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The Participant Reference Group (PRG) consists of 23 participant and carer representatives across Australia.

These individuals have been nominated from groups including the Disability Representative and Carer Organisations (DRCO), the Independent Advisory Council (IAC) and the Participant First Engagement Initiative. Together, they represent the disability experiences of NDIS participants.

The PRG can provide:

- valuable insights and perspectives
- lived participant experience
- advice to help develop, test and improve ideas
- guidance on policy and service delivery challenges.

Members

Annette Holden - NDIS participant

Annette lost her sight later in life and has found meaning and purpose through raising awareness and changing perceptions. She says that people who live with disability should not be defined by it: it's a part of their life, but not who they are. Opportunity, equity, accessibility, and community engagement are key to a better life for everyone. Inclusion CREATES community.

Annette is a disability 'elder', inclusion awareness facilitator, advocate and presenter, and enthusiastic volunteer. She is passionate about the benefits to everyone when people who live with disability are seen, and treated as equitable individuals who enrich the community.

Ben Paor - Smith - NDIS participant

Ben is a young adult who is committed to supporting others with disability and presents a view not often directly heard by those in power.

Ben currently works at NOVA 919, is a volunteer for WOMAD and is on the Youth Advisory Group. Ben has been involved in a range of disability advocacy activities including working groups for the NDIA.

Alongside this, Ben runs a microenterprise for clothing called Hazzah Apparel and is currently in the process of developing a new content creation business. He has a passion for making music, public speaking and helping others. Ben loves his mum and thanks her for everything. His voice adds great diversity to the Participant Reference Group.

Cat Walker - NDIS participant

Cat Walker lives in rural South Australia with her husband, horses, and Kelpie. Her disability is a mix of Autism, ADHD, Ehlers Danlos Syndrome, and the ways they interact.

Cat is an experienced advocate for horses with invisible disabilities that mirror her own story. She brings her research background to systemic advocacy around the support needs of neurodivergent adults, invisible and multiple disabilities.

Cat's horse work taught her that evidence-based practice can be slow to catch up, and that lived experience evidence is important to recognise even when it is hard to measure.

Cat hopes her autistic directness will be valued and met with equal directness by NDIA staff as we work together to make the NDIS better and protect it for those who will come after her.

Charlotte Bailey - NDIS participant

Charlotte is a young woman with Down syndrome. She is an Employment Ambassador for Down Syndrome Australia and advocates for meaningful employment for everyone.

Charlotte has spoken to the United Nations and was a finalist for ACT Young Australian of the year 2024. Charlotte is passionate about educating everyone on the true meaning of inclusion.

Chris Klepacz - NDIS

Chris Klepacz - NDIS participant

Chris is a young person who lives with a physical disability who has experience and a passion for advocating on behalf of people with a disability especially for school leavers and youths. He is a member of the Yooralla Partnership Advisory Committee and has past been a member of a steering committee at a state youth peak disability advocacy organisation.

He is skilled at providing advice and input on organisational policies and has presented some of his findings at a state parliamentary inquiry on the behalf of the organisation.

He brings to the PRG his experience including some of the barriers that people with a disability have encountered and give advice on how the NDIS can reduce these barriers in policies and guideline development.

Debbie Hamilton - NDIS participant

Debbie is a mental health advocate and sits on several Boards and committees. She is undertaking a PhD on the NDIS and brings her Lived Experience expertise to policy advice and the advocacy work she does.

Debbie has experience facilitating workshops and groups and has a keen awareness of inclusive practices. She is passionate about improving the NDIS for people with psychosocial disabilities.

Ellen Gould - NDIS participant - IAC reference group member

Ellen is a youth member of PRG. Ellen advocates for inclusion of autistic people through her work with organisations including the I CAN Network and CYDA. Ellen has recently become a member of the IAC Children, Young People and Families Reference Group.

Ellen has worked with the Autism CRC, Futures Connect, Aspergers Victoria, Yellow Ladybugs and others to increase understanding of autism in girls. Ellen was recently awarded Nillumbik Young Woman of the Year for her advocacy work.

Ellen hopes to establish herself as a diversity and inclusion consultant, helping organisations to ensure their policies and programs are accessible and welcoming for the neurodivergent community.

Francesca Lee - NDIS participant

Francesca is an experienced advocate with eight years in the self-advocacy movement. Francesca has an excellent reputation for improving the lives of people with Acquired Brain Injury (ABI) through awareness raising activities and projects, representation on various committees and advisory groups, and promotion of inclusion and accessibility across all sectors for people with ABI.

Francesca has been a representative on numerous committees and was a co-facilitator with Voice at the Table, training for others with disability to be on boards and committees. She is a

member of Brain Injury Matters (BIM) and Voices for Change (VIC) and is a past President and Vice president of BIM. Francesca has done many speeches all over Australia, including Parliament House.

Dr George Taleporos - NDIS participant, IAC member

Dr George Taleporos has a physical disability and high support needs. He joined the Independent Advisory Council (Council) on 1 January 2022 for a three-year term. Since February 2021, George has been a member of Council's Home and Living Reference Group. George has over 20 years' experience advocating for disability rights and self-directed supports. Over this time, he has managed advocacy services for young people with disability across Victoria. He has also worked as a policy manager at the Summer Foundation.

George currently works as:

- Chair, Victorian Disability Advisory Council
- Senior policy analyst and communications producer, Summer Foundation
- Board member, InLife Independent Living
- Board member, Self Manager Hub
- Committee Member, COVID-19 Response for People with Disability.

Dr Taleporos has a PhD in psychology. He hosts and produces a fortnightly podcast series about the NDIS, called 'Reasonable and Necessary'.

Henry Hudson - NDIS participant

Henry has been a NDIS participant since its inception, Henry is a fervent supporter of the scheme. His increasing disability due to Multiple Sclerosis (MS) allows special insight into the often-fluctuating issues faced by many participants.

As a (now retired) small business owner living in rural Australia, Henry is enthusiastic in sharing his business acumen and networking expertise with the PRG.

Elizabeth (Lizzy) Satour - Parent Representative

Lizzy is a mum to 8-year-old Sadie a NDIS participant who has DDX3X syndrome. The family live in Alice Springs where Lizzy works as a registered nurse part time in palliative care.

Lizzy brings insights from both living in a remote community and being a parent of an indigenous participant.

Maggie Visser - Parent Representative of NDIS participant

Maggie aims to ensure people with disabilities are included and able to participate actively in their communities. Through her involvement in the PRG, Maggie shares her experience of navigating the NDIS with her son who is Autistic, has an intellectual disability, is non-speaking and who has high complex needs. Maggie also works in the disability sector where she seeks to empower people to live their best lives.

Maggie can share what is working and what is not working for families.

Naomi Colville - Parent Representative of NDIS participant

Naomi brings with her a diversity of experiences including corporate recruitment, leadership roles at a disability employment agency and migrant support services,

With various community governance roles, Naomi is a passionate advocate for regional and rural families with additional needs who continually face the challenges and complexities of limited service provision and supports.

In the final year of tertiary study and maintaining a busy household of two children with disabilities, Naomi hopes to continue to represent the unique challenges faced by marginalised and, at times, isolated families.

Neale Radley - NDIS participant

Neale is a NDIS participant after being involved in a diving accident in 2014 and becoming a C3 C4 incomplete quadriplegic.

After over 12 months of rehab, Neale moved into an aged care facility before transitioning to community living with NDIS support. Neale trains and employs his own support workforce.

Neale brings to the PRG his extensive lived experience of life as a person with complex health and disability needs of life in residential aged care and the negative impact this has on younger people. He also knows what it means to move out of aged care to live in the community and the positive impact this has had on his health, his independence, and his engagement with his local community.

Neale is keen to make a positive difference to the NDIS' continuing growth and evolution and is committed to NDIS being a world leading social insurance scheme for people with a disability.

Pauline David - NDIS participant

Born in Australia to parents from Assyrian background who migrated from Iraq, Pauline is a person with physical disability. She has experienced cultural, structural, and systemic barriers throughout her life, which have fuelled her passion to work in the disability space.

Pauline is currently peer worker and president at Diversity and Disability Alliance (DDA), a user led organisation run by and for peers from diverse backgrounds, as well as being self employed as a lived experience, access, and inclusion consultant & on various reference groups/committees.

As an advocate, facilitator & consultant, Pauline continuously challenges perceptions, attitudes, and stigma to help improve community access and promote inclusion for people with disability from CALD backgrounds.

Pauline values her independence and enjoys a very active social life and a healthy work/life balance.

Santiago Martinez - NDIS participant

Santi is a 40-year-old graphic designer deeply entrenched in various facets of the marketing industry. Santi is currently a Senior UI Designer at "the Field," a jobs platform that connects inclusive employers with talented people with disabilities seeking employment. He champions the cause of bridging the gap between inclusive job opportunities and the remarkable abilities of individuals with disabilities.

Santi is also Executive Creative Director and Founder of Bracoon Creative, an agency committed to enhancing accessibility in marketing, collaborating with designers, marketers, and developers. He strives to propel his clients' brands towards human-centered accessibility, ensuring inclusivity remains at the forefront of their brand strategies.

Santi's commitment lies in amplifying the voices of NDIS participants, echoing their aspirations for a life rich in independence, opportunities, and equality. Together with the rest of the PRG members, he aims to unleash their untapped potential, celebrating diversity as an integral part of our world. With an unwavering heartfelt commitment to advocating for accessibility, diversity, and the untapped potential within our communities.

Sarah Empey - NDIS participant

Sarah is legally blind and has been consulting in accessible, barrier-free, and inclusive design both in Australia and Canada.

An advocate for the rights of people with disabilities, Sarah has sat on various committees with organizations in policy making, funding for projects, and updating accessibility guidelines.

With her background in accessible design and lived experience Sarah has now set her focus on audio descriptions and more accessibility in navigating art museums and galleries in Queensland and NSW.

Sarah Hirst - NDIS participant

Sarah is a NDIS participant and a passionate advocate for the rights of people with disabilities. She works to influence inclusion and accessibility as the coordinator of a lived experience presenting program for one of Australia's leading not-for-profits.

Sarah is also a member of the Lived Experience Advisory Panel for The Physical Disability Council of NSW. Through her work with the NDIS PRG, Sarah hopes to continue to improve the NDIS by sharing her experiences while learning from others.

Sarah Skopellos - NDIS participant

Sarah has lived with Multiple Sclerosis for over 20 years and is a legally blind wheelchair user. Despite this, Sarah is very fit, active, and involved in community activities.

Sarah currently sits on a range of disability advocacy-related committees, including government, community and not for profits. By participating in the PRG, Sarah hopes to contribute to systemic improvements that make a real difference to NDIS participants, their families, and the broader community.

Tahlia Blanshard- NDIS participant

Tahlia (Pronouns: They/ She) is a multiply disabled and chronically ill young person from regional NSW. Tahlia is a proud advocate for the rights of the disability, youth and LGBTQIA+ communities. They believe it is extremely important that the voices of youth NDIS participants are heard and valued. They are passionate about evolving systems to improve accessibility and ensure all communities can be supported in the most inclusive and beneficial ways.

Tahlia has had the privilege of working with many organisations, including CYDA, CPActive, CPSN and Physical Disability Council NSW through a variety of reference groups, boards, and co-design projects. Tahlia is a recent addition to the Independent Advisory Council's Children, Young People and Families reference group.

During 2023 Tahlia also completed a Bachelor of Health Science. In 2022 they had the privilege of making their international para-football debut at the Women's Cerebral Palsy Football World Cup and has now played for the ParaMatildas in 11 international games and has scored 2 goals for Australia.

Tammy Milne - NDIS participant

Tammy Milne is a NDIS participant who lives in Lutruwita/Tasmania.

Tammy is a wheelchair/mobility scooter user and have has been disabled since birth.

Tammy spends a lot of time advocating for PWD in Tasmanian and beyond.

She is currently studying a graduate Diploma of Counselling at the University of Tasmania. Tammy is deputy chair of Disability Voices Tasmania and a Director of Physical Disability Australia and sits on the ministers advisory group for disability in state government.

In her spare time, she writes articles and letters for newspapers.

You can see some of her writing in the Tasmanian Times website and the Physical Disability Blog website.

Tammy is a proud person who lives with a disability and a mum to two small doggies and a daughter who is 23 years old now and has just graduated with a law degree.

Tammy's motto: I never give up!

Tiana Offord - NDIS participant

Tiana is a 20 year old woman and youth member of the PRG. Tiana involves herself in as many disability advocacy groups as she can, feeling they are invaluable in our progression as a country in relation to disability employment, education, and other relevant services.

As a linguistics and Spanish student, she is very interested in advocating for CALD communities, seeing the importance of ensuring these people have equal access to information and can understand supports.

Tiana brings the lived experience of blindness and self-advocacy to the group and looks forward to helping to shape a better NDIS for future generations of young people.

Uli Cartwright - NDIS participant

Uli Cartwright is a rambunctious member of the disability and mental health community who uses his lived experience and his time spent in foster care and group homes to advocate for human rights and to advocate a better and more dignified approach to the way service providers support people with disability.

Uli has produced a feature length film about his life, and in 2022 he spoke at the Disability Royal Commission about his experience on a Guardianship Order. Uli runs a company dedicated to advocacy in the disability and healthcare sectors, as well as providing people with services in media and support.

Uli is also an employee of VALID (Victorian Advocacy League for Individuals with Disability), through his work he visits group homes and talks to residents with disability about empowerment and self-advocacy within the 'Valid 8 Program'. Uli also provides consulting work where he is known to be candid and insightful.

Uli uses his welcomingly progressive ideas and his lived experience within the healthcare sector and having a disability to make the process practical and streamlined within the framework, whilst always keeping the individual in mind.

Zachary Colton - NDIS participant

Zac is a NDIS participant and youth member of the PRG.

Zac currently works with The Growing Space as a content developer for the Learning Team. He helps create courses which are turned into modules and offered online as courses. All research is peer lead content and is either by a person with a disability or a parent or career who has kids with special needs.

Working for The Growing Space has led Zac to have more courage in public speaking for special events. He was the MC The Growing Space Internal launch.

He is currently completing a Cert III in Information Technology at Tafe SA, in Adelaide CBD.

Zac was nominated for an Amelia Rix Award for Community Bridging Services.

Meeting dates for 2024

Online meeting times are all 2:00 - 4:00pm Sydney time.

- Wednesday, 13 March
- Wednesday, 10 April
- Wednesday, 8 May
- Wednesday, 12 June
- Tuesday, 16 to Wednesday, 17 July (2 day face to face meeting)
- Wednesday, 14 August
- Wednesday, 11 September

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- Wednesday, 9 October
 - Tuesday, 12 to Wednesday, 13 November (2 day face to face meeting)
 - Wednesday, 11 December

Meeting summaries

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