

3-4 AUGUST

MELBOURNE, AUSTRALIA



2023

LINKING HEALTH, WELLBEING &
PARTICIPATION

PROGRAM

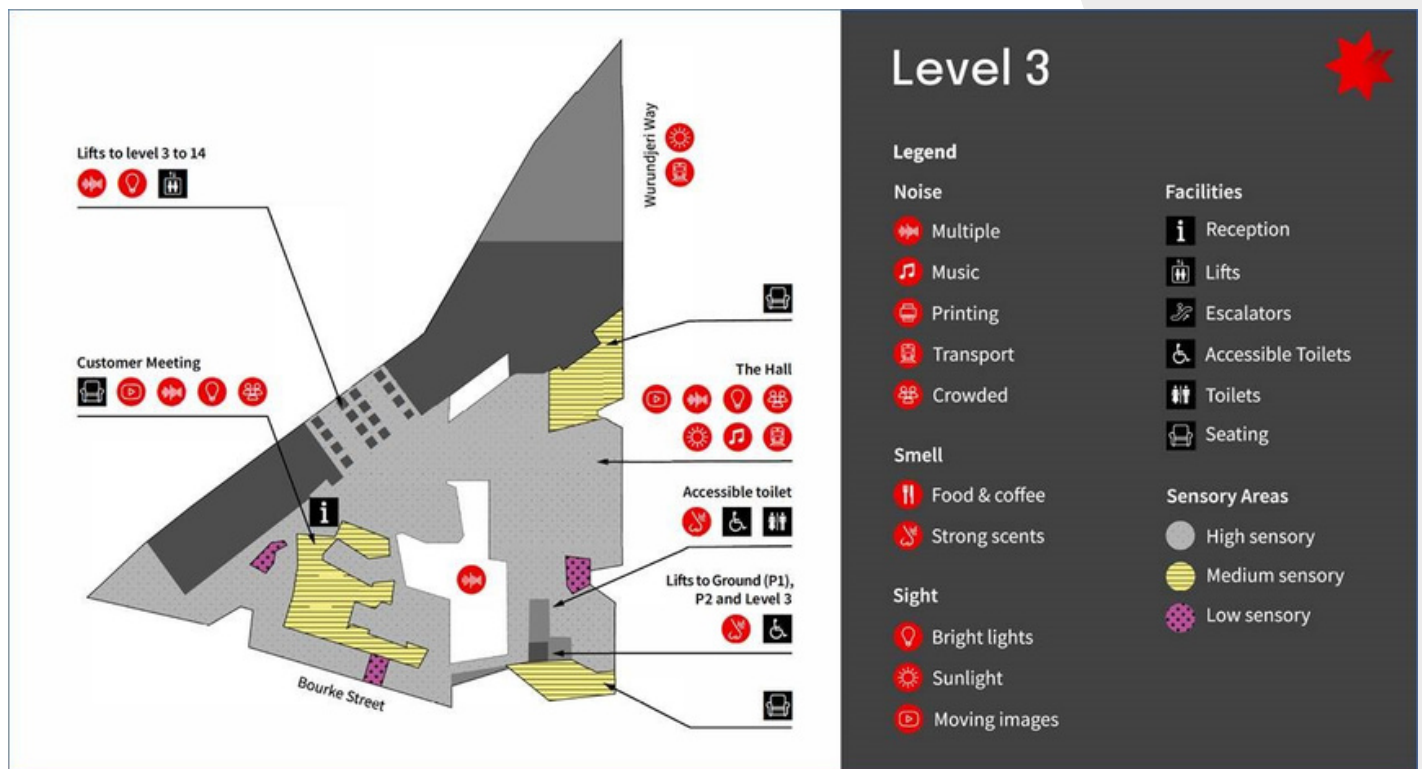
CP-ACHIEVE AND AusACPD
CEREBRAL PALSY SYMPOSIUM

VENUE

NATIONAL AUSTRALIA BANK LIMITED (NAB), DOCKLANDS

We are grateful for the support of the National Australia Bank who has provided the venue at 700 Burke St, Docklands, as part of their social commitment to not for profit organisations.

The symposium will be held in the Hall on level 3.



The venue has accessible bathrooms. The nearest Changing Places facilities can be found at RMIT University Building 8, Level 4 360 Swanston Street, which is an 11 minute walk away.

SPONSORS

Thank you to our sponsors for providing various levels of financial support to enable consumer involvement and participation at the symposium.

Main Sponsor



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Keynote Opening Address Sponsor



ABOUT CP-ACHIEVE & AusACPDM

CP-Achieve



CP-Achieve is a National Health and Medical Research Council (NHMRC) funded Centre of Research Excellence that supports the development of collaborative cerebral palsy research.

CP-Achieve is made up of a multidisciplinary team of national and international researchers, adolescents and young adults with cerebral palsy, their families, clinicians, and students. The team conducts research to find ways to help adolescents and young adults with cerebral palsy live full and healthy lives and participate in life situations which are important to them.

Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM)



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.

SOCIAL EVENT

Please join us for the CP-Achieve and AusACPDM symposium dinner where you will have an opportunity to socialise and network with other attendees and speakers. Dinner will include a selection of 8 dishes enjoyed over the course of the evening. Places are limited so get in quick.

Thursday 3rd
August

FROM 5.30-8.30PM

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2023 CP-ACHIEVE AND AusACPDM CEREBRAL PALSY SYMPOSIUM
LINKING HEALTH, WELLBEING & PARTICIPATION



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Ticket sales close 26 July

PROGRAM SCHEDULE

DAY 1 ————— **THURSDAY AUGUST 3RD**

MENTAL AND PHYSICAL HEALTH OF ADOLESCENTS AND YOUNG ADULTS WITH CEREBRAL PALSY

8.30AM - 9.00AM	Registration Networking
9.00AM - 10.00AM	Welcome & Keynote addresses
10.00AM -10.30AM	Co-designing pain assessment for children and young people with cerebral palsy
10.30AM -11.00AM	Morning tea break
11.00AM -11.45AM	Musculoskeletal issues- what we don't talk about!
11.45AM -12.30PM	Sleep problems and fatigue
12.30PM -1.30PM	Lunch break & AusACPDM AGM
1.30PM -2.00PM	Building a connected service: what are the key ingredients?
2.00PM -2.30PM	The intersection between physical and mental health with disability in first nations cultures and in regional and remote communities
2.30PM -3.00PM	Parents and wellbeing
3.00PM -3.30PM	Afternoon tea break
3.30PM -4.45PM	Cerebral palsy and mental health: where are we now and initiatives to improve wellbeing

PROGRAM SCHEDULE

DAY 2 ————— **FRIDAY AUGUST 4TH**

BUILDING SUPPORTIVE FAMILY, COMMUNITY, AND SERVICE ENVIRONMENTS

8.30AM - 9.00AM	Registration & networking
9.00AM - 9.50AM	Keynote addresses
9.50AM -10.30AM	Equity, law and the NDIA
10.30AM -11.00AM	Morning tea break
11.00AM -11.45AM	Pathways between education and employment
11.45AM -12.30PM	Opportunities for all people with cerebral palsy and similar disabilities
12.30PM -1.30PM	Lunch break & CP-Achieve consumers networking session
1.30PM -2.10PM	Independent Living: "My mum doesn't know what colour my undies are!"
2.10PM -2.40PM	Relationships & friendships
2.40PM -3.20PM	Fitness for life. Fitness for everyone
3.20PM -3.50PM	Afternoon tea break
3.50PM -4.30PM	Bright lights- PhD in 3
4.30PM -5.00PM	Closing address

THURSDAY AUGUST 3RD DAY 1

8:30-9:00AM
Registration

9:00-10.00AM
Welcome

Professor Dinah Reddihough and Dr Sarah McIntyre will welcome attendees to the symposium with CP-Achieve Consumer Coordinators, Carolyn Pinto and Sevastine Katsakis.



Dinah Reddihough



Sarah McIntyre



Carolyn Pinto



Sevastine Katsakis

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

Dr Sarah McIntyre is a Senior Research Fellow at Cerebral Palsy Alliance and current Co-President, AusACPDm.

Carolyn Pinto is the CP-Achieve Consumer Coordinator for parents and families, Murdoch Children's Research Institute.

Sevastine Katsakis is the Consumer Coordinator for Young People in CP-Achieve, Murdoch Children's Research Institute.

THURSDAY AUGUST 3RD **DAY 1**

Keynote Opening address to the symposium



Priya Cooper

Priya Cooper, O.A.M, was one of Australia's leading Paralympians and has cerebral palsy. Priya was honoured with an Order of Australia Medal in 1992 after the Barcelona Paralympics for her services to sport. In 1999 she was named Young Australian of the Year for Sport. In 2015 Priya was inducted into the Sports Australia Hall of Fame at the same ceremony as Ricky Ponting and Casey Stoner. Priya has since retired from competitive swimming and is now involved in raising awareness and funding for people with disabilities to be involved in sport. She is currently Chair of WA Institute of Sport, Deputy Chair of WA Disability Services Commission and President of the WA Disabled Sporting Association.

Keynote: Physical and mental health in cerebral palsy



David Coghill

Professor David Coghill is a CP-Achieve Chief Investigator and the lead for the theme 1 program of work which focuses on improving physical and mental health for young adults with cerebral palsy. He is also the Financial Markets Foundation Chair of Developmental Mental Health Departments of Paediatrics and Psychiatry, University of Melbourne and Professor of Child and Adolescent Psychiatry, Royal Children's Hospital Melbourne.

THURSDAY AUGUST 3RD DAY 1

10:00-10:30AM

Co-designing pain assessment for children and young people with cerebral palsy

This workshop will explore assessment tools suitable for assessing chronic pain for all people with cerebral palsy within a biopsychosocial framework, which aims to facilitate accurate identification, assessment beyond pain intensity, and ensure timely referral to multidisciplinary teams for best practice management. Potential adaptations to key assessment tools to ensure they are appropriate for use in cerebral palsy will be presented and discussed. The session will be presented by clinician-researchers and people with lived experience of cerebral palsy.

Speakers

Associate Professor Adrienne Harvey is a physiotherapist and Principal Research Fellow in Neurodisability and Rehabilitation at the Murdoch Children's Research Institute.

Nadine Smith is a CP-Achieve PhD student and physiotherapist from Perth.

Meredith Smith is a physiotherapist, PhD student, and lecturer in Physiotherapy at The University of Adelaide.

Amy Hogan and **Caitlin Doyle** are researchers who have lived experience of cerebral palsy. They bring both professional and personal perspectives to this work.



Adrienne Harvey



Nadine Smith



Meredith Smith



Amy Hogan



Caitlin Doyle

THURSDAY AUGUST 3RD DAY 1

10:30-11:00AM

Morning tea break

11:00-11:45AM

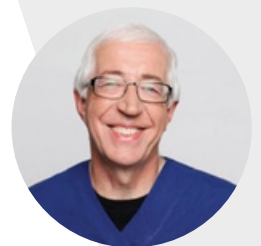
Musculoskeletal issues- What we don't talk about!

The orthopaedic session brings together experienced surgeons and physiotherapists to discuss some of the more challenging and confronting musculoskeletal issues with a focus on the non-ambulant population. Discussion will cover the importance of managing and monitoring the musculoskeletal system to maximise function, participation and minimise pain and pressure concerns for those reliant on wheelchairs for mobility. This session will provide an overview of surgical and conservative interventions in the lifespan management of complex musculoskeletal issues, including dislocation of the hip, windswept hips, and spinal deformities.

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 for 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.



Kerr Graham



Erich Rutz

THURSDAY AUGUST 3RD DAY 1

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



Carlee Holmes

Pam Thomason is a senior physiotherapist and manager of the Hugh Williamson Gait Analysis Laboratory at the Royal Children's Hospital, Melbourne.



Pam Thomason

11:45AM-12:30PM

Sleep problems and fatigue

Sleep is essential for recharging both physical and mental energy levels and preventing fatigue. In this session, Dr Sue McCabe will provide a practical overview of the diverse factors (body structures and functions, activity, environment) which can affect the sleep of children and young people with cerebral palsy. Professor Susan Sawyer will explore the measures used to understand how fatigue is experienced by people with cerebral palsy. Together Sue and Susan will then ask questions of the audience to understand what people would like future research to cover.

Speakers

Dr Sue McCabe is an occupational therapist and founder of SleepLinks, WA. Over the past 20+ years Sue's clinical work has been community based, providing sleep support for people of all ages with neuro-motor and developmental conditions. Her PhD research explored the diverse factors that affect sleep of children



Sue McCabe

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and young people with cerebral palsy, with a specific focus on thermoregulation during sleep.

Professor Susan Sawyer is the Geoff and Helen Handbury Chair of Adolescent Health at the University of Melbourne, and Director of the Centre for Adolescent Health at the Royal Children's Hospital, Melbourne.



Susan Sawyer

12:30-1:30PM
Lunch Break

12:45-1:30PM
AusACPDM Annual General Meeting

Hybrid meeting for AusACPDM members, zoom link available soon for those not in attendance.

1:30-2:00PM
Building a connected service: What are the key ingredients?

Respiratory disease is the number one cause of mortality in cerebral palsy and is the leading cause of unplanned admission to hospital. We have identified those with the highest risk having complex medical, but also modifiable risk factors that often co-exist including, severe gross motor involvement (GMFCS level V), previous respiratory admissions or respiratory illness, epilepsy, gastroesophageal reflux, oro-motor dysphagia, and dental disease. Despite recent advances in the care of children with cerebral palsy the mortality rate has remained unchanged. In 2020 we published a consensus statement for the

THURSDAY AUGUST 3RD DAY 1

prevention and treatment of respiratory illness in cerebral palsy. One of the key recommendations was the need for frequent evaluation and treatment of any modifiable risk factors within a coordinated service. We will use a case example from our experience of our recent pilot RCT evaluating implementing recommendations of the consensus delivered as a complex care intervention service. Using this case, we will offer a list of active ingredients utilised in our intervention. Combining this with knowledge in the literature, we will present the theories underpinning each “key ingredient’s” effectiveness. Using a second case we will identify the key ingredients in a current hospital complex care service and use this case to challenge participants about what changes they may need to make in their workplace with consideration of different cultural and economic contexts.

Speakers

Dr Monica Cooper is a general paediatrician in the Department of Neurodevelopment & Disability at the Royal Children’s Hospital, Melbourne. Monica works with children with physical and intellectual disabilities. Monica’s clinical and research work focuses on optimising tone, saliva control, mood and sleep. Monica was the lead author for the AACPDMD care pathway for respiratory health in cerebral palsy and is currently completing her PhD on the Epilepsies of Cerebral Palsy.



Monica Cooper

Dr Noula Gibson is the Research Coordinator for the Department of Physiotherapy and works clinically in the cerebral palsy mobility service at Perth Children’s Hospital. Noula is the lead author of the *2020 Consensus Statement for the Prevention and Management of Respiratory Illness in Cerebral Palsy* and is the CPI for a grant funded trial (RESP-ACT) looking at implementing the recommendations from the consensus statement to improve respiratory outcomes in children with cerebral palsy. Her other research focus is on improving physical activity participation in children with disability and chronic illnesses.



Noula Gibson

THURSDAY AUGUST 3RD DAY 1

2:00-2:30PM

The intersection between physical and mental health with disability in first nations cultures and in regional and remote communities

This session will introduce the concepts of knowing, being, doing, and social and emotional well-being central to First Nations cultures. These will be discussed in the context of providing culturally safe support to young people with disability in the community. We will then shift gears to focus on regional and remote communities, where we will hear from a person with lived experience of cerebral palsy who will share some of their firsthand experience of service access and service provision in regional and remote communities and the impact on physical and mental health for young people with disabilities and their support networks.

Speakers

Robyne Burridge, OAM, was born in 1945 with cerebral palsy. Her family were told she would never sit up, walk or talk. She is a Founding and Life Member of Integrated DisAbility Action Inc. an advocacy support organisation for people with disability, family, carers and guardians. Robyne is highly regarded as a leader, advocate and activist in the disability sector. Her lived experience and expertise in disability has seen her mentor many executives in the sector. In January 2020 she was awarded an OAM. In 2022 Robyne was the NT Senior Australian of the Year and was also awarded an Honorary Doctorate by Charles Darwin University for her work in disability.



Robyne Burridge

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Dr Helen Milroy, AM, is a descendant of the Palyku people of the Pilbara region of Western Australia, but was born and educated in Perth. Helen is recognised as Australia's first Indigenous doctor and is currently Professor of Child and Adolescent Psychiatry at the University of Western Australia, Honorary Research Fellow at Telethon Kids Institute and a Commissioner with the National Mental Health Commission. Helen was recently appointed as the AFL's first indigenous commissioner. She is also a storyteller who has written three books for children.



Helen Milroy

2:30-3:00PM

Parents and Wellbeing

This session will explore what the research is telling us about parent wellbeing. Dr Sarah Giles will present an overview of the literature examining risk and protective factors to parent mental health/wellbeing. A panel made up of parents of young people with cerebral palsy will then talk about their experiences and challenges to mental health from diagnosis, and early childhood, to facilitating independence and cover "three wishes to help support parent wellbeing".

Speakers

Helen Tossell is the mother of two amazing young men with disabilities aged 25 and 27. Andrew, the eldest has a number of medical conditions including cerebral palsy. She has worked as a teacher both here and in British Columbia, Canada. For the last 15 years she has helped develop resources and present workshops for parents of children with disabilities through the Association for Children with a Disability.



Helen Tossell

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Joan Gains is a parent with a 25 year old son Nicholas, who has cerebral palsy and an intellectual disability. For the past 20 years, she has been involved with many organisations associated with improving outcomes for people with cerebral palsy and their families. With a professional background in Early Childhood Education, Joan has been working in research for the past 10 years. Firstly, as a Consumer Representative and then as a Research Assistant at Melbourne University, working primarily around research into the mental health of mothers of children with cerebral palsy and as one of CP-Achieve's previous Community Coordinators. Joan is a trainer and speaker on the benefits of community engagement in research.



Joan Gains

Rowland Mosbergen has 25 years of experience in complex Information Technology environments in the not-for-profit, private, and research sectors. He has established four multi-disciplinary teams and founded Practical Diversity and Inclusion, a boutique consultancy that extends best practice in Diversity, Equity, and Inclusion (DEI) and not for profit organisational development. Rowland has lived experience navigating disability service providers for his disabled son Jerome and advocating for him to the NDIS.



Rowland Mosbergen

Dr Sarah Giles is a Postdoctoral Research Fellow at CP-Achieve and leads the Improving Mental Health project.



Sarah Giles

3:00-3:30PM
Afternoon tea break

THURSDAY AUGUST 3RD DAY 1

3:30-4.45PM

Cerebral Palsy and Mental Health: Where are we now and initiatives to improve wellbeing

This session will look at the key mental health challenges identified by people with cerebral palsy through CP-Achieve's Understanding Survey. This will be followed by a discussion of treatments and concepts that can help improve mental health. Speakers will talk about the mindfulness programs and school connectedness and its impact on depression and anxiety with an opportunity for the audience to engage in Q&A.

Speakers

Dr Ingrid Honan is a CP-Achieve Chief Investigator, Senior Research Fellow and Psychologist at Cerebral Palsy Alliance Research Foundation, University of Sydney and a member of the Awards and Advocacy Committee of AusACPDM.

Dr Hayley Smithers-Sheedy is a Senior Research Fellow at Cerebral Palsy Alliance, Adjunct Associate Professor at The University of Sydney and Senior Research Associate at the University of New South Wales. She is a non-Indigenous researcher committed to supporting Indigenous-led projects and partnering with people with lived experience. She has expertise in cerebral palsy epidemiology, congenital infection, neurodevelopmental disability and consumer involvement in research with over 65 publications and over \$6 million dollars in funding.

Professor Susan Sawyer- see previous summary

Dr Sarah Giles- see previous summary



Ingrid Honan



Hayley Smithers-Sheedy



Susan Sawyer



Sarah Giles

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8:30-9:00AM
Registration

9:00-9:50AM

Keynote: Building supportive environments



**Kurt
Fearnley**

Kurt Fearnley, AO, is an experienced government and non-government director and five-time Australian Paralympian. In 2022, Kurt was appointed Chair of the National Disability Insurance Scheme board.

Kurt is also a current Board Commissioner of the Australian Sports Commission and Board Director of the Brisbane 2032 Olympic and Paralympic Organising Committee. He is a former member of the boards of several organisations with a disability and community focus including Paralympics Australia, Life Without Barriers, Australian Volunteers International and the Newcastle Permanent Charitable Foundation. Kurt was also a member of the inaugural NDIS Independent Advisory Council. He is a high-school teacher, television presenter, podcaster and broadcaster, and former professional wheelchair athlete.

Keynote: The National Disability Insurance Scheme review

Kirsten Deane is the General Manager of the Melbourne Disability Institute (MDI). An interdisciplinary institute based at the University of Melbourne, the work of MDI is focused on providing much needed evidence, data and research to address the complex

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**Kirsten
Deane**

problems faced by people with disability in this country. Prior to joining MDI, Kirsten was the Campaign Director for Every Australian Counts, the grassroots campaign that fought for the introduction of the National Disability Insurance Scheme (NDIS). With her ability to bring people together and her clear communication skills, Kirsten played a critical role in building political and public support for this world-leading reform. Since then, she has continued to push for the NDIS to achieve its original vision. Kirsten has also served on numerous ministerial councils and advisory committees, including Co-Chair and Deputy Chair of the National People with Disability and Carer Council. A former journalist, Kirsten has three children and, as a result, has excellent conflict mediation skills.

At the end of last year, the Minister for the NDIS the Hon Bill Shorten announced a year-long review of the National Disability Insurance Scheme. The review is led by Professor Bruce Bonyhady, widely regarded as one of the architects of the NDIS, and experienced Commonwealth public servant Ms Lisa Paul. The review is also being assisted by a panel of experts, Kirsten is a member of the panel.

Kirsten will talk about what the review is looking at, and what the panel has been hearing as they talk to people with disability, their families, their representative organisations, providers and researchers from across the country. Kirsten will then be happy to answer any questions you might have. But most importantly she wants to use the time in this short session to hear from you.

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Kirsten has four simple questions:

1. What parts of the NDIS are working well for young people with cerebral palsy and their families?
2. What are the biggest problems with the NDIS?
3. How do those problems impact young people with cerebral palsy and their families?
4. What do we need to do to fix those problems?

Kirsten is keen to hear about your solutions. The Review will report at the end of the year so this is a great chance to tell the Review what you think needs to change before they finish up their important work.

9:50-10:30AM

Equity, law and the NDIA

This session will discuss the NDIA unit data outcomes for cerebral palsy from a recent research project. A panel of experts in disability, human rights and administrative law will then explore the complex needs of those with cerebral palsy and issues of equity and access in the NDIS, how we can lessen the administrative burden and improve decision making for people with cerebral palsy, and how we can reform the scheme to build better supportive environments and good health.

Speakers

Dr Piers Gooding (Chair) is a Senior Research Fellow at the University of Melbourne Law School. He is a socio-legal researcher looking at disability and mental health-related law and policy. Piers is the author of *A New Era for Mental Health Law and Policy: Supported Decision*



Piers Gooding

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Making and the Convention on the Rights of Persons with Disabilities (2017) with Cambridge University Press and serves on the editorial board of the *International Journal for Mental Health and Capacity Law* and the *International Journal of Disability and Social Justice*.

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.

Dr Kay Wilson is a Post-Doctoral Research Fellow at the Melbourne Law School. She is the author of *Mental Health Law: Abolish or Reform?* (OUP, 2021), lead editor of *The Future of Mental Health, Disability and Criminal Law* (Routledge, forthcoming) and co-convenor for the Disability Law Network at Melbourne Law School.

Dr Michelle King is a sociologist and lawyer: her research focuses on decision-making and the operation of law and regulation in practice for people with disabilities and other impairments to communication and legal capacity. Her work examines decision-making in practice in a range of areas, including the NDIS, health and aged care, banking and finance, income support, and voting. She works as a researcher at the Queensland Aphasia Research Centre at the University of Queensland on communication and decision-making in health and aged care. Michelle is also a parent and supporter of her 24-year-old daughter, Daelle, who has profound intellectual and multiple disabilities including cerebral palsy.



George Disney



Kay Wilson



Michelle King

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Dr Darren O'Donovan is a Senior Lecturer in the La Trobe Law School. His main teaching and research specialisation is Administrative Law and he has written extensively on rights, oversight and public administration, including the book *"Law and Public Administration in Ireland"* (co-authored with Dr Fiona Donson). Darren is currently undertaking research projects in relation to the NDIS and the social security system.



Darren O'Donovan

10:30-11:00AM

Morning tea break

11:00-11:45AM

Pathways between education and employment

Transition periods for young people with disability can be challenging and exciting. The pathway from education to employment can provide new opportunities, greater social connections and independence but can also be a difficult process discovering what is the right fit and what is provided within our communities and society. This session will focus on what happens in the transition process using real world examples of the St Vincent's Young Persons team in Melbourne and the Breaking Out of Silos research project.



Loretta Sheppard



Carlee Holmes

Speakers

Associate Professor Loretta Sheppard is the Occupational Therapy Head of Discipline (Acting) and National Professional Practice Lead, Deputy Head, School of Allied Health, VIC & ACT.

Dr Carlee Holmes- see previous summary.



David Murphy

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Dr David Murphy is the Director of Rehabilitation, St Vincent's Hospital, Melbourne.

Emma Fredrickson is a senior occupational therapist, with over 20 years' experience working at the Young Adult Complex Disability Service, St Vincent's Hospital, Melbourne. She has a Master's in public health and her clinical interests involve complex equipment prescription, to enable young adults with disabilities to participate in meaningful activities. Emma is a clinical advisor for the state wide equipment service.

Veronica Saunders is a social worker at Young Adult Complex Disability Service, HIP, St Vincent's Hospital in Melbourne.

Steve Odgers is the Diversity Coordinator at ALF House-Melbourne.



Emma Fredrickson



Veronica Saunders



Steve Odgers

11:45AM-12:30PM

Opportunities for all people with CP and similar disabilities (addressing participation in their communities)

Opportunities to participate in all aspects of community life, and to have choices, is essential. Rohan Symonds will talk about his Churchill fellowship and PROJECT TEAM, a program that aims to assist more young people with disabilities to achieve active and independent participation in their communities. Dr Ann Edwards and Associate Professor Alison Holm will discuss the facilitators and barriers to church attendance and participation as described by 138 parents of children with disability, and the follow-on work of the Anglican Diocese of Southern Queensland to address equity in church participation.

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Speakers

Rohan Symonds has lived experience of cerebral palsy, is a research partner at CP-Achieve and was recently awarded a Churchill Fellowship. He is currently studying a Bachelor of Psychological Science at Federation University Australia.

Dr Ann Edwards has been a speech pathologist for over 20 years, is an Anglican priest, and is the parent of twins, one of whom has autism.

Associate Professor Alison Holm is an Associate Professor of speech pathology at the University of Tasmania. Her main areas of research are speech, language and literacy development, disorders and interventions, particularly for multilingual children.



Rohan Symonds



Ann Edwards



Alison Holm

12:30-1:30PM

Lunch break & CP-Achieve consumer partners networking session

This networking session is open to all CP-Achieve Consumer Research Partners currently working within CP-Achieve advisory groups or projects (young adult, adolescent and parent groups or individual partners).

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1:30-2:10PM

Independent Living: “My mum doesn’t know what colour my undies are!”

This workshop will explore the experience, challenges and benefits of independent living for adults with cerebral palsy.

The session will be presented by people with lived experience of cerebral palsy and researchers. Through a panel discussion, we will explore the following: 1) What does independent living mean and what is most important? and 2) What are the opportunities and challenges for young people with cerebral palsy in relation to moving to independent living? We will draw on the expertise of people with lived experience of cerebral palsy and what CP-Achieve is learning about young people with cerebral palsy and their family member perspectives on this important transition in an exploratory study on this topic.

Speakers

Dr Lyndal Hickey is a Lecturer – Teaching and Research in the Department of Social Work at the University of Melbourne. She is a Research Associate with CP-Achieve.

Peta Hooke is a disability advocate. Peta has cerebral palsy and lives in Melbourne. She is the host of The I Can’t Stand Podcast, a weekly podcast answering questions about life when you have a disability.

Dr Jane Tracy is a retired medical practitioner who worked at the Centre for Developmental Disability Health for nearly 30 years before her retirement in 2021. She has a 38 year-old son with cerebral palsy, intellectual disability and related health conditions and so has both a professional and personal understanding of the issues.



Lyndal Hickey



Peta Hooke



Jane Tracy

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Evelyn Culnane leads the Transition Support Service at the Royal Children's Hospital, Melbourne. Evelyn's leadership in the field of transition care has resulted in positive outcomes for patients with complex needs and their families including the implementation of a new model of care for adolescents with an intellectual disability and/or autism spectrum disorder with mental health or behavioural concerns.



Evelyn Culnane

Oliver Hunter is loveable, laconic and a little bit dark. Oliver is a comedian and has been cracking jokes about living with a disability for over 7 years. Having worked in the disability space in a variety of roles, Oliver's aim is to be a strong advocate for his community and continue to break down barriers and change attitudes towards disability. He's the guy you get when you can't afford Dylan Alcott.



Oliver Hunter

2:10-2:40PM

Relationships & friendships

This session will cover establishing and sustaining friendships and social connections. Associate Professor Leanne Sakzewski will provide an overview of the Education and Enrichment of Relational Skills (PEERS) program. Leanne will provide insights into the social skills development outcomes from the PEERS program for young people with cerebral palsy. A facilitated panel discussion will give lived experience insights and advice to other consumers about building relationships and friendships.

Speakers

Associate Professor Leanne Sakzewski is an occupational therapist and NHMRC Career Development Fellow at the Queensland Cerebral



Leanne Sakzewski

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Palsy and Rehabilitation Research Centre, The University of Queensland.

Gaurav Thakkar works in I.T. and is a CP-Achieve advisory group member.

Feona Magtanum is a CP-Achieve advisory group member and is currently completing her studies and a placement in childcare.

Joan Gains- see previous summary.

2:40-3:20PM

Fitness for life. Fitness for everyone

This dynamic discussion will explore physical activity for young people with cerebral palsy, functioning at GMFCS Levels IV and V. We will delve into the current evidence and provide detail on why fitness for life really is for everyone, irrespective of motor ability. We will share the experiences of young people and their supporters and let them tell us about what works, what doesn't, and what health professionals can do to support them in increasing their physical activity participation. Through a series of case studies, we will discuss the breadth of physical activity possibilities for this group, practicalities, and safety considerations.

Hosts

James Plummer is 30 years young and has a passion for adventure and challenging his disability. He has a proud desire to explore all he



Gaurav Thakkar



Feona Magtanum



Joan Gains



James Plummer

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can and exercise his dignity of risk in the process. James contributes his knowledge and expertise to the CP-Achieve Adult Transition Team. When he is not doing that, he enjoys exploring custom assistive technology solutions (much to his OT's worried bemusement) and talking enthusiastically about not a lot.

Dr Stacey Cleary is Research Physiotherapist, and a Postdoctoral Research Fellow with CP-Achieve, at Murdoch Children's Research Institute. Her research interests are: learning from those with lived experience of disability, promotion of physical activity for young people with cerebral palsy, enhancing environments to allow for physical activity for all, and translation of research knowledge into clinical practice.

Dr Carlee Holmes- see previous summary.



Stacey Cleary



Carlee Holmes

Conversation Guests

Professor Prue Morgan, Department of Physiotherapy, Monash University.

Professor Nora Shields, Olga Tennison Autism Research Centre, La Trobe University.

Mr James Czencz, Physiotherapist & PhD Candidate, Australian Catholic University.

Mr John Carey, Physiotherapist & PhD Candidate, University of Melbourne.



Prue Morgan



Nora Shields



James Czencz



John Carey

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3:20-3:50PM

Afternoon tea break

3:50-4:30PM

Bright lights- PhD in 3

PhD students working on cerebral palsy research and associated with CP-Achieve will give short presentations of their work and outcomes.

Speakers

Nadine Smith is a CP-Achieve PhD student at Murdoch Children's Research Institute and physiotherapist at the Kids Rehab WA at Perth Children's Hospital.

Jacinta Pennacchia is a speech pathologist completing her PhD at the the University of Melbourne.

Jackie Ding is a Project Officer at Murdoch Children's Research Institute in the Centre for Community Child Health and a CP-Achieve PhD student at Monash University.

James Czencz is a physiotherapist at Portland District Hospital and is undertaking a PhD with the Australian Catholic University.

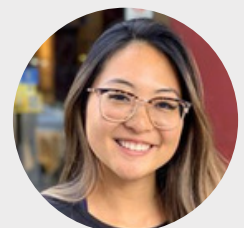
Kerry Britt is the State Project Administrator for the ENVISAGE-Families and is completing a PhD at the Department of Paediatrics at the University of Melbourne.



Nadine Smith



Jacinta Pennacchia



Jackie Ding



James Czencz



Kerry Britt

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Georgia McKenzie is a physiotherapist at the St Vincent's Hospital Young Adult Complex Disability Service and a CP-Achieve PhD student at La Trobe University.

John Carey is a physiotherapist and PhD candidate at the University of Melbourne.

Abby Thevarajah is a physiotherapist, board director of the United Nations Association of Australia's (UNAA) Young Professional Network and a PhD student with the Australian Catholic University.



Georgia McKenzie



John Carey



Abby Thevarajah

4:30-5:00PM

Closing Address- Beyond 30 years, where to from here?

Professor Dinah Reddihough will cover the cerebral palsy journey touching on what happened 30 years ago, what is happening now and hopes for the future.

Speakers

Professor Dinah Reddihough- see previous summary.



Dinah Reddihough



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