



ANNUAL REPORT

CP-ACHIEVE



2022/
2023



CP-ACHIEVE
Centre of Research Excellence



TABLE OF CONTENTS

Message from Dinah Reddihough	02
Steering Committee	03
Advisory groups	04
CP-Achieve team	05
Themes and programs	06
CP-Achieve theme highlights	07
Postdoctoral Research Fellow & PhD highlights	12
Project progress	18
Research outputs	24
Thank you & funding	29
Partners	30



A MESSAGE FROM DINAH REDDIHOUGH

It gives me great pleasure to share with you the annual CP-Achieve report. Our vision is an Australia where people with cerebral palsy receive the best health care throughout their lives, not just in childhood, and can live in and contribute to supportive communities that enable their participation.

In this report, you will read about the many projects that are being undertaken by CP-Achieve's committed team in partnership with our consumers and their families. This rich partnership is ensuring that all the studies that we undertake are relevant and that the results will be of use in achieving better outcomes for young adults with cerebral palsy.

Our team continue to travel both nationally and internationally to deliver their findings at various key conferences and have received several awards for their presentations.

As we enter the final year of CP-Achieve, we are aware that so much more needs to be done. Fortunately, during the past four years, doctoral and postdoctoral students have been trained to continue the work alongside their senior colleagues. Together we will strive to progress the work that has been started to improve the lives of all people with cerebral palsy.

Thank you again to all our consumers, their families, students, postdoctoral researchers, research associates, investigators and staff, for your amazing contribution.

I hope that you will enjoy reading this report.

Dinah S. Reddihough

STEERING COMMITTEE

Our Steering Committee is made up of the theme and program leads, members of the operational team and a chairperson.



Dinah Reddihough
Principal Investigator
(Chair)



Christine Imms
Participation Theme
Leader



David Coghill
Program 1 Leader



Prue Morgan
Program 2 Leader



Nora Shields
Workforce Theme
Leader



Margaret Wallen
Consumer Involvement
Theme Leader



Rob Carter
Economics Theme
Leader



Carolyn Pinto
Consumer Coordinator



Debora Markelis
Research Coordinator
(Executive Support)

ADVISORY GROUPS

Our advisory groups provide input and direction to our program of work and contribute to project consumer involvement.

Stakeholder Advisory Group

Our Stakeholder Advisory Group includes key personnel from major non-government organisations involved in the care of people with disability.

This group aims to improve the applicability and quality of research, knowledge translation for end-users and outcomes for young people with cerebral palsy and their families.



Consumer Advisory Groups

Our Consumer Advisory Groups provide input into our research projects by sharing their advice and expertise.

We have four Consumer Advisory Groups.

CP Unite: Young adult advisory group with 10 advisors

CP Voice: Adolescent advisory group with 7 members

Parent and Carer Advisory Group: Parents and carers group with 10 members

One Group Our Voice: People with cerebral palsy who use alternative and augmentative communication (AAC) group with 4 members



CP-ACHIEVE TEAM

PRINCIPAL INVESTIGATOR



DINAH REDDIHOUGH

PROGRAM 1



DAVID COGHILL
Program 1 Leader, CI

Kerr Graham, CI
Susan Sawyer, CI
Evelyn Culnane, AI
Gabrielle Drake, AI
Leanne Johnston, AI
Jane Tracy, AI
Lyndal Hickey, AI
Sarah Giles, Postdoctoral
Research Fellow
Carlee Holmes, Postdoctoral
Research Fellow

PROGRAM 2



PRUE MORGAN
Program 2 Leader, CI

Ingrid Honan, CI
Bruce Bonyhady, AI
Mats Granlund, AI
Jan Willem Gorter, AI
Peter Rosenbaum, AI
Stacey Cleary, Postdoctoral
Research Fellow
Gaela Kilgour, Postdoctoral
Research Fellow
Iain Dutia, Honorary Postdoctoral
Research Fellow

THEMES



NORA SHIELDS
Specialist Workforce
Theme Leader, CI



MARGARET WALLEN
Consumer Involvement
Theme Leader, CI



CHRISTINE IMMS
Participation
Theme Leader, CI



ROB CARTER
Health Economics
Theme Leader, CI

OPERATIONAL TEAM



CAROLYN PINTO
Consumer Involvement
Coordinator Families



SEVASTINE KATSAKIS
Consumer Involvement
Coordinator Young People



DEBORA MARKELIS
Research Coordinator

RESEARCH ASSOCIATES

Abby Thevarajah*, Adam Scheinberg, Adrienne Harvey, Barry Rawicki, Dana Anaby, Darryl Sellwood, Elise Woodman, Gina Hinwood, Helen Bourke-Taylor, Ian Wong, James Czencz*, Jessica Kramer, Jocelyn Cohen, John Carey*, Kate Anderson, Kathleen Ooi, Loren Apokourastos*, Loretta Sheppard, Michelle McInerney, Petra Karlsson, Rachel Toovey, Sue Reid, Utsana Tonmakuyakul*, Ximena Camacho

**Also a CP-Achieve and associated higher degree research student*

CP-ACHIEVE HIGHER DEGREE RESEARCH STUDENTS

Georgia McKenzie, Jacinta Pennacchia, Jacqueline Ding, Megan Walsh, Nadine Smith

ASSOCIATED HIGHER DEGREE RESEARCH STUDENTS

Jacinta Quartermaine, Katie Headrick, Rowan Johnson, Kerry Britt, Magnus Ivarsson

Themes

Promotion of Participation

Health Economics

Developing a Specialist Workforce

Consumer Involvement

Program 1

Aim: Improving the physical and mental health of adolescents and young adults with cerebral palsy

Projects:

- Estimate prevalence of physical and mental health problems
- Victorian-based birth cohort of adults with cerebral palsy follow up
- Understand health service use and outcomes
- Determine impact on participation in education, employment and community
- Evaluate the outcomes of transition services for young people with cerebral palsy
- Evaluate impact of screening on the identification of mental health problems

Program 2

Aim: Building supportive family, community and health service environments which help young people take part in life situations which are important to them

Projects:

- Expand available exercise evidence to those with complex disability
- Adapt an evidence-based lifestyle program to the Australian context
- Understand the needs and perspectives of people with cerebral palsy and their families
- Create pathways from rehabilitation to recreation
- Translate available participation- focused intervention evidence to the Australian context



CP-ACHIEVE THEME HIGHLIGHTS

CP-Achieve continues to include the themes of promoting participation, economic evaluation, developing a specialist workforce, and consumer involvement in all research projects

Promotion of Participation

The Participation theme team provides information and guidance to researchers across CP-Achieve on how to study and assess participation with the aim of building fitness, providing recreation, promoting meaningful social and community connections, increasing workforce participation and supporting self-management of health needs wherever possible.



Key achievements

- The main goal in 2023 was to report on our collaborations together as a team. We were particularly interested to reflect on how we were working together in partnership – including researchers, young people with cerebral palsy and parent- partners. We undertook a structured process of reflection, thematically summarised our reflections and co-wrote a paper.
- The second goal was to review the findings of the Participation Survey which will now carry over into 2024.

Health Economics

The Health Economics theme aims to support the CP-Achieve research team determine outcomes in relation to cost. The team applies economic principles to the evaluation of health research and health services and assists in identifying the most efficient solutions to research problems.



Key achievements

- Assistance and advice provided on an ongoing basis through the CP-Achieve Steering Committee, research programs and project meetings, and various grant applications.
- Ongoing involvement with the data linkages project.
- Continued involvement in the 'Improving Physical and Mental Health' and the 'Building Supportive Environment' program streams of CP-Achieve

Developing a Specialist Workforce

The Developing a Specialist Workforce theme aims to grow a multidisciplinary clinical and research workforce that is knowledgeable and expert in adolescent and young adult cerebral palsy.

Key achievements

- Continued to support the training of our five doctoral students and four postdoctoral research fellows.
- Monthly webinar series showcasing the Fellows, Chief Investigators, Associate Investigators and Research Associates.
- Eight travel scholarships awarded to CP-Achieve Postdoctoral Research Fellows and CP-Achieve associated PhD students to present their evidence-based work at international or national conferences and disseminate their research findings, foster partnerships and participate in professional development opportunities.



Consumer Involvement

Consumer involvement continues to be a critical enabler for CP-Achieve. In 2022-23, the CP-Achieve advisory groups met with CP-Achieve researchers and investigators throughout the year to provide their crucial lived experience insights and perspectives, ensuring that our research is meaningful and relevant to both young people with cerebral palsy and their families.

Key achievements

- One Group Our Voice (advisory group of people with cerebral palsy who use alternative and augmentative communication) formed.
- Strategy to increase diversity of experience amongst consumers involved with CP-Achieve developed and disseminated.
- Contributed to a CP-Achieve response to the redevelopment of the cerebral palsy definition at the European Academy of Childhood Disability (EACD) 35th annual meeting held in Slovenia.
- Student research exploring perspectives of CP Unite and mentors about the mentor program completed and disseminated.
- Evaluation of consumer involvement in CP-Achieve commenced.
- State Trustees funding awarded to a project aiming to increase the involvement of people with cerebral palsy and complex communication needs within CP-Achieve and more broadly.



Parent Advisory Group

The Parent Advisory Group comprises parents of young people with a range of cerebral palsy types and severities.

Key Achievements

- Input to design and implementation of a physical and mental health survey.
- Contribution to MCRI's submission to the NDIS review.
- Identified appropriate terminology and recruit barriers, and provided advice on how researchers can support people with complex consumer needs to participate in an advisory group.



One Group Our Voice

One Group Our Voice is a CP-Achieve Advisory Group of people with cerebral palsy who use augmentative and alternative communication (AAC).

Key Achievements

- Developed a toolkit for researchers to support them in working with AAC users.
- Submitted a journal article on the importance of AAC user inclusion.
- Supported researchers and students to work with people who use AAC.



CP Voice

CP-Voice is CP-Achieve's adolescent advisory group comprising young people with cerebral palsy aged 10-18 years.

Key Achievements

- Informed the design and implementation of a physical and mental health survey.
- Involved in the co-design of a series of lifestyle modules in key life areas ('CP-Pathfinding').



CP Unite

CP- Unite is CP-Achieve's young person's advisory group representing young people with cerebral palsy aged 18-30 years.

Key Achievements

- Named Associate Investigators on the development of participation focused learning modules for young adults with cerebral palsy.
- Informed the design and implementation of physical and mental health survey.
- Provided advice on protocols and recruitment of consumers for One Group Our Voice.
- Involved in the 2023 CP-Achieve and AusACPDM Symposium planning.



Research Partners

In addition to Advisory Group meetings, many CP-Achieve consumers also participate as consumer partners in individual research projects.

Key Achievements

- Contributed to the feasibility of the FitSkills program for young adults with cerebral palsy who use wheeled mobility to access the community.
- Involved in a project investigating screening approaches for mental health conditions in young people with cerebral palsy.
- Involved in the development of a systematic review evaluating the effect of exercise on quality of life and participation for adolescents and adults with cerebral palsy.
- Contributed to a qualitative study, exploring the wants and needs of adults with complex cerebral palsy for community based physical activity.
- Identified and prioritised strategies to optimise community gym participation for young adults with cerebral palsy: an e-Delphi study.
- Involved in a scoping review of the experience of participation in daily life for young people with cerebral palsy.



POSTDOCTORAL RESEARCH FELLOW & PHD HIGHLIGHTS

CP-Achieve supports Postdoctoral Research Fellows and PhDs as part of the Developing a Specialist Workforce Theme.

Postdoctoral Research Fellows



Sarah Giles

Dr Sarah Giles is a Postdoctoral Research Fellow at CP-Achieve with a clinical and research

background in mental health. Sarah's role as the Postdoctoral Research Fellow lead for Program 1, is to oversee the projects which aim to improve the mental health of young people with cerebral palsy.

Key Achievements

- Recruited over 300 participants into the Understanding Survey and the Participation Survey.
- Developed a mental health screening project grant proposal in partnership with three parents from the Parent Advisory Group.
- Developed a systematic review examining the prevalence of mental health issues in young people with cerebral palsy.



Carlee Holmes

Dr Carlee Holmes is the senior physiotherapist at the Young Adult Complex Disability Service, St Vincent's Hospital Melbourne and a CP-Achieve Postdoctoral

Research Fellow. Carlee's role as a Postdoctoral Research Fellow in Program 1 is to develop the physical health survey with a focus on pain, fatigue and sleep and to further the understanding of the experiences of healthcare for adolescents and young adults.

Key Achievements

- Continued work on developing home-based motorised movement therapy for non-ambulant adults with cerebral palsy.
- Collaborated on the Physical and Mental Health survey.
- Contributed to a systematic review to evaluate the effects of participation in community-based, structured, physical activity interventions for young people with disabilities.
- Co-designed a series of lifestyle modules ('CP-Pathfinding') to enhance the knowledge and develop the skills of young adults with cerebral palsy in key life areas.



Stacey Cleary

Dr Stacey Cleary is a research physiotherapist and a Postdoctoral Research Fellow at CP-Achieve. Stacey's role

is the postdoctoral researcher in Program 2 where the focus is on building supportive environments.

Key Achievements

- Research dissemination via presentations at the EACD 35th annual meeting and a research tour in Northern Ireland, England, and the Netherlands.
- Contributed to a scoping review of community-based exercise for people with complex disability.
- Commenced a lifestyle program scoping review, to synthesise components and implementation methods of internationally delivered lifestyle programs for people with cerebral palsy.
- Undertook a mixed methods scoping review aiming to identify and synthesise the literature describing or measuring participation experiences of adolescents and young adults with cerebral palsy, across key life situations.
- Mentored eight students in the CP-Achieve Higher Degree Research program, including supervision of a PhD student and supporting weekly writing sessions.



Gaela Kilgour

Dr Gaela Kilgour is a physiotherapist from New Zealand and a Postdoctoral Research Fellow focusing on

Participation at CP-Achieve.

Key Achievements

- Completion of three PhD related articles.

- Contributed to the development of a paper promoting the Participation theme team's collaborative approach to research in collaboration with two lived experience co-researchers.
- Member of the CP-Achieve and AusACPDM Cerebral Palsy Symposium 2023: Linking Health, Wellbeing and Participation planning committee.
- Involved in the management of the CP-Achieve surveys.

PhD Candidates

Jacqueline Ding, Monash University

Supervisors: Professor Prue Morgan, Dr Stacey Cleary.

Project name: Exploring young adulthood: Experiences and perceptions of participation for those with cerebral palsy.

Key Achievements

- Manuscript for study 1 completed and submitted to Developmental Medicine and Child Neurology.
- Two studies presented at the EACD 35th annual meeting. Won an Early Career Researcher Award [3rd place].
- Systematic review completed for study 2 and submitted to Disability and Rehabilitation.
- Protocol developed and ethics submitted for study 3.

Georgia McKenzie, La Trobe University

Supervisors: Professor Nora Shields

Project name: Facilitating community based physical activity in the gym for young adults with cerebral palsy.

Key Achievements

- Paper published for part of e-Delphi study: identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy.
- Draft manuscript developed for a qualitative study on industry perspectives on the implementation of social support for young adults with disability in community gyms.
- Organised CP-Achieve PhD writing retreat to facilitate writing progress.
- Research presented at the EACD 35th annual meeting.



- Preliminary results obtained for mixed methods study on current practice and future needs of the workforce involved in identifying mental health concerns in young people with CCN.
- Early design underway of the experiences of, and language used by, AAC-users when communicating about mental health.
- Research presented at the CHILD Autumn Conference.

Jacinta Pennacchia, University of Melbourne

Supervisors: Professor Christine Imms, Professor Dave Coghill, Professor Mats Granlund

Project name: Assessing the mental health of young people with complex communication needs.

Key Achievements

- Preliminary results obtained for the systematic review of instruments measuring wellbeing in people with complex communication needs (CCN).

Nadine Smith, MCRI

Supervisors: Associate Professor Adrienne Harvey, Professor Christine Imms, Dr Noula Gibson

Project name: Pain measurement for all young people with cerebral palsy: A best practice biopsychosocial model.

Key Achievements

- Established and completed a clinically feasible chronic pain assessment framework for young people with cerebral palsy.

- Consumer and clinician workshops held as part of the chronic pain assessment framework study.
- e-Delphi survey underway to reach consensus on the most feasible tools to include in a cerebral palsy specific framework for chronic pain assessment.

Megan Walsh, Deakin University

Supervisors: Dr Kate Anderson, Professor Susan Sawyer, Dr Jo Watson, Dr Amie O’Shea

Project name: Conversations about sexuality: Experiences of adolescents with cerebral palsy and complex communication needs (CCN) and their guardians.

Key Achievements

- Systematic review manuscript drafted in collaboration with consumer co-authors.
- Parent arm of study interviews completed.
- Recruitment underway for Adolescent arm of study.



Affiliated CP-Achieve Higher Degree Research Students

John Carey (PhD), University of Melbourne

Supervisors: Dr Rachel Toovey, Dr Alicia Spittle, Professor Christine Imms, Professor Nora Shields.

Project Name: CycLink: Linking young people with disability to community participation in cycling.

Abby Thevarajah (PhD), Australian Catholic University

Supervisors: Professor Elspeth Froude, Dr Margaret Wallen, Professor Christine Imms, Professor Chris Lonsdale.

Project Name: An investigation and evaluation of an adapted bike program for children 4 to 18 years with disabilities.

Loren Apokourastos (Masters), University of Sydney

Supervisors: Associate Professor Kimberley Docking, Dr Hans Bogaardt.

Project Name: Dysphagia in young adults with cerebral palsy.

Utsana Tonmakuyakul (PhD), Deakin University

Supervisors: Professor Suzanne Robinson, Emeritus Professor Rob Carter, Professor Cathy Mihalopoulos, Professor Dinah Reddiough, Associate Professor Gang Chen.

Project Name: Preference-based quality of life measurement in children with cerebral palsy.

Jacinta Quartermaine (PhD), University of Queensland

Supervisors: Associate Professor Leanne Johnston, Dr Tanya Rose, Dr Megan Auld.

Project Name: Participation experiences of young people with cerebral palsy.

James Czencz (PhD), Australian Catholic University

Supervisors: Professor Peter Wilson, Professor Christine Imms, Professor Nora Shields, Dr Margaret Wallen.

Project Name: Evaluating exercise interventions to improve activity, participation and quality of life for those living with complex forms of cerebral palsy.

Magnus Ivarsson (PhD), Linköping University

Supervisors: Professor Henrik Danielsson, Professor Christine Imms, Associate Professor Lena Almqvist, Assistant Professor Lina Homman.

Project Name: Are we measuring mental health problems in young people with developmental disabilities the wrong way?

Katie Headrick (PhD), Australian Catholic University

Supervisors: Dr Margaret Wallen, Dr Elise Woodman, Professor Christine Imms.

Project Name: Consumer involvement in CP-Achieve research: A mixed methods approach to evaluating multiple perspectives.

Kerry Britt (PhD), University of Melbourne

Supervisors: Professor Christine Imms, Dr Sarah Knight, Ms Bridget O'Connor, Ms Rose Babic.

Project Name: ENVISAGE-SP: Creating opportunities to change how service providers think, talk about and approach childhood disability.

Rowan Johnson (PhD), Curtin University

Supervisors: Dr Sian Williams, Prof Daniel Gucciardi, Dr Noula Gibson, Dr Becky White

Project Name: Mobile health technology for home and school therapy program prescription.

Emily Moore (PhD), University of South Australia

Supervisors: Associate Professor Adrienne Harvey, Dr Carolyn Berryman, Professor Lorimer Moseley, Dr Abi Thirumanickam.

Project Name: Giving children with cerebral palsy and complex communication needs (CCN) agency to self-report their pain .





PROJECT PROGRESS

CP-Achieve projects have continued to progress and deliver outcomes.

PROGRAM 1

PHYSICAL AND MENTAL HEALTH

Prevalence of health problems & issues

- Two surveys continue to recruit to understand young people with cerebral palsy and their physical & mental health.
- Initial work commenced on vibration plates to improve bone health.
- Pain measurement for young people with cerebral palsy underway by a PhD student.
- Dysphagia in cerebral palsy project completed by a master's student.
- PhD student researching conversations about sexuality for adolescents with cerebral palsy and CCN.
- Medical care of adults living with cerebral palsy clinical guidelines underway.



Understanding health service use & outcomes

- Major data linkage study underway to determine use of a range of health services.
- Project with National Prescribing Service MedicineWise to determine General Practitioner involvement with people with cerebral palsy continuing.
- Funding secured and project commenced to analyse the NDIA unit record data of participants with cerebral palsy.
- Scoping review underway to explore the profile of general practice access and interventions among adults with cerebral palsy.

Impact on participation in education, employment & community

- Survey continues to recruit to identify participation in key life situations



PROGRAM 1

PHYSICAL AND MENTAL HEALTH



Evaluate the outcomes of transition services for young people with cerebral palsy

- Transition to independent living project underway.
- Transition and services for adults including care pathways ongoing.

Evaluate impact of screening on the identification of mental health problems

- PhD student assessing mental health of people with CCN.
- Systematic review underway to understand the prevalence and nature of mental health conditions in young people with cerebral palsy.
- Development of a mental health screening tool for health professionals commenced.
- PhD student looking at measuring mental health problems in young people with developmental disabilities.
- A randomised control trial of mindfulness for adults with anxiety is ongoing.
- Emotional regulation and mood in adults with cerebral palsy project completed.
- Systematic review of longitudinal trajectories of mental health problems in children with disability completed.



PROGRAM 2

BUILDING SUPPORTIVE ENVIRONMENTS



Exercise in complex disability

- PhD student looking at cycling resources and programs in disability. Current practices online survey published, and data collected for the evaluation of an online training program and the co-design of a community cycling program.
- PhD student published systematic review on the impact of adapted bicycle riding. Data collected and analysed for stakeholder perspectives of the Freedom Wheels program.
- PhD student published systematic review on effect of exercise on quality of life and participation. Obtained early findings for study exploring the wants and needs for community based physical activity for complex cerebral palsy.
- Barriers and facilitators for participation in physical activity project completed.
- Pilot work on using the Motomed for severe disability underway.

Adapting an evidence-based lifestyle program to Australian context

- PhD student developed and piloted educational lifestyle module on maximising participation. Health literacy systematic review submitted for publication.
- Scoping review looking at the components and implementation methods of lifestyle programs for young people with cerebral palsy in progress.
- Lifestyle web-based educational module program underway and expanded series of modules ('CP-Pathfinding') developed.



PROGRAM 2

BUILDING SUPPORTIVE ENVIRONMENTS



Creating pathways from rehabilitation to recreation

- PhD student published Delphi study to determine and prioritise strategies to improve participation in community based physical activity. Manuscript on social support implementation in community gyms completed.
- Gym Sparc project in progress.

Understanding the needs & perspectives of people with cerebral palsy & their families

- PhD student submitted manuscript on exploring experiences and perceptions of participation for adolescents and young adults with cerebral palsy.
- Honours student projects investigating publicly available NDIS data; frequency and reasons for GP access completed.
- Experience of participation in daily life scoping review manuscript drafted.



- PREP project feasibility work completed by honours students. Young Adults in Australia translation completed. Approval in progress from CanChild for publishing as part of suite of resources.
- Consumer partner travelled to the US via Churchill Fellowship to meet colleagues and consumer partners who developed Project TEAM.
- Two-stage feasibility trialled at Young Adults with Complex Disability Service (YACDS) and Omenda.
- CEval – Consumer involvement evaluation project completed by two honours students.

Translating available participation-focused intervention evidence to the Australian context

OTHER HIGHLIGHTS

GRANTS

State Trustees Community Inclusion grant

Experts in their own lives: Involving people with cerebral palsy and complex communication needs in CP-Achieve research – a human right and a means for inclusion- *Megan Walsh, PhD candidate*

Churchill Fellowship

To measure the effects of Project Team in America – learnings for Australia's implementation- *Rohan Symonds, Consumer Partner*

PUBLICATIONS & PRESENTATIONS

42 Presentations, talks & podcasts (national, international and online platforms)

19 Publications and articles published

CP-ACHIEVE REACH

10 Webinars held with over 230 attendees
1,154 Newsletter subscribers
2,719 Social media followers

AWARDS

Rotary Shine On Award for community service by people with disabilities- *Brenton Ponza, One Group Our Voice member*

Nestle Health Science Clinical Research Award 1st place, EACD- *Nora Shields, CI*

EACD Early Career Researcher Award (equal) 3rd place- *Jaqueline Ding, PhD candidate*



RESEARCH OUTPUTS

Publications & articles

- 1.** Bekteshi, S., Konings, M., Karlsson, P., Crieckinge, T. V., Dan, B., & Monbaliu, E. (2023). Teleintervention for users of augmentative and alternative communication devices: A systematic review. *Developmental medicine and child neurology*, 65(2), 171–184. <https://doi.org/10.1111/dmcn.15387>
- 2.** Bhowon, Y., Prendergast, L., Taylor, N., & Shields, N. (2023). Using Geospatial Analysis to Determine the Proximity of Community Gyms for a Population-based Cohort of Young People with Cerebral Palsy. *Physiotherapy Canada*. 10.3138/ptc-2022-0064.
- 3.** Cavens, C., Imms, C., Drake, G., Garrity, N., & Wallen, M. (2022). Perspectives of children and adolescents with cerebral palsy about involvement as research partners: a qualitative study. *Disability and rehabilitation*, 44(16), 4293–4302. <https://doi.org/10.1080/09638288.2021.1900927>
- 4.** Culnane, E., Efron, D., Williams, K., Marraffa, C., Antolovich, G., Prakash, C., & Loftus, H. (2023). Carer perspectives of a transition to adult care model for adolescents with an intellectual disability and/or autism spectrum disorder with mental health comorbidities. *Child: care, health and development*, 49(2), 281–291. <https://doi.org/10.1111/cch.13040>
- 5.** Czencz, J., Shields, N., Wallen, M., Wilson, P. H., McGuckian, T. B., & Imms, C. (2022). Does exercise affect quality of life and participation of adolescents and adults with cerebral palsy: a systematic review. *Disability and rehabilitation*, 1–17. Advance online publication. <https://doi.org/10.1080/09638288.2022.2148297>
- 6.** Dutia, I., Eres, R., Sawyer, S. M., Pennacchia, J., Johnston, L. M., Cleary, S., Reddihough, D., & Coghill, D. (2023). Fatigue experienced by people with cerebral palsy: a systematic review of assessment tools and decision tree. *Disability and rehabilitation*, 1–9. <https://doi.org/10.1080/09638288.2023.2205175>
- 7.** Eres, R., Lim, M. H., & Bates, G. (2023). Loneliness and social anxiety in young adults: The moderating and mediating roles of emotion dysregulation, depression and social isolation risk. *Psychology and psychotherapy*, 10.1111/papt.12469. Advance online publication. <https://doi.org/10.1111/papt.12469>
- 8.** Honan, I., Waight, E., Bratel, J., Given, F., Badawi, N., McIntyre, S., & Smithers-Sheedy, H. (2023). Emotion Regulation Is Associated with Anxiety, Depression and Stress in Adults with Cerebral Palsy. *Journal of Clinical Medicine*, 12(7), 2527.
- 9.** Huggins, J., Karlsson, P., & Warschausky, S. (2022). Challenges of Brain-Computer Interface Facilitated Cognitive Assessment for Children with Cerebral Palsy. *Frontiers in Human Neuroscience*. 648: 10.3389/fnhum.2022.977042.
- 10.** Karlsson, P., Honan, I., Warschausky, S., Kaufman, J.N., Henry, G., Stephenson, C., Webb, A., McEwan, A., & Badawi, N. (2022). A validation and acceptability study of cognitive testing using switch and eye-gaze control technologies for children with motor and speech impairments: A protocol paper. *Frontiers in Psychology*. 5453: DOI: 10.3389/fpsyg.2022.991000.
- 11.** Kennedy, R. A., McKenzie, G., Holmes, C., & Shields, N. (2022). Social Support Initiatives That Facilitate Exercise Participation in Community Gyms for People with Disability: A Scoping Review. *International journal of environmental research and public health*, 20(1), 699. <https://doi.org/10.3390/ijerph20010699>
- 12.** Lim, M.H., Thurston, L., Eres, R. et al. A pilot randomised controlled trial of the Peer Tree digital intervention targeting loneliness in young people: a study protocol. *Trials* 24, 77 (2023). <https://doi.org/10.1186/s13063-022-07029-7>
- 13.** McKenzie, G., Shields, N., & Willis, C. (2023). 'Finding what works for me' - a qualitative study of factors influencing community gym participation for young adults with cerebral palsy. *Disability and rehabilitation*, 45(12), 1984–1991. <https://doi.org/10.1080/09638288.2022.2083243>
- 14.** McKenzie, G., Willis, C., Yao, A., Munzel, F., Kennedy, R., & Shields, N. (2023). Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: an e-Delphi study. *Disability and rehabilitation*, 1–9. Advance online publication. <https://doi.org/10.1080/09638288.2023.2193431>
- 15.** Morgan, P., Cleary, S., Dutia, I., Bow, K., & Shields, N. (2023). Community-based physical activity interventions for adolescents and adults with complex cerebral palsy: A scoping review. *Developmental medicine and child neurology*, 65(11), 1451–1463. <https://doi.org/10.1111/dmcn.15611>
- 16.** Ralph, E., Carroll, K., Danks, M., & Harvey, A. (2022). Development of a clinical framework for the assessment of upper limb function in children with cerebral palsy and dyskinesia. *Physical and Occupational Therapy in Pediatrics*, 43(1): 1-13.
- 17.** Rutz, E., Novacheck, T. F., Dreher, T., Davids, J. R., McCarthy, J., Kay, R. M.,

Shore, B. J., Shrader, M. W., Veerkamp, M., Chambers, H., Narayanan, U., Pierz, K., Rhodes, J., Shilt, J., Theologis, T., Van Campenhout, A., & Graham, K. (2022). Distal femoral extension osteotomy and patellar tendon advancement or shortening in ambulatory children with cerebral palsy: A modified Delphi consensus study and literature review. *Journal of children's orthopaedics*, 16(6), 442–453.
<https://doi.org/10.1177/18632521221137391>

18. Smith, N. L., Smith, M. G., Gibson, N., Imms, C., Thornton, A. L., & Harvey, A. R. (2023). Pain coping tools for children and young adults with a neurodevelopmental disability: A systematic review of measurement properties. *Developmental medicine and child neurology*, 65(3), 318–328. <https://doi.org/10.1111/dmcn.15410>

19. Thevarajah, A., Wallen, M., Imms, C., Lonsdale, C., Carey, J. J., & Froude, E. H. (2023). Impact of adapted bicycle riding on outcomes for children and adolescents with disabilities: A systematic review. *Developmental medicine and child neurology*, 65(4), 456–468.
<https://doi.org/10.1111/dmcn.15446>



Presentations, talks & podcasts

- 1.** Carey, J. (2022). 5 things I wish I'd known about co-design: Reflections of a graduate researcher. *Methods and Implementation Support for Clinical and Health research Hub (MISCH)*, University of Melbourne. October.
- 2.** Carey, J. (2023). Bike-riding for all abilities. *Exercise, Sport and Participation in the NDIA context*. Australian Physiotherapy Association Online Lecture Series. February.
- 3.** Carey, J., Toovey, R., O'Keefe, F., Yates, M., & Skilbeck, H. (2023). *CycLink Co-Design Study*. Melbourne Disability Institute (MDI), University of Melbourne, Community of Practice. 26 June.
- 4.** Cleary, S. (2023). *Research Works Podcast EACD Edition, Day 2*. Cleary, S. et al. (2023). The experiences and perceptions of participation in daily life of adolescents and young adults with cerebral palsy: a scoping review. 35th European Academy of Childhood Disability (EACD) Annual Meeting, Ljubljana Slovenia, 24-27 May.
- 5.** Cleary, S., Morgan, P., et al. (2023). The experiences and perceptions of participation in daily life of adolescents and young adults with cerebral palsy: a scoping review. *International Cerebral Palsy Symposium*, Belfast, Northern Ireland. 19 May.
- 6.** Cleary, S., Willis, C., & Shields, N. (2023). The effects of community-based physical activity interventions on adolescents and young adults with

- disability: A systematic review. Rehabilitation Department, Erasmus University Medical Centre, Rotterdam, The Netherlands. May.
- 7.** Cleary, S., Willis, C., & Shields, N. (2023). The effects of community-based physical activity interventions on adolescents and young adults with disability: A systematic review [poster presentation]. 35th European Academy of Childhood Disability (EACD) Annual Meeting, Ljubljana, Slovenia. 24-27 May.
 - 8.** Czencz, J. (2023). PhD Project Plan. ACU Healthy Brain and Mind Research Centre, Research Forum.
 - 9.** Ding, J., Cleary, S., & Morgan, P. (2003). A mixed-methods systematic review of health literacy in adolescents and young adults with cerebral palsy, and the relationship to quality of life [poster presentation]. 35th European Academy of Childhood Disability (EACD) Annual Meeting, Ljubljana Slovenia, 24-27 May.
 - 10.** Ding, J., Cleary, S., & Morgan, P. (2023). Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy. 35th European Academy of Childhood Disability (EACD) Annual Meeting, Ljubljana Slovenia, 24-27th May.
 - 11.** Ding, J., Cleary, S., & Morgan, P. (2023). Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy. Rehabilitation Department Erasmus University Medical Centre, Rotterdam, The Netherlands. May.
 - 12.** Honan, I., Stephenson, C., & Karlsson, P. (2022) *Neuropsychological Assessment for Children with Cerebral Palsy and Severe Motor Impairment CogTEST-C*. APS College of Clinical Neuropsychologists Conference, Sydney, Australia. 4-5 November.
 - 13.** Karlsson, P. (2022). *Emerging Assistive Technology for Communication*. APAC

IAP, Association in Favor of People with Cerebral Palsy. First International Forum on Cerebral Palsy, Mexico City, Mexico. October.

14. Karlsson, P. (2022). Technology across the lifespan with a focus on mobility, communication and cognition. Neurology Update Seminar, Sydney, Australia. November.

15. Karlsson, P., Arthur, N., & Davies, N. (2022). Eyes on Communication Research Group and Advisory Panel: New Clinical Guidelines 2021 - Eye-gaze control technology for children and adults with cerebral palsy. 15th Biennial AGOSCI Conference, Tasmania, Australia. 3-6 September.

16. Karlsson, P., Korkalainen, J., Clarke, M., Weight, E., & Smithers-Sheedy, H. (2022). Communication disorders and use of augmentative and alternative communication with children with cerebral palsy: A cross-sectional observational study. Developmental Medicine & Child Neurology conference, Las Vegas, USA. 21-24 September.

17. Kilgour, G., Stott, S., Steele, M. Adair B., Hogan A., & Imms, C. (2023). Effects of a high-level mobility programme on sustained participation of adolescents with cerebral palsy: A single subject research design study. International Society of Adapted Physical Activity, Dunedin, NZ. June.

18. Kilgour, G., Stott, S., Steele, M. Adair B., Hogan A., & Imms, C. (2023). Experiencing the journey to sustained participation in physical activity: Navigating your own waka (Māori canoe). Kids Rehab Conference, Brisbane, Australia. March.

19. Kilgour, G., Stott, S., Steele, M. Adair B., Hogan A., & Imms, C. (2023). More than having fun: understanding the experience of involvement in physical activity. International Society of Adapted Physical

Activity, Dunedin, NZ. June.

20. Kilgour, G., Stott, S., Steele, M. Adair B., Hogan A., & Imms, C. (2023). Navigating their own Waka: The journey to sustain participation in physical activity with cerebral palsy and their parents. International Society of Adapted Physical Activity, Dunedin, NZ. June.

21. McKenzie, G. (2022). "Finding what works for me" – Supporting gym participation for young adults with cerebral palsy. CP-ACHIEVE Webinar series, online, 31 August.

22. McKenzie, G. (2022). Disability and Physical Activity. Australian Physiotherapy Association, Melbourne, Australia. 10 October.

23. McKenzie, G. (2023). Cerebral Palsy and Health Clubs. Victorian Diversity Inclusion and Leisure Forum, Aquatics and Recreation Victoria, Melbourne, Victoria. February.

24. McKenzie, G. (2023). Finding what works for me - a qualitative study of factors influencing community gym participation for young adults with cerebral palsy. Research Works, Podcast, Episode 77.

25. McKenzie, G. (2023). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. 35th European Academy of Childhood Disability Annual Meeting. Ljubljana, Slovenia. 24-27 May.

26. McKenzie, G. (2023). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. Aquatics and Recreation Victoria Diversity and Inclusion forum. Victoria, Australia. 9 February.

27. McKenzie, G., Willis, C., Kennedy, R.,

Shields, N. (2023). Industry perspectives on the implementation of social support for young adults with disability in community gyms: A qualitative study. International Cerebral Palsy Symposium, Belfast, Northern Ireland. 19 May.

28. McKenzie, G., Willis, C., Shields, N. (2022). 'Finding what works for me' - a qualitative study of factors influencing community gym participation for young adults with cerebral palsy. Women in Sport Congress, Melbourne, Victoria. 17-19 August.

29. McKenzie, G., Willis, C., Yao, A., Munzel, F., Kennedy, R., & Shields, N. (2023). Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: an e-Delphi study. 35th EACD Annual Meeting, Ljubljana, Slovenia. 24-27 May.



- 30.** McKenzie, G., Willis, C., Yao, A., Munzel, F., Kennedy, R., & Shields, N. (2023). Identifying and prioritising strategies to optimise community gym participation for young adults with cerebral palsy: an e-Delphi study. Rehabilitation Department, Erasmus University Medical Centre, Rotterdam, The Netherlands. 30 May.
- 31.** Morgan, P., Cleary, S., Dutia, I., Bow, K., & Shields, N. (2023). Community-based physical activity interventions for adolescents and adults with complex cerebral palsy: A scoping review investigating implementation and safety [poster presentation]. 35th European Academy of Childhood Disability Annual Meeting. Ljubljana, Slovenia. 24-27 May.
- 32.** Pennacchia, J. (2022). Assessing mental health in young people with complex communication needs: a PhD update. CHILD Autumn Conference, Jonkoping, Sweden. 8 September.
- 33.** Pennacchia, J. (2022). Assessing the mental health of young people with complex communication needs. AGOSCI Member webinar series, online. 8 August.
- 34.** Pennacchia, J. (2022). Assessing the mental health of young people with complex communication needs. AGOSCI webinar, virtual. 8 August. <https://www.agosci.org.au/event-4850789>
- 35.** Pennacchia, J. (2023). Assessing mental health in young people with complex communication needs: project update and consumer perspectives'. CP-ACHIEVE webinar series, virtual. 19 April.
- 36.** Shields, N. (2023). Research Works Podcast EACD Edition, Day 3.
- 37.** Shields, N. (2023). Victorian Diversity Inclusion and Leisure Forum, Aquatics and Recreation Victoria, Melbourne, Victoria. February.
- 38.** Shields, N., Bhowon, Y., Willis, C., Taylor, N., Mudiyansele, S. B., Watts, J., Imms, C., & Prendergast, L. (2023) Effect of a community-based intervention (FitSkills) for young people with disability on physical activity participation: a stepped wedge cluster randomised trial. International Cerebral Palsy Symposium, Belfast, Northern Ireland. 19 May.
- 39.** Smith, N., & Ostojic, K. (2022). Chronic pain assessment and management in cerebral palsy. Australian Physiotherapy Association Online lecture. 7 November.
- 40.** Smith, N., & Ostojic, K. (2022). Chronic pain assessment and management in cerebral palsy. Australian Physiotherapy Association Online lecture. 7 November
- 41.** Thevarajah, A. (2023). DMCN Podcasts.
- 42.** Thevarajah, A., Wallen, M., Imms, C., Lonsdale, C., Carey, J. J., & Froude, E. H. (2023). Impact of adapted bicycle riding on outcomes for children and adolescents with disabilities: A systematic review. World Physiotherapy Congress, Dubai. 2-4 June.

THANK YOU

We are grateful for the support of our research team, partnership organisations and for the professional relationships we have with our stakeholders including people with cerebral palsy, their families and carers, clinical services, universities, support groups, volunteers and so many others who provide support and advice to our program.

We deeply appreciate the input that has been provided by our Stakeholder Advisory Group and other Advisory Groups. We thank them for their time, commitment and useful suggestions, and their ongoing support of CP-Achieve.

FUNDING



This program is funded by the National Health and Medical Research Council.

PARTNERS

CP-Achieve is carried out in partnership with the following organisations:

