

Our aim is to improve supports for children and families in their early years, make schools and education more inclusive, and improve healthcare and mental health for people with disabilities.

Information Session

We are hosting a 1-hour Zoom information session to learn about our research and the Families Council.

Families Council

We are looking for you to be part of our Families Council and advise on our research.

You will undertake 2 to 4 paid hours per month in research meetings over Zoom.

How We Will Support You

We will support you to be involved in a way that works for you. You will be paid for your time.

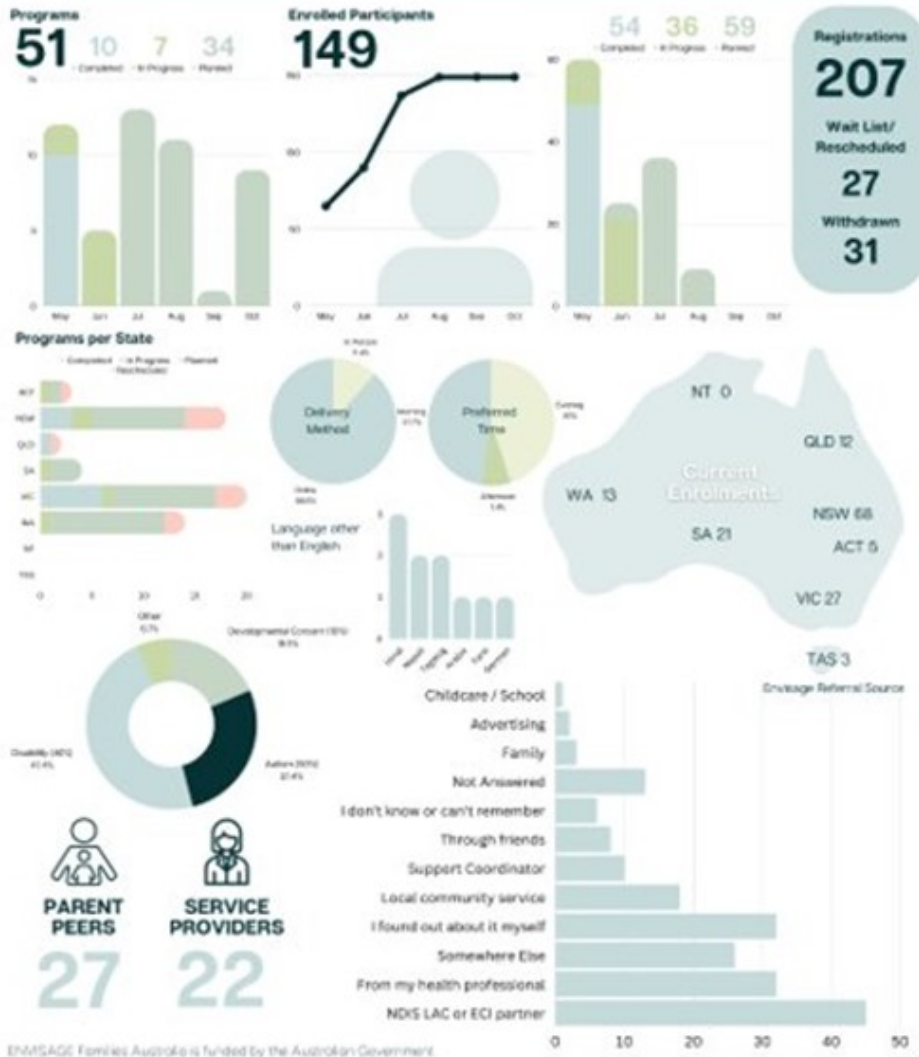
If interested, you can contact Sevastine, our Consumer Engagement Officer,
at healthy-trajectories@unimelb.edu.au.



Register for Information Session



- **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 27 service provider facilitators and 22 parent peer facilitators and 149 caregivers have enrolled to participate in the program. 10 programs have been completed and 34 programs are scheduled to be delivered in the next 3 months. Evaluation is underway to capture the experiences and impact of the program for caregivers.



ENVISAGE Families Australia is funded by the Australian Government Department of Social Services. Go to dss.gov.au for more information.

Envisage ~ F
Free Peer Support Program for Parents

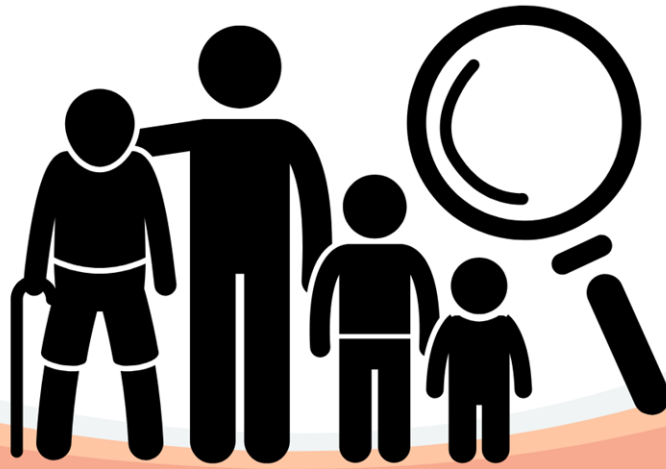


For caregivers raising children 0 – 8 years with developmental concerns or disability, including autism (or autism like characteristics).

Small group workshops with other caregivers, facilitated by a Health Professional and Parent Peer, are included in this program. The 5 workshops are 1 hour each over 5 weeks, with an additional 1 hour per week to access online learning materials for preparation.

Learn more or register online using the QR code or heading to <https://envisage.community>
For further help you can contact envisage@acu.edu.au or call 07 3861 6079 for assistance.

Exploring Family-centered Approaches to Practice



**Are you a health
professional working with
children aged 0-12 years
and their families?**

**WE WOULD LIKE TO
HEAR FROM YOU!**

**We are recruiting service providers (SPs) who work
with children with neurodisabilities and their
families to take part in a research project about
how these service providers understand, think
about and implement family-centred
approaches to practice.**

HOW TO GET INVOLVED

For further information, and to participate in the stage 1 survey please scan the QR code, or use link:

<https://redcap.link/j06fn9r4>.



For further information contact:
Kerry Britt (PhD Candidate)
kerry.britt@mcri.edu.au

[Get Involved Here](#)

CP-Achieve and AusACPDM Symposium

2023 LINKING HEALTH, WELLBEING & PARTICIPATION

CP-ACHIEVE AND AUSACPDM
CEREBRAL PALSY SYMPOSIUM

[REGISTER NOW](#)

www.trybooking.com/CHXKZ

cp-achieve@mcri.edu.au

cp-achieve.org.au ausacpdm.org.au



Join us for a two day in-person event focusing on maximising health, participation and social opportunities for adolescents and young adults living with cerebral palsy. It will include experts, guest speakers, panels, and opportunities for symposium attendees to engage, contribute and network

3-4 AUGUST
MELBOURNE, AUSTRALIA
8:30AM-5:00PM



#CP-ACHIEVE23



@CPACHIEVE

[CP-Achieve](#) and the [Australasian Academy of Cerebral Palsy and Developmental Medicine](#) (AusACPDm) invite you to the 2023 Cerebral Palsy Symposium which will be held in Melbourne on Thursday 3 and Friday 4 August.

The 2023 CP-Achieve and AusACPDm Symposium focus of Linking Health, Wellbeing and Participation will bring together the CP-Achieve team, collaborators, invited researchers, thought leaders, people with lived experience and other advocates to explore and share new knowledge about maximising health, participation and social opportunities for adolescents and young adults living with cerebral palsy (CP).

The symposium will explore two themes: 'mental and physical health of adolescents and young adults with cerebral palsy' and 'building supportive family, community, and service environments'.

- **Want more information?**

Visit [CP-Achieve](#) for more information including registration types and rates.

See more of the sneak peak [Symposium program](#).

Read about the [keynote speakers](#).

Have questions? Get in touch today! cp-achieve@mcri.edu.au

[Register Here](#)

AAC-Users Recruitment Pool

- **CP-Achieve is seeking expressions of interest from AAC-users**

If you are interested in our research – whether as an advisor or co-researcher, or as a research participant, or if you just want to hear about what we are up to – please let us know. You can fill out an online form with your details and we will keep you updated about opportunities for AAC-users. We welcome people who use any type of AAC! For example: you might use

pictures or words, communication books or devices, and type, point, or say yes and no. The link to the online form is here: <https://tinyurl.com/AACusergroup>. If you would rather go through this form with someone, you can e-mail Megan at mcwalsh@deakin.edu.au or text her on 0497 839 661.



Are you an AAC-user?
Are you aged 10-25 years old?
Are you interested in research?

Fill out this online form to express your interest in CP-Achieve projects.

Click this link:

<https://tinyurl.com/AACusergroup>

Or scan this QR code:



If you would rather go through this form with someone, you can e-mail Megan at mcwalsh@deakin.edu.au or text her on 0497 839 661.

Express your Interest Here

Follow Healthy Trajectories on social media! Click on the icons below:



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.

