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CP-ACHIEVE
Centre of Research Excellence

AusACPDM
Australasian Academy of Cerebral Palsy
and Developmental Medicine

CP-ACHIEVE & AusACPDM
Cerebral Palsy Symposium

PROGRESS & POSSIBILITIES

Celebrating 5 years of research through
lived experience & planning the future

PROGRAM

3-4 APRIL
2025
MELBOURNE

About the CP-Achieve & AusACPDM Symposium

The 2025 CP-Achieve and AusACPDM Symposium aims to explore research looking at the health, well-being, and participation of adolescents and young people with cerebral palsy and discuss the future of cerebral palsy research beyond CP-Achieve.

It will bring together the CP-Achieve team, collaborators, invited researchers, people with lived experience and other advocates to share the work that has been accomplished in the past 5 years and new knowledge on the advancement of lifespan outcomes for young people with cerebral palsy.

This is the third collaborative symposium held between this partnership and the last event for CP-Achieve.

About CP-Achieve & AusACPDM

CP-Achieve is a five-year NHMRC funded centre of research excellence that is working to find ways to help adolescents and young adults with cerebral palsy live full and healthy lives. CP-Achieve does research aiming to support people with cerebral palsy aged 10 to 30 years to achieve good health, access to excellent health services, and to participate in relationships, work, leisure, physical activity and the community.

The Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) aims to provide multidisciplinary scientific education for health professionals and to promote excellence in research and best practice clinical care for children and adults with cerebral palsy and developmental conditions.

VENUE

RACV City Club, Melbourne

The 2025 CP-Achieve and AusACPDM Symposium will be held a the RACV City Club Melbourne, Australia.

Conveniently positioned in the heart of the Melbourne CBD at 501 Bourke Street, RACV Club features impressive conference and event facilities and offers a range of facilities that can be used by our symposium attendees.

Safe changing space

The venue has accessible bathrooms. In addition, the symposium will also be providing a safe changing space for people who are not accommodated by standard accessible toilets. Please advise the symposium organisers if you require the use of this space.

Getting there

Parking
The RACV City Club offers 460 car parking spaces, providing safe and convenient parking which is available to registered symposium attendees at a discounted flat rate of $45.00 per day. Please advise the symposium organisers if you require ticket validation.

Entrance for the car park is located on New Chancery Lane.

Public Transport
The RACV City Club is accessible by public transport.

- By Tram: The Queen St/Bourke St #4 (86/96) tram stop is located outside the main entrance and is an accessible tram stop catering for low-floor trams. There is also the William St/Bourke St #5 (86/96/58) Tram stop on the corner.
- By Train: The nearest train stations are Flagstaff and Flinders Street Stations and are an 8–15-minute walk.

SPONSORS

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Aidacare offers a national retail, wholesale and distribution network providing truly local support from our many locations and partnerships.

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AIMedical is the distributor for Galileo® therapy systems / medical devices. The side-alternating original made in Germany. Whole body vibration has the potential to provide symptomatic relief for patients with cerebral palsy. Whole body vibration may improve spasticity, muscle strength and coordination.

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Second Skin
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Second Skin is a world leader in the design, manufacture and service delivery of custom-made dynamic splints and orthoses for the management of children and adults with neurological conditions.

Second Skin provides services in Australia, United Kingdom, Ireland and New Zealand.

2025 CP-ACHIEVE & AusACPDM Cerebral Palsy Symposium

Progress & possibilities

PROGRAM SCHEDULE

Day 1- Health & Well-being

Thursday 3rd April

8:30-9:00am	**REGISTRATION**
9:00- 9:30am	**OPENING ADDRESS** & launch of CP-Achieve consumer translational material
9:30- 10.15am	**KEYNOTE ADDRESS** Emma Livingstone
10.15-10.45am	**MORNING TEA BREAK**
10.45-11.45am	**SESSION 1:** Why surveillance is better than salvage: The impact of the Victorian Cerebral Palsy Register on new directions in musculoskeletal management for persons with cerebral palsy
11.45am-12.45pm	**SESSION 2:** WHAT'S NEW? 2A. Epilepsy in cerebral palsy due to injury 2B. What is the "new black" in dystonia management? 2C. What's new in pain management?
12.45-1.45pm	**LUNCH**
1.45-3.15pm	**SESSION 3:** BREAKING THE BARRIERS 3A. Discussions about sexual health with adolescents with cerebral palsy: who says what, to whom, and when? 3B. Conversations about independent living: exploring experiences of young people with cerebral palsy and their families 3C. Intersectionality and young people with cerebral palsy 3D. Branching into adulthood: views of young adults with cerebral palsy
3.15-3.45pm	**AFTERNOON TEA BREAK**
3.45-4.45pm	**SESSION 4:** Empowering research and empowering voices: Five years of consumer involvement in CP-Achieve
5.30pm	Symposium Dinner Event Trinket Bar

2025 CP-ACHIEVE & AusACPDM Cerebral Palsy Symposium

Progress & possibilities

PROGRAM SCHEDULE

Day 2- Participation and future focus

Friday 4th April

8:30-9:00am	**REGISTRATION**
9:00- 10.00am	**KEYNOTE ADDRESS** Professor Christine Imms- Preventative health care in adulthood: reviewing the evidence Professor Bruce Bonyhady- NDIS Moving Forward: A whole system approach to improving outcomes for children and families
10.00-10.30am	**MORNING TEA BREAK**
10.30-11.20am	**SESSION 1:** FORGING THE WAY FORWARD 1A. Physical activity options for young adults with more complex forms of cerebral palsy 1B. Improved diagnosis of mental health problems 1C. Forging your own path as a young adult with cerebral palsy: Setting the direction, making choices and building skills
11.20am-12.30pm	**SESSION 2:** DATA – HOW USEFUL IS IT? 2A. Long term value of cerebral palsy registers 2B. The Understanding Survey– what does it tell us and how can we use the findings? 2C. What can health service data tell us about healthcare use in people with cerebral palsy? 2D. A profile of use and impacts of the NDIS on people with cerebral palsy
12.30-1.30pm	**LUNCH**
1.30-3.00pm	**SESSION 3:** PARTICIPATION – IN SO MANY WAYS 3A. The power of Para sport for people with cerebral palsy 3B. Effect of HLMP on participation in physical activity 3C. Supporting adults with cerebral palsy to participate in community gyms 3D. Physical Activity: It's a Lifelong Journey
3.00-3.30pm	**AFTERNOON TEA BREAK**
3.30-4.15pm	**SESSION 4:** THE JOURNEY FORWARD 4A. Collaborations Across Australia – the Who, What and How 4B. Demystifying transition from paediatric to adult care 4C. Young Adulthood: A case for optimism in a complicated landscape 4D. The changing role of family as children move into adulthood
4.15-4.45pm	**REFLECTIONS & CLOSE**

DAY 1 THURSDAY 3RD APRIL

Health & Well-being

8:30-9:00am

Registration

9:00-9.30am

Opening address- What has been achieved?

Professor Dinah Reddihough from CP-Achieve and Amy Hogan from AusACPDM will welcome attendees to the symposium and open the two day event with a discussion on what has been achieved in cerebral palsy research at CP-Achieve over the last five years.

During the opening address, materials will be launched that celebrate CP-Achieve's consumer involvement journey and the role played by consumers and researchers within the program. These materials celebrate CP-Achieve's successes, explore the challenges and provide guidance for researchers to continue to improve their practice, mentor and teach others, and to establish consumer involvement across a program.

Speakers

Professor Dinah Reddihough is a paediatrician and the Principal Investigator of CP-Achieve, Murdoch Children's Research Institute.

Amy Hogan is based in Auckland, New Zealand and has 20 years' experience implementing and overseeing national disability research projects as a researcher, analyst, writer, and advocate focusing on health and social justice. Amy lives with cerebral palsy and has, over the past decade, incorporated her day-to-day experience into her work at the Cerebral Palsy Society of New Zealand. Here she has developed and implemented research, policy, advocacy, system change. Amy also has a Masters (Msc First Class Honors Psychology) and significant experience as a lecturer, panellist, keynote speaker and provider of subject-matter expertise.

Dinah Reddihough

Amy Hogan

DAY 1 THURSDAY 3RD APRIL

Health & Well-being

9:30- 10.15am

KEYNOTE ADDRESS

An advocay journey

Emma Livingstone

Emma Livingstone qualified as a Speech and Language Therapist at Birmingham University in 1998 and has worked predominantly with children, running services for both pre-school and school-age children across London. More recently she has worked at City University supporting student speech and language therapists and also practices as a life coach. Emma is married and mum to three young and active children.

Emma was born with Cerebral Palsy and has seen a significant decline in her mobility in recent years leading to several surgeries and having to give up work. It was her frustration at the lack of knowledge and understanding of cerebral palsy as a disability affecting adults that spurred her on to begin campaigning. In 2018 she founded the charity Adult Cerebral Palsy Hub, now renamed Up – The Adult Cerebral Palsy Movement, to campaign for better support and services and give voice to the adult Cerebral Palsy community.

10.15-10.45am

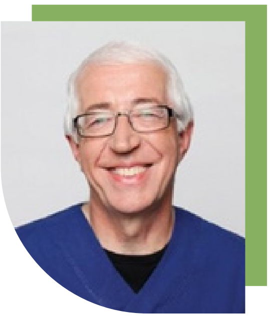
MORNING TEA BREAK

DAY 1 THURSDAY 3RD APRIL

Health & Well-being

10.45-11.45am

SESSION 1: Why surveillance is better than salvage: The impact of the Victorian Cerebral Palsy Register (VCPR) on new directions in musculoskeletal management for persons with Cerebral Palsy



Kerr Graham

This session will provide an update on the population-based prevalence of musculoskeletal pathology in the 90-92 cohort. The development of the musculoskeletal pathology classification system (MSPCS) will be discussed with respect to hip surveillance, spine surveillance and knee surveillance.

Erich Rutz

Speakers

Professor Kerr Graham is an Honorary Professorial Fellow in the Department of Paediatrics at The University of Melbourne.

Associate Professor Erich Rutz is the Bob Dickens Chair of Paediatric Orthopaedic Surgery at the University of Melbourne and consultant orthopaedic surgeon Orthopaedic Department and Director of The Hugh Williamson Gait Laboratory at the Royal Children’s Hospital, Melbourne.

11.45am-12.45pm

SESSION 2: WHAT’S NEW?

2A. Epilepsy in Cerebral Palsy Due to Injury: Past Insights and Future Directions

Epilepsy in children with cerebral palsy presents a substantial burden on individuals, society, and the healthcare system. Borrowing Darwin’s "hair splitters and lumpers" approach, I

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Health & Well-being

explore how the concept of cerebral palsy represents a "lumping" diagnostic label because they have more shared key clinical characteristics than differences. However, to gain high-quality insights into epilepsy, a "splitting" approach is needed, focusing on aetiology, neuroimaging, and electroencephalogram (EEG) findings. In my research involving children with cerebral palsy due to presumed brain injury, I found the full spectrum of epilepsy syndromes, including self-limited epilepsies. These findings are important for raising awareness about seizures, informing treatment options, and guiding counselling. They also provide valuable insights into the pathogenesis of epilepsy in the injured brain, particularly in relation to delayed maturation and microstructural white matter abnormalities.

Speaker

Dr. Monica Cooper is a General Paediatrician working in the Department of Neurodevelopment and Disability at The Royal Children's Hospital. Monica runs a weekly teaching clinic for paediatric trainees, is a tutor for medical students, and supervises PhD students. Monica was lead author of the evidence-based care pathway for respiratory health in cerebral palsy, published for the American Academy for Cerebral Palsy and Developmental Medicine, and serves on the Clinical Ethics Response Group at The Royal Children's Hospital.

Monica Cooper

2B. What is the "new black" in dystonia management?

Dystonia is recognised to have a major impact on the function, participation and well-being of children and adolescents with cerebral palsy. This update will explore approaches to care and management of this common and sometimes difficult to manage problem.

Speaker

Giuliana Antolovich is a paediatrician with over 25 years of clinical, education and research experience in the field of childhood

Giuliana Antolovich

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onset neurodisability, focused on the care of children and adolescents with complex disability and chronic medical conditions. She has an interest in bioethics and decision making and communication for this complex group.

2C. What's new in pain management?

Our pain research team has recently advanced the way chronic pain is identified and assessed in children and young people with cerebral palsy. Nadine will present the findings from her PhD where she has developed a framework for assessing pain underpinned by a biopsychosocial approach. Adrienne will present on modifications to assessment tools to increase feasibility for young people with complex communication needs and/or cognitive impairments as well as research currently underway to better understand underlying mechanisms of pain and improved ways of managing pain in children and young people with cerebral palsy.

Speakers

Associate Professor Adrienne Harvey is a physiotherapist and Principal Research Fellow in Neurodisability and Rehabilitations at Murdoch Children's Research Institute. She has extensive clinical and research expertise in improving outcomes for children with cerebral palsy and their families. She currently leads a national program of research into pain in children and young people with cerebral palsy.

Adrienne Harvey

12.45-1.45pm

LUNCH BREAK

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Health & Well-being

1.45pm-3.15pm

SESSION3 : BREAKING THE BARRIERS

3A. Discussions about Sexual Health with Adolescents with Cerebral Palsy: Who Says What, to Whom, and When?

Developing one's sexual and gender identity is a central aspect of adolescence. Adolescents can obtain information about sexuality from multiple sources including parents, peers, the media and health professionals. However, too often families and health professionals struggle to discuss sexuality with adolescents with disabilities, which risks leaving them without the information they want and need. Our research found that adolescents with cerebral palsy and their parents report that health professionals rarely addressed sexual and reproductive health. Our study, focused on adolescents with cerebral palsy who use augmentative and alternative communication (AAC), underscored the critical role communication plays in accessing this information.

In this presentation, we share a framework for health professionals that considers who shares what (content) to whom (audience) and when (developmental timing) as an approach to ensuring that adolescents with complex disabilities are engaged in meaningful discussions about their sexual and reproductive health.

Speakers

Professor Susan Sawyer AM MBBS MD FRACP is an adolescent physician whose clinical, research, education and advocacy efforts have been instrumental in establishing the field of adolescent health in Australia, the Asia Pacific region, and globally. A paediatrician by training, Susan has held the chair of adolescent health at the University of Melbourne for the past two decades, concurrently as director of the Centre for Adolescent Health at the Royal Children's Hospital. Susan is also an investigator with CP-Achieve.

Susan Sawyer

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Health & Well-being

Megan Walsh is an experienced speech pathologist with a background working with people with complex communication needs. Megan is doing her PhD with Deakin University and CP-Achieve at the Murdoch Children's Research Institute. This participatory research involves conversations about sexuality for adolescents with cerebral palsy who use augmentative and alternative communication (AAC).

Megan Walsh

3B. Conversations about Independent Living: Exploring Experiences of Young People with Cerebral Palsy and Their Families

This session will feature a panel discussion, including people with lived experience of cerebral palsy, and researchers from CP-Achieve, exploring the transition to independent living. Through their shared perspectives and insights, the discussion will focus on:

1. Understanding the meaning of the transition to independent living
2. The opportunities and challenges within family, community and service systems that impact on a young person's transition to independent living

By bringing together lived experience and research insights, this panel aims to further our understanding of independent living for young people living with cerebral palsy and their families.

Speakers

Dr Lyndal Hickey is a Lecturer in the Department of Social Work at the University of Melbourne and an Associate Researcher at CP-Achieve. Lyndal's research focuses on supportive psychosocial interventions for families caring for a person with a disability or health condition.

Lyndal Hickey

DAY 1 THURSDAY 3RD APRIL

Health & Well-being

Carlee Holmes

Chris Silcock

Anand Haveri

Dr Carlee Holmes is a clinical and research physiotherapist, currently appointed as a Postdoctoral Research Fellow at CP-Achieve, Murdoch Children's Research Institute, and as a senior clinical Physiotherapist with the Young Adult Complex Disability Service, St. Vincent's Hospital Melbourne.

Chris Silcock is 40 years old and lives independently which he loves. He leads an active lifestyle, including going to the gym twice a week hydro and physio and seeing his girlfriend. Chris loves all things Disney, film and the St Kilda football club. He also loves podcasts, history and going down a YouTube hole

Anand Haveri is a full-time business executive in the corporate world and a proud parent of Yatish, a 24-year-old with cerebral palsy. Anand actively shares his experiences of having a disabled child while learning how to include Yatish in daily activities, providing him opportunities to experience various aspects of young adulthood.

3C. Intersectionality and young people with cerebral palsy

The session will explore the topic of intersectionality, what we mean by intersectionality and what it means for our understanding of young people with cerebral palsy. We will discuss how the multiple identities of young people, such as their culture, gender, sexuality and socioeconomic status can interact with their disability. The session will leave researchers and clinicians with thoughts to consider when working with young people with disability, such as cerebral palsy.

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Speakers

Claire Rowland is CP-Achieve's Knowledge Translation Fellow for consumer involvement. She has a background in the International Development sector, where she has engaged in a range of advisory roles focusing on the promotion of gender equality, disability and social inclusion across Asia and the Pacific. Claire has a special interest in consumer involvement, framework and toolkit development and health focused behaviour change communication.

Claire Rowland

Carolyn Pinto is CP-Achieve’s Consumer Coordinator for parents and families. Carolyn has worked in State Government in acute health and human services policy and program design, program implementation and management. She has managed a range of policy and program initiatives to support vulnerable children and families with disability and prevent child protection issues arising in children with disability. Carolyn is passionate about the consumer voice in program design and research and initiatives to support families with disability. She is the mother of a young person with acquired disabilities as a result of childhood encephalitis.

Carolyn Pinto

3D. Branching into adulthood: views of young adults with cerebral palsy on navigating life, their information seeking behaviours and how to support their healthcare decision-making

This presentation will highlight key findings from Jackie’s PhD research studies. It will focus on the experiences and needs of young adults with cerebral palsy as they ‘branch out into adulthood’. Jackie will explore the wants and needs of young people with cerebral palsy in their daily participation across major areas of adult life. Jackie will also cover findings from a systematic review, which identified that young adults with cerebral palsy want tailored and credible health information to support health-related decision making. Recommendations will be provided on how healthcare professionals and support systems can better address these evolving needs during this critical period. Additionally, insights from the development of CP-Pathfinding: Your Health – an online module co-designed by young adults with cerebral palsy, clinicians, and families, will be shared. This collaborative initiative demonstrates how equal involvement from diverse stakeholders can empower young adults with cerebral palsy to take control of their health and improve healthcare outcomes.

Speaker

Jacqueline (Jackie) Ding is a CP-Achieve PhD candidate at Monash University and a Project Officer at Murdoc Children's Research Institute in the Centre for Community Child Health. Her PhD research focuses on understanding the experiences of young adults with cerebral palsy transitioning to adulthood and developing resources to support the transition.

Jacqueline Ding

3.15-3.45pm
AFTERNOON TEA BREAK

3.45-4.45pm
SESSION 4: Empowering research and empowering voices: Five years of consumer involvement in CP-Achieve

This session will reflect on and celebrate five years of CP-Achieve consumer involvement, covering what we have learnt and the successes and challenges of championing consumer involvement over an extended period. You will hear from consumers, research partners and researchers about the personal, professional and research impacts of being involved in CP-Achieve and learn how CP-Achieve consumer involvement knowledge will be translated and shared once the program concludes

Claire Rowland

DAY 1 THURSDAY 3RD APRIL

Health & Well-being

Speakers

Claire Rowland- see pervious summary

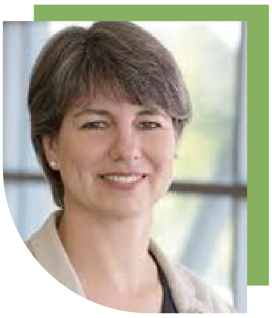
Carolyn Pinto- see pervious summary

Associate Professor Margaret Wallen is a chief investigator with CP-Achieve and leads the consumer involvement theme. Margaret is also an Occupational Therapy lecturer at the Australian Catholic University where she promotes involvement of people with lived experience in research amongst research students and staff.

Michelle King is a sociologist and lawyer, with interests in complex health care, transition between child and adult services and systems, decision making and decision-making capacity. Michelle's daughter has cerebral palsy and profound intellectual and multiple disabilities. Michelle is a member of CP-Achieve's Parent Advisory Group.

Gaurav Thakker is an Enrolment Centre Assistant at Melbourne Polytechnic, where he supports students by providing them with exceptional assistance in their educational journey. Gaurav actively engages in community initiatives, such as an advisor for CP-Achieve.

Carolyn Pinto



Maragaret Wallen

Michelle King

Gaurav Thakker

Progress & possibilities

DAY 2 FRIDAY 4TH APRIL

Participation and future focus

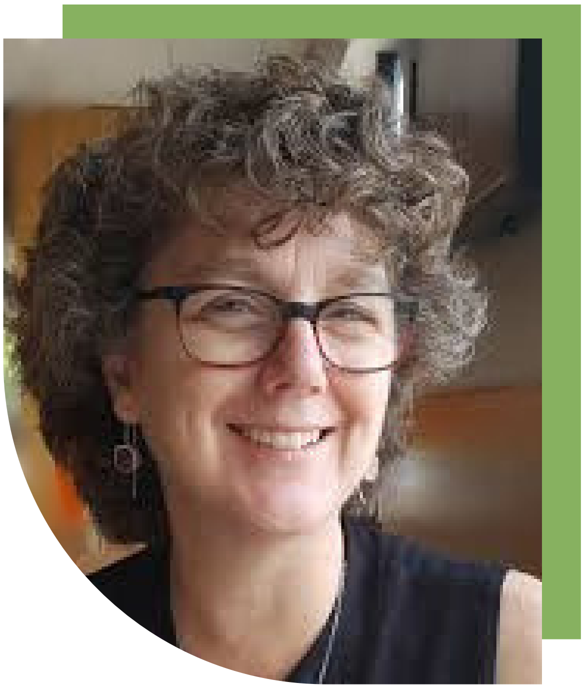
8:30-9:00am

Registration

9:00- 9.30am

KEYNOTE ADDRESS

Preventative health care in adulthood: reviewing the evidence



Christine Imms

Internationally, health services for adults with cerebral palsy are frequently inadequate and/or inaccessible. Adults often encounter fragmented care, lack of support to navigate health services, lack of specialist services and health professionals with limited knowledge about cerebral palsy and its sequelae.

Recent focus of research in adult health care has been on prevalence and incidence of a range ofassociate health conditions. The focus of the work described in this presentation is on potentially preventable health conditions, such as heart disease, mental health problems, to understand prevalence (or incidence), risk factors, intervention effects, and suitable measures for adults with cerebral palsy.

Through undertaking a suite of systematic reviews, the goal is to understand the landscape of evidence, create clinical practice guidelines, and improve health outcomes for adults with cerebral palsy.

Professor Christine Imms is the Apex Australia Foundation Chair in Neurodevelopment and Disability at the University of Melbourne and The Royal Children's Hospital, Melbourne. She is also founding Director of Healthy Trajectories – a child and youth disability research hub on the campus, and a chief investigator at CP-Achieve. Christine's research focuses on those with childhood-onset disability and their families, with the goals of learning how to optimise their participation outcomes; development and evaluation of interventions; and development and validation of measures.

DAY 2 FRIDAY 4TH APRIL

Participation and future focus

9.30-10.00am
KEYNOTE ADDRESS- NDIS Moving Forward: A whole system approach to improving outcomes for children and families

Bruce Bonyhady

The National Disability Insurance Scheme (NDIS) has made an enormous difference to the lives of children with disabilities, developmental delay and developmental concern and their families. However, a focus on medical diagnosis and market settings which have favoured clinical supports have led to an unintended medicalisation of supports for these children. The NDIS Review found that there is insufficient support for families and children and they are not being supported where they live, learn and play. Since the commencement of the NDIS there has also been a lack of supports for children not eligible for the scheme. The NDIS Review therefore recommended a new system of Foundational Supports. It also recommended a system of lead practitioners, working with families and trans-disciplinary teams. In 2024 the best-practice framework for early childhood early intervention is being reviewed as part of Australia's Disability Strategy. This presentation will look at what has been achieved and what still needs to be done to ensure children with disability, developmental delay and developmental concerns and their families can thrive.

Professor Bruce Bonyhady is the Director at the Melbourne Disability Institute at The University of Melbourne. He is a disability reformer, economist and one of the key architects of the NDIS. He was Co-Chair of the NDIS Review in 2022-23 and was the inaugural Chair of the National Disability Insurance Agency (NDIA) from 2013-16. Professor Bonyhady is the

DAY 2 FRIDAY 4TH APRIL

Participation and future focus

father of three adult sons, two of whom have disabilities and in the 2010 Queen's Birthday Honours, he was appointed as a Member of the Order of Australia for services to people with disabilities, their families and carers, and to the community as a contributor to a range of charitable organisations.

10.00-10.30am
MORNING TEA BREAK

10.30-11.20am
SESSION 1: FORGING THE WAY FORWARD

1A. Physical activity options for young adults with more complex forms of cerebral palsy

Young adults with cerebral palsy reliant on wheelchairs for mobility are vastly under-represented in the literature on physical activity. Practically, this means that there is less knowledge available about exercise prescription and participation, and the result is that young adults with cerebral palsy who use wheelchairs are less likely to be involved in physical activity. This talk will focus on physical activity options for young adults with more complex forms of cerebral palsy. We will also hear from young adults and their families who are helping to change the expectations and knowledge base in this area through their involvement.

Carlee Holmes

Speakers

Dr Carlee Holmes- see pervious summary

1B. Improved diagnosis of mental health problems

This talk will present the findings of two studies focused on identifying mental health conditions in young people with cerebral palsy. The first study explores screening methods

DAY 2 FRIDAY 4TH APRIL

Participation and future focus

for anxiety and depression, comparing self-report questionnaires to determine the most effective, accessible, and accurate approaches. Key results will highlight differences between approaches and the importance of building capacity in healthcare professionals to deliver an evidence-based initial response for young people with cerebral palsy who are experiencing mental health concerns. The second study explores the practices and future needs of professionals involved in identifying mental health concerns in young people with complex communication needs, based on focus groups with practitioners from fields like speech pathology, education, medicine, physiotherapy, and psychology. Results are shared through a "Practitioners' Story," offering suggestions for facilitating the identification process. Together, these studies provide valuable insights on optimising mental health screening and support for diverse populations in need

Speakers

Dr Sarah Giles is a CP-Achieve Postdoctoral research fellow. Her research focusses on improving physical and mental health for young adults with cerebral palsy. Dr Sarah Giles is co-leading a research project investigating the physical and mental health experiences of young adults with cerebral palsy, with a focus on anxiety, depression, social isolation, and mental health service utilisation.

Sarah Giles

Jacinta Pennacchia is a speech pathologist completing her PhD at the University of Melbourne. She works with children and young adults in education and hospital environments

Jacinta Pennacchia

1C. Forging your own path as a young adult with cerebral palsy: Setting the direction, making choices and building skills

This presentation will provide an overview of the collaborative journey our team has been on to better understand and support the lifestyle preferences of young adults with cerebral palsy. Research findings from a scoping review on the participation experiences of young people with cerebral palsy will be shared, followed by discussion of the practicalities of growing in autonomy. We will hear from young adults with cerebral palsy involved in this research and share a sneak peek of the resources we are currently developing

Speaker

Dr Stacey Cleary is a clinical and research physiotherapist, working as a Postdoctoral Research Fellow with CP-Achieve, at the Murdoch Children's Research Institute. Stacey loves working alongside people with disabilities to support them in following their interests, growing their autonomy, and enhancing their health and well-being, particularly through physical activity participation.

Stacey Cleary

Freya Munzel is a Consumer Investigator, is experienced in creating and facilitating programmes for young people with disability and sharing her lived experience of cerebral palsy as a key partner in research projects. "I am passionate in making sure our voices are front and centre in the issues that affect us.

Freya Munzel

11.20am-12.30pm

SESSION 2: DATA- HOW USEFUL IS IT?

2A. Long term value of CP Registers

This talk will summarise the 38-year history of the Victorian Cerebral Palsy Register and the contribution it has made to the cerebral palsy research agenda. The contribution includes population research on clinical characteristics, neuroimaging, and causal pathways in cerebral palsy. Other important activities include assistance with recruitment to external studies and data linkage.

Speaker

Professor Dinah Reddihough- See previous summary

Dinah Reddihough

DAY 2 FRIDAY 4TH APRIL

Participation and future focus

2B. The Understanding Survey – what does it tell us and how can we use the findings?

This talk presents the findings from a comprehensive survey examining the mental and physical health of young people with cerebral palsy. By analysing self-reported data on emotional well-being, stress, anxiety, physical functioning, pain, sleep, and fatigue, the survey sheds light on the complex interaction between mental and physical health in this population. The presentation will highlight key insights, including common health concerns, the impact of mobility issues on psychological well-being, and the importance of tailored support systems. Attendees will gain a deeper understanding of how these findings can inform interventions to improve overall health outcomes for individuals with cerebral palsy.

Sarah Giles

Carlee Holmes

Speakers

Dr Sarah Giles- see pervious summary

Dr Carlee Holmes- see pervious summary

2C. What can health service data tell us about healthcare use in people with cerebral palsy?

Individuals with cerebral palsy may experience multiple physical and mental health issues that impact their capacity to achieve optimal health, well-being, quality of life, and social and economic participation in the community. Research suggests that people with cerebral palsy may access health services to address their healthcare needs more frequently than people without disabilities. However there is little information available to date describing why people with cerebral palsy may access a health service, how often, and what services they receive. Through data linkage processes, whereby selected databases describing primary care (Medicare, PBS), hospital and emergency department

DAY 2 FRIDAY 4TH APRIL

Participation and future focus

admissions are linked, evidence describing health service use by individuals with cerebral palsy will be synthesised. Characteristics that may influence a person's interaction with a health service will also be explored. Findings may facilitate opportunities to strengthen health outcomes by enhancing primary care practice.

Speaker

Professor Prue Morgan, PhD, is a Professor of Physiotherapy at Monash University and a CP-Achieve chief investigator leading Program 2. Professor Morgan has over 30 years of clinical experience in neurological practice, in acquired and developmental disability. Her research is focused on identification and strategies to optimise health and manage physical decline experienced by adults with cerebral palsy, enhance healthcare access, and workforce education to facilitate service provision to this population. Professor Morgan was awarded the prestigious title Specialist Neurological Physiotherapist by the Australian College of Physiotherapists in recognition of her clinical expertise, research and scholarship.

Prue Morgan

2D. A profile of use and impacts of the NDIS on people with cerebral palsy

While there have been many advantages and successes associated with the implementation of the National Disability Insurance Scheme data (NDIS), participants with cerebral palsy and their families often report dissatisfaction with accessing the NDIS supports they need. In addition, service providers have raised concerns that that capacity building investment and outcomes are not as effective as they could be and that there has been a progressive reduction in individuals' annual plan size. Using NDIS (at unit record level) data, it is possible to identify people where cerebral palsy is listed as either a "secondary condition" or the primary disability group. The purpose of this project is describe the profile of those with cerebral palsy who use the NDIS, track individuals over time to examine changes in plans and spending at key points in life course, and conduct more detailed analysis that takes into account known drivers of NDIS service use.

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Speaker

George Disney

Dr George Disney is a social epidemiologist. He is a Senior Research Fellow – NDIS at the Melbourne School of Population and Global Health. His current research focuses on analysing the determinants of the (avoidable) gap in health between people with and without disabilities.

12.30-1.30pm

LUNCH BREAK

1.30pm-3.00pm

SESSION 3: PARTICIPATION – IN SO MANY WAYS

3A. The power of Para sport for people with cerebral palsy

This presentation will provide an overview of current opportunities in Paralympic sport for people with cerebral palsy. Research findings from a longitudinal evaluation of the therapeutic benefit of Para sport for people with cerebral palsy (the ParaSTART project at The University of Queensland) will be presented. The potential for the Brisbane 2032 Paralympic Games to benefit people with cerebral palsy living in Australia will be discussed.

Speaker

Iain Dutia

Dr Iain Dutia is a lecturer in Physiotherapy at Australian Catholic University and a research officer at The University of Queensland, School of Human Movement and Nutrition Sciences. He is also an Honorary Fellow at CP-Achieve

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3B. Effect of a high-level mobility skills training programme on sustained physical activity participation among ambulant children with cerebral palsy

Sustained participation in physical activity is important for everyone. This talk will share Gaela's PhD work that assessed the effect of a community-based high-level mobility skills programme (HLMP) on participation in physical activity among ambulant adolescents with cerebral palsy. The presentation will explore the complex and dynamic journey of sustained participation in physical activity and its impact on motivation, confidence, and physical well-being. Gaela will discuss the ongoing implications for community participation, clinical practice and research for young children through to young adults with cerebral palsy.

Speaker

Dr Gaela Kilgour is a Post Doctoral Research Fellow at Queensland Cerebral Palsy and Rehabilitation Research Centre and Honorary Fellow at CP-Achieve. Gaela is a physiotherapist from New Zealand with over 30 years of clinical experience. Gaela completed her PhD investigating participation in physical activity for adolescents with cerebral palsy and exploring their experiences and their families of sustaining participation now and into their future.


Gaela Kilgour

3C. Supporting adults with cerebral palsy to get in the door, get started and continue to participate at community gyms

This presentation will cover the latest evidence, current resources, and practical strategies for promoting exercise in community gym settings for individuals with complex disabilities. Over the past five years, CP-Achieve has dispelled the myth that community-based exercise is unsafe for young adults with complex disabilities, with the right supports in place. In collaboration with gym staff, we have developed resources to address gaps in disability knowledge and skills within the recreation industry, and partnered with gyms to explore how

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they have integrated inclusive programs within the existing policy and funding frameworks. We are currently collaborating with adults with cerebral palsy who use wheelchairs to create tailored resources that facilitate 'getting in the door' of community-based physical activity, support 'getting started', and encourage long-term participation. This session will offer attendees an exclusive preview of these new resources.

Speakers

Professor Nora Shields is Research Director at the Olga Tennison Autism Research Centre. She aims to improve the health and wellbeing of people with disability by increasing their participation in exercise and physical activity.

Nora Shields

Dr Georgia McKenzie is a physiotherapist at St Vincent's Hospital Young Adult Complex Disability Service, Melbourne, and a Research Fellow with CP-Achieve. Her interest is in supporting adults with cerebral palsy to be active and connected within their local communities.

Georgia McKenzie

3D. Physical Activity: It's a Lifelong Journey

Physical activity is crucial for the development of individuals, particularly those with disabilities. Early engagement, supported by healthcare professionals, sets the foundation for lifelong participation. In infancy, clinicians promote movement and sensory exploration, which integrate with developmental milestones. For children and adolescents with disabilities, both specialized and mainstream programs help build skills, confidence, and physical competence, fostering inclusion through adapted sports and recreational activities. As individuals transition into adulthood, the focus shifts to empowering them to self-direct their physical activity, with physical literacy playing a central role in maintaining engagement. Rehabilitation professionals must ensure that supports from childhood extend into adulthood, promoting self-efficacy and autonomy. Frameworks like the SPORTS Participation Framework and the Family of Participation and Related Constructs emphasize a holistic, person- and family-centered approach to physical activity, recognizing that preferences evolve over time. By addressing individual, familial, and environmental factors, professionals can ensure lifelong participation, helping individuals with disabilities benefit from physical activity throughout their lives.

Speaker

Associate Professor Leanne Johnston is the Executive Director of Allied Health at Children's Health Queensland Hospital and Health Service and former Head of Physiotherapy at The University of Queensland. She is the founding lead of the Children's Motor Control Research Collaboration. This interprofessional team have made a significant contribution to research literature, clinical services development, and professional education to support children with movement disabilities become healthier and more active. They have empowered children and families through projects to establish child-led goal setting, early developmental intervention, family empowerment, environmental enrichment, physical education and physical activity programs, community engagement and health equity initiatives. This is the story of some of that work.

Leanne Johnston

3.00-3.30pm
AFTERNOON TEA BREAK

3.30pm-4.15pm
SESSION 4: THE JOURNEY FORWARD

4A. Collaborations Across Australia – the Who, What and How

One of the greatest outcomes of CP-Achieve as a Centre for Research Excellence, is the incredible workforce that it has brought together and created in the adolescent/young

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adulthood cerebral palsy space. In this presentation we will discuss other groups and avenues for ongoing connection and collaboration across Australia, so that we can continue to build on the positive momentum that has been established. We will specifically discuss opportunities for people with lived experience to continue to shape research, and some of the mechanisms available to support this. We will also highlight the CP Strategy and the ways it can be used to facilitate collaboration and support funding applications across Australia and New Zealand.

Speaker

Dr Ingrid Honan is a Psychologist and Senior Research Fellow at Cerebral Palsy Alliance, and Clinical Senior Lecturer at the University of Sydney. Ingrid's interest areas are cognition, mental health, pain and well-being across the life span, and supporting collaborations within the cerebral palsy community via her work with the Australian and New Zealand CP Strategy.

Ingrid Honan

4B. Demystifying transition from paediatric to adult care - what do we need to think about and ask?

Transition from paediatric to adult care can often be a confusing and anxiety-provoking time when other changes are also occurring simultaneously. There are, however, many resources, people and services which can be helpful. Understanding what you can ask for, when and who you can access for support, will be explored.

Speaker

Evelyn Culnane is passionate about supporting and learning from young people and their families as they prepare for transition from paediatric to adult care. She leads the Transition Support Service at the Royal Children's Hospital (RCH) Melbourne and over the last 15 years, has enjoyed the challenge of developing and advocating for innovative pathways and resources to contribute to positive outcomes for people with cerebral palsy and other conditions.

Evelyn Culnane

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4C. Young Adulthood: A Case for Optimism in a Complicated Landscape

Reflections on the practicalities of adulthood and the different ways to approach the challenges and opportunities from a lived experience and research retrospective


Amy Hogan

Speaker

Amy Hogan- see previous summary

4D. The changing role of family as children move into adulthood

As young people with cerebral palsy move from childhood into adulthood, their priorities and needs change. Our role as parents and other family members is to recognise and acknowledge these changes and to move with them. In this presentation, we will explore the transformation of the young people we care for and about; our changing roles; and ways in which we can continue to support and enrich the lives of the young people we love.

Speaker

Jane Tracy has an adult son with cerebral palsy and intellectual disability. He now lives in supported accommodation and their shared journey through his childhood, adolescence and adulthood taught them both about the inherent challenges and opportunities at different life stages. Jane is also a retired medical practitioner who spent her professional career working to improve the health and healthcare of adults with developmental disabilities


Jane Tracy

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4.15-4:45pm

REFLECTIONS & CLOSE

Professor Dinah Reddihough and Emma Livingstone will reflect on the two days of the symposium and CP-Achieve's five years of reseach covering where the research commenced, what is happening now, and plans for future cerebral palsy research.

Dinah Reddihough

Speakers

Professor Dinah Reddihough- see previous summary.

Emma Livingstone- see previous summary

Emma Livingstone

murdoch children's research institute

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