Children and Young People with Disability Australia (CYDA)

Annual Report 2022 to 2023

Children and Young People with Disability Australia (CYDA) would like to thank the children and young people with disability who have engaged with CYDA to generously share their lived experience, expertise and time to create a more equitable, inclusive and accessible community for all.

CYDA also thanks our members who ensure representation of the disabled community and accountability in all actions and advocacy.

CYDA appreciates the financial support from our funding partners and donors throughout the 2022/23 year.

Acknowledgement

Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands across Australia, whose cultures and customs have nurtured, and continue to nurture, this land since the Dreamtime. CYDA pays respect to Elders past, present and future. This is, was, and always will be Aboriginal land.

# About us

Children and Young People with Disability Australia is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA is a not-for-profit organisation that was incorporated as a Company Limited by Guarantee in November 2009.

## Vision

Children and young people with disability are valued and living empowered lives with equality of opportunity.

## Purpose

To ensure governments, communities and families are empowering children and young people with disability to fully exercise their rights and aspirations.

## Strategic goals

### Drive inclusion:

* ensure families, caregivers, communities and systems have high expectations and aspirations for children and young people
* drive inclusion from the earliest age, focusing on early learning and school
* create inclusive environments where children and young people are welcomed and valued.

### Create equitable life pathways and opportunities:

* increase pathways to post-school independence
* place children and young people at the centre of policy and reform
* leverage the flexibility of digital inclusion and entrepreneurship.

### Lead changes in community attitudes and aspirations:

* develop the voices of young leaders through codesign and paid opportunities
* change community attitudes about children and young people with disability
* build a network of allies to support social change.

### Support young people to take control:

* grow the confidence, leadership capability, and agency of young people
* connect young people with change agents and networks – building an ecosystem
* provide platforms and opportunities for young people to use their expertise to solve problems.

### Call out discrimination, abuse, and neglect:

* highlight systemic injustices and drive reform
* coordinate action to ensure rights are upheld
* support and empower children and young people and their families and caregivers to hold those in power to account.

CYDA Board Chairperson & Chief Executive Officer Report

# CYDA Board Chairperson & Chief Executive Officer Report

Dear friends and supporters,

I would like to take this opportunity to reflect on CYDA’s remarkable journey through 2022/23 and the progress we have made in advancing the rights of children and young people with disability across Australia.

One of the standout moments of the year was the National Youth Disability Summit, which for the first time was successfully held both online and in-person in Canberra. The event brought together nearly 100 passionate young individuals from all corners of the country and facilitated insightful discussions on important topics like diagnosis, education, and self-care.

Moreover, the Summit served as the launch pad for an exciting new CYDA venture, with the Hon Anne Aly MP announcing the success of our grant application to run a disability youth employment and leadership project.

The DREAM Employment Network was designed to bridge the gap between eager young jobseekers with disability and forward-thinking employers who recognize that diversity fosters creativity, innovation, and success in the workplace. The project will play a vital role in forging an Australia that recognises and embraces young people with disability as equal and valuable participants in the working landscape.

This year, CYDA also celebrated the third cohort of graduates from its popular codesigned Young Leaders Program. These individuals have gone on to become amazing community advocates and I look forward to seeing them continue to further disability rights in the coming years and decades. The future is a brighter place for their being in it.

CYDA’s influence on government policy and practice also intensified over 2022/23 as important appraisals like the Independent Review of the NDIS and the review of the National School Reform Agreement rolled out.

Our workshops with children and young people with disability and their families provided invaluable insights, based on lived experience, into what a truly functional and supportive National Disability Insurance Scheme should look and feel like.

The year also saw hearings for the long-running Disability Royal Commission come to a close. CYDA continued its advocacy for an end to violence, abuse, discrimination and neglect of children and young people with disability through its direct submissions to this body.

A personal highlight of mine involved taking our advocacy efforts to the global stage. In June 2023, I had the privilege of accompanying four members of our Youth Council to the 16th Conference of State Parties to the Convention on the Rights of Persons with Disability at the United Nations headquarters in New York.

There, our delegates fronted a crowd of distinguished advocates and policymakers from around the world and spoke about the importance of ensuring children and young people with disability are not underestimated by decision-makers. They further championed inclusive education as a critical building block of an inclusive life.

Finally, our board was thrilled to welcome three new young people with disability as members in December 2022: Chloë Polglaze, Ebe Ganon, and Margherita Dall’Occo Vaccaro. The board also established a Fundraising and Strategy Committee to support CYDA’s pursuit of diverse funding sources and secure its long-term sustainability.

It has been an incredible honour to watch CYDA evolve and expand its projects and advocacy efforts since I joined as CEO in October 2022. There is much to come, and I’m excited to see what the next year holds.

Sincerely,

Matthew Hill - Chairperson

Skye Kakoschke-Moore - Chief Executive Officer

# CYDA Board

### Matthew Hill (Vic) Chairperson Appointed October 2019

Matthew is a senior executive with more than 15 years experience in governance and board roles involving both the not-for-profit and private sectors. Matthew has a strong interest in providing value and support to communities and associations like CYDA.

Over Matthew’s career, he has developed skills in leadership, growth strategies, building relationships, seizing control of critical problems and delivering on customer commitments.

Matthew is a father of two children and has family experience of disability. Matthew is extremely committed to progressing the rights of children and young people with disability, particularly inclusive education.

### Pamela Williams (Vic) Deputy Chair and Secretary Appointed August 2021

Pam is a senior executive with experience in government and consulting. Her leadership roles have included operational service delivery, emergency management, strategic policy and planning, research, audit and evaluation. Pam has experience in policy and provision of state government community and disability services. She has also undertaken board director roles in a cemetery trust, community housing association, tenancy support group, and local community organisations.

Pam has family experience of disability and through her role on the CYDA Board is proud to promote the voices and rights of children and young people with disability.

### Timothy Lachlan (Qld) Appointed December 2020

Timothy (he/him) is an Occupational Therapist and the first Australian to land a wheelchair backflip. He is Neurodivergent and lives with Spina Bifida and Ehlers Danlos Syndrome (EDS). Since age 15, Timothy has hosted wheelchair skate workshops that teach wheelchair users advanced mobility skills. His lived experience made him a passionate advocate for Universal Design, invisible disabilities, and intellectual disabilities. His passion for helping others is what led him to become a member of the Codesign Committee for the first National Youth Disability Summit (NYDS) in 2020 and subsequently, a CYDA Board Member.

### Lara Maia-Pike (Qld) Appointed December 2020

Lara is an equity practitioner and mother of two boys. She has worked in higher education for over 14 years and is passionate about education and social justice.

Lara is a PhD candidate in inclusive education with research focusing on transition planning for students on the autism spectrum in senior high school. She is an Associate Fellow for the Higher Education Academy and a member of the Centre for Inclusive Education.

### Andrew Dean (Vic) Appointed December 2021

Andrew is a corporate lawyer with more than 13 years’ experience in the insurance and property industries. He has worked closely with multiple Australian Government departments, and has also gained very strong governance experience, through serving as both company secretary and director for corporate entities within Australia and overseas.

Personally, and most importantly, Andrew is a father to two boys and has experience of disability as a parent giving him exposure to, and first-hand experience with, the often daunting and confusing world of NDIS and educational support for those living with disability. It has become very clear to Andrew that significant work is still needed to ensure that the system meets the needs of children and young people with disability.

Andrew’s experience in advocating for his son is a key driver for him joining the CYDA Board.

### Kristen Desmond (Vic) Appointed December 2021

Kristen is a mother of three young people with autism and an advocate for many young people in Tasmania. Kristen is the Founder of the Tasmanian Disability Education Lobby and has lobbied the Tasmanian Government for a complete reform of the Tasmanian disability education system for more than 15 years. She is committed to ensuring all children receive an education that meets their needs.

Kristen was a former director for CYDA from November 2014 to December 2016 before she resigned to concentrate on disability reform in Tasmania.

Kristen, now having achieved real reform in Tasmania, would like to use those same skills to contribute to CYDA’s national work through its Board.

### Ebe Ganon (ACT) Board Appointed December 2022

Ebe Ganon is a young Canberran with extensive experience in communications, community engagement and project management. Ebe currently works as an equity and accessibility specialist and was a member of CYDA’s inaugural Youth Council. Ebe is undertaking postgraduate studies in disability and inclusion at Deakin University and has completed a Certificate IV in Auslan. Ebe also works as a group fitness instructor promoting accessibility and inclusion in mainstream gym settings.

### Margherita Dall’Occo-Vaccaro (WA) Appointed December 2022

Margherita is a migrant, queer, young woman with a disability who works across organisations, Australian and international committees and businesses to advocate for young people with disabilities and multiple other identities. With a background in law and human rights, she works on a wide range of projects to advocate in many intersecting areas through policy, media, representation, communications and law reform.

### Chloë Polglaze (VIC) Appointed December 2022

Chloë (she/her) is a disabled graduate civil engineer with a communications background who is passionate about disability advocacy and inclusion. Previously she worked at a university where she created and facilitated a disability allyship workshop. Chloë was part of CYDA’s first Youth Council and first Young Leaders Program. She was motivated to join the CYDA Board after experiencing first hand how impactful CYDA can be on the lives of disabled young people.

# CYDA Board

## Committees

Finance and Risk Management Committee membership

Pamela Williams (Chair), Andrew Dean (until December 2022), Matthew Hill, Timothy Lachlan (until December 2022) and Ebe Ganon (from January 2023)

Policy and Governance Committee membership

Kristen Desmond (Chair), Lara Maia-Pike, Timothy Lachlan and Margherita Dall’Occo-Vaccaro (from January 2023)

Fundraising and Strategy Committee membership (formed 2023)

Andrew Dean (Chair), Chloë Polglaze and Pamela Williams

## Meeting attendance

A total of eight board meetings were held during the reporting period.

Matthew Hill was eligible to attend 6 meetings and attended 6.

Pamela Williams was eligible to attend 6 meetings and attended 6.

Andrew Dean was eligible to attend 6 meetings and attended 6.

Chloe Polglaze was eligible to attend 4 meetings and attended 4.

Ebe Ganon was eligible to attend 4 meetings and attended 4.

Kristen Desmond was eligible to attend 6 meetings and attended 5.

Lara Maia-Pike was eligible to attend 6 meetings and attended 5.

Margherita Dall’Occo Vaccaro was eligible to attend 4 meetings and attended 3.

Timothy Lachlan was eligible to attend 6 meetings and attended 3.

# CYDA staff

Skye Kakoschke-Moore

Chief Executive Officer (from October 2022)

Liz Hudson

Policy and Research Manager

Daniel Munter

Youth Programs Manager

Sonia Regan

Community Impact Manager

Joanne Ellingworth

Business Manager\*

Madeleine Clarke

Youth Programs Coordinator\*Senior Youth Programs Coordinator\* (from June 2023)

Kim Collinson

Inclusion Support Officer (until March 2023)

Miranda Cross

Senior Policy Officer (until October 2022)

Jason McCurry

Youth Leadership and Development Coordinator\*Senior Youth Programs Coordinator\* (from June 2023)

Megan McBaron

Capacity Building Project Coordinator\* (until September 2023)

Sarah Priest

**C**ommunications and Media Adviser\*

Ewen Rawet

Policy Engagement Officer\* (until June 2023)

Sue Tape

Project Coordinator – Inclusive Education\*

Husna Amani

Youth Project Support Officer\* (until June 2023)

Kay Barnard

Youth Connection and Opportunities Officer\* (until June 2023)

Naomi Chainey

Communications and Media Adviser\*

Shae Hunter

Policy Officer\* (until December 2022)

Jess Rosenthal

Administration Officer\*

David Kavanagh

Communications and Media Adviser\* (from August 2023)

Sharon O’Mara

Policy Officer\*

Dula Hettiarachchi

Policy Officer\*

Laura Pettenuzzo

Inclusion Support Officer\* (from September 2023)

Dylan McBurney

Youth Trainee (from March 2023)\*

Georgia Ferrari

Youth Trainee (from March 2023)\*

\*Part time

CYDA would like to acknowledge the contributions of the 2022/23 Youth Council members and youth casuals, as part of the CYDA staff. CYDA also recognises the support of volunteers, in tasks like administration and office operations.

CYDA 2022/23The year in review

# Membership by state

ACT 2.5%

NSW 24.8%

NT 0.6%

VIC 44.4%

QLD 10.5%

SA 9.2%

TAS 3.4%

WA 4.5%

INT 0.1%

# Membership

5226 members

**254** Calls were received by CYDA for phone information services.

**CYDA in Action**

In 2022/23, CYDA saw an increase in followers and engagements across all social media platforms, as a direct result of a focused effort on communications across the organisation.

21,711 Facebook followers

5,861 Twitter followers

2,149 LinkedIn connections

1,310 Instagram followers

CYDA distributed two newsletters during the year. The eNews is a monthly newsletter that is shared with members and subscribers from across the disability community. The Platform was introduced in 2022 and was designed to be a youth-specific newsletter. It was supported by an Instagram profile of the same name.

13 Platform issues with **2,704** opens

12 E-news with 15,119 opens

## Organisational development

### Communications

With an increase in staffing to support the organisation’s communications, CYDA is moving toward a more strategic approach to managing our internal and external communications with members and the broader community. This has included the development of a communications strategy and a targeted approach to sharing key advocacy messages, and incorporating the voices of young people with disability.

### Impact measurement

CYDA continues to make changes to the way we measure and evaluate our activities, including consideration to the impact we are having across the sector. In December 2022, a survey of our community members to measure their perception of the impact CYDA had made on outcomes for children and young people with disability. The survey highlighted where CYDA was having an impact, and key areas for improvement.

### Fundraising and membership

CYDA has developed a fundraising strategy to explore the long-term sustainability of the organisation. This has included reviewing opportunities for philanthropic and corporate partnerships, as well as community fundraising initiatives. A fundraising coordinator was recruited in March 2023 to progress this work for the organisation.

CYDA’s membership program includes young people with disability, families and supporters. An audit of the membership was conducted in April 2023, to identify areas of strength and opportunities for future growth.

### Organisational restructuring

2022 saw the consolidation of the leadership structure within CYDA with all management positions confirmed.

Due to continual growth in project staffing, the Youth Action Team (YAT) created two new senior project coordinator roles in June 2023, as part of a restructure. Two existing project coordinators were successful in being promoted to these roles, providing continuity and depth to the YAT and the organisation as a whole.

The restructure allows the YAT to develop deeper connections between program participants and staff. This will ensure the ongoing quality of programs and supports, and create new leadership and representation opportunities for disabled young people within the organisation.

### Ongoing opportunities for Youth Council members

CYDA was also able to extend professional development opportunities for Youth Council alumni through continued work on our projects, consultations, policy analysis and communications. Nurturing a relationship with our Youth Council members has also allowed CYDA to respond quickly to new opportunities to influence government policy and engage with our community.

### Child Safe Practices

CYDA is committed to ongoing review of our child safe practices, to ensure compliance with national legislation and the National Principles of Child Safe Organisations. Throughout 2022/23, CYDA undertook an internal review of child safe practices and sought feedback from staff and young people about areas for improvement.

Additional areas of focus included:

* Staff training in cultural competency and intersectionality
* Public statement on website and in recruitment processes
* Ongoing review of policies, particularly those related to Code of Conduct, interactions with young people and social media usage.
* Commitment to quality and effective safeguarding across all states and territories, despite variations in legislative requirements in each jurisdiction.

Strategic Goal 1 - Drive inclusion

To achieve this goal, CYDA will:

* ensure families, caregivers, communities and systems have high expectations and aspirations for children and young people
* drive inclusion from the earliest age, focusing on early learning and school
* create inclusive environments where children and young people are welcomed and valued.

## Key achievements

### Ensuring Inclusive Education in Australia Project

In 2022, CYDA designed and delivered a series of inclusive education webinars for families of young children with disability, and those who support them. The aim of the webinars was to share the direct experiences of young people with disability to support families, caregivers, and communities to have high expectations and aspirations for all children and their education. The webinars are designed to promote inclusion in early childhood in day-to-day activities that set up children for success.

CYDA staff delivered 11 webinars, with over 1,159 registrations and developed worksheets, resources and materials covering early years and transition to school. The webinars and resources are now being developed into accessible formats to enable public access via the CYDA website.

### Australian Coalition for Inclusive Education

The Australian Coalition for Inclusive Education (ACIE) is a national coalition of organisations working together to advance inclusive education in Australia and across state and territory education systems. Throughout 2022 and 2023, CYDA continued to undertake the role as chair and convenor of ACIE. CYDA co-ordinated the first in-person meeting of ACIE to formalise the 2023 strategic planning process. As a result, coalition members are tailoring the Roadmap for Achieving Inclusive Education in Australia for specific states and audiences.

### Disability Standards for Education Resources

Since 2021, CYDA has worked with the Department of Education to develop a set of resources to explain the Disability Standards for Education (DSE), for young people, families and educators. The community have continually reported that the DSE is complex and hard to understand, making it difficult for individuals to know and understand their rights and how they can be utilised for self advocacy in an education environment.

The resources were codesigned by CYDA and the Department of Education with more than 100 students with disability, parents, and caregivers. Partnerships were also formed with external stakeholders including the First Peoples Disability Network, Inclusion Australia, and the National Ethnic Disability Alliance.

The first batch of resources was released in later 2022, to support students with disability and their caregivers to understand their rights within the education system. A second batch of resources will be released in late 2023, and the final batch will launch in 2024.

**Strategic Goal 1** - Drive inclusionKey achievements

Disappointment and discrimination: CYDA’s surveys of the learning experiences of children and young people with disability in 2022 and 2023

96% of young people with disability believe CYDA create inclusive environments

78% of young people with disability report that CYDA has helped their understanding of inclusion

(source: CYDA’s Impact Survey 2023)

CYDA conducted three education surveys during 2022 and 2023:

* Early Childhood Education & Care Survey 2022 – for families and caregivers of children in early childhood education and care settings
* Youth Education Survey 2022/23 – for students with disability who are at school or who have recently left or finished school.
* Education Survey 2022 – for families and caregivers of children and young people in school

CYDA partnered with researchers from the Melbourne Graduate School of Education, University of Melbourne and Public Service Research Group, University of New South Wales (UNSW) Sydney?? Canberra to analyse the data and prepare each of the three reports.

These surveys and resulting reports are part of CYDA’s ongoing commitment to understanding the experience of children and young people with disability in Australia. Taken together they give a comprehensive view into the experiences and challenges faced by children and young people with disability and their families as they begin their lifelong learning journey.

## Policy submissions

CYDA made the following submissions to drive inclusion:

* Education and Employment References Committee’s Inquiry into the national trend of school refusal and related matters (Inquiry) (December 2022)
* Disability Royal Commission: Vision for Inclusive Australia (December 2022)
* Senate Inquiry into School disruption (March 2023)
* Education Department’s National Vision for Early Childhood Education and care (April 2023).

Strategic Goal 1 - Drive inclusionPartnerships, collaboration and representation

CYDA developed strong relationships with the following campaigns, organisations and groups, to ensure inclusive education for children and young people across Australia.

* Australian Coalition for Inclusive Education (ACIE)
* Thrive by Five campaign
* The Parenthood (Thrive by Five campaign partner)
* Disability representative organisations and disability people’s organisations networks
* National School Reform Agreement Ministerial Advisory Council
* The Advisory Group as part of the National Mental Health Commission’s Early Childhood Health Checks Project.

### We had representatives in the following groups:

* Disability Strategy Reference Group, convened by the NSW Department of Education
* Disability Inclusion Reference Group, convened by the Department of Education (Victoria)
* Disability Standards for Education Peaks Groups, convened by the Department of Education, Skills and Employment
* National Advisory Group, convened by the Playgroup Australia
* Thrive by Five Early Childhood Education and Care campaign, convened by the Thrive by Five – Mindaroo Foundation
* Australian Coalition for Inclusive Education, convened by the CYDA chairs, convenes and provides secretariat services
* Students with Disability Working Group, convened by the Australian Curriculum, Assessment and Reporting Authority
* Interagency Policy Group, convened by the Physical Disability Council of NSW
* Advisory Group for the Development of National Guidelines for Wellbeing Indicators in Early Childhood Health Checks, convened by the National Mental Health Commission
* Income Support and Employment Services Network, convened by the Australian Council of Social Service

## Involving young people in raising awareness about inclusion

As a member of CYDA’s Youth Council 2022, university student Ashleigh Keating received training in media and facilitation. This enabled her to grow the confidence and leadership capability to give voice to issues important for young people.

Ashleigh was diagnosed with autism as a child. In her interview with the media in 2023 about inclusive education, Ashleigh said she was not supported at all during her schooling. She discussed the exclusion that students with disability often experience and reflected on the direct impact of reduced resources on student inclusion.

CYDA invited Ashleigh to be the lead facilitator in the Reimagining NDIS focus groups. These were held to provide children, young people and families an opportunity to share their experiences of the NDIS, as part of the Independent Review of the NDIS. Ashleigh was also a member of CYDA’s delegation to the United Nations.

By including voices of young people like Ashleigh in community engagement and sector capacity-building activities, CYDA is ensuring advocacy is strongly informed by lived experience. Participants also report a better understanding of an individual’s personal experiences of exclusion.

Ashleigh was also a member of CYDA’s delegation to the United Nations in June 2023.

Strategic Goal 2 - Create equitable life pathways and opportunities

To achieve this goal, CYDA will:

* increase pathways to post-school independence
* place children and young people at the centre of policy and reform
* leverage the flexibility of digital inclusion and entrepreneurship.

## Key achievements

### In Control Our Way resources for parents and caregivers

In 2020, a series of resources were developed to build the capacity of families and caregivers to self manage their child’s NDIS plan. The resources were hosted on CYDA’s website, and were shared via sector partners and on parenting websites, including the Raising Children Network.

Due to ongoing changes to the NDIS, the resources have required significant rewriting. This has been commenced in 2023, and the resources are expected to be shared in early 2024.

The resources will support families and caregivers to maximise their child’s NDIS funding, to ensure equitable life pathways.

### Reimagining NDIS by children, young people and families

CYDA received funding from the Australian Government to facilitate consultations as part of the Independent Review of the NDIS in early 2023. The project began in March 2023 with children, young people with disability and parents or caregivers, invited to share their experiences of the NDIS.

The project included:

* a total of 10 two-hour
* a total of 67 participants comprising 47 parents or caregivers and 20 young people aged 15-29 years
* all states and territories were represented
* diverse representation including Aboriginal and Torres Strait Islander participants, culturally and linguistically-diverse participants and participant with a refugee background.
* 96% of young people state that CYDA place children and young people at the centre of policy and reform
* 83% of adults believe CYDA are working to create equitable life pathways for young people with disability

CYDA will continue to consult and test ideas with focus groups in the second half of 2023. The data gathered during these consultations will contribute to the final report of the Independent Review of the NDIS, which is expected to be published by the government in late 2023.

### Placing young people at the centre of policy reform

During 2022/23 CYDA was approached to facilitate consultations on a range of important policy issues. Children and young people with disability were invited to contribute their lived experience and expertise to guide policy reform which included:

### Conduct e-safety language review

The Office of the e-Safety Commissioner sought to review our research report examining the online experiences of young people with disability and their parents and caregivers. Two young people with disability, Emily and Georgia, were recruited by CYDA to conduct a language review to ensure appropriate, inclusive and strength-based language throughout. Emily and Georgia will both appear as contributors to the report once published. The E-Safety Commission gave positive feedback about the involvement of the young people.

“Georgia and Emily have done a brilliant job. Please pass on our thanks for their thoughtful and instructive feedback. We will certainly acknowledge their contribution in the report”

Manager, Research, Data & Evaluation, E-safety.gov.au

### Getting young people’s research interests on the agenda

CYDA partnered with the National Disability Research Partnership to consult with young people about disability-related topics they would like to see researched further. Topics highlighted by young people included:

* the prevalence and underreporting of abuse and neglect of children and young people with disability
* the impact of ableism on mental health and access to healthcare, employment and education
* intersectionality of disability and identity (gender, sexuality, cultural)
* how ignorance about invisible disability results in being locked out of services.

### Develop good practice guidelines for engagement with people with disability

CYDA facilitated consultations with young people with disability in conjunction with the Centre for Inclusive Design about establishing good practice guidelines for engaging with people with disability.

### Consult on the guide to the Australian Disability Strategy

CYDA partnered with Disability Advocacy Network Australia (DANA) to deliver two consultation sessions, cofacilitated by young people with disability. The sessions were designed to gather feedback from young people with disability about the Australian Disability Strategy guide. Two 90-minute online sessions were held in November 2022 with 17 young people with disability.

CYDA continues to build a strong reputation across Australia as a leader in engaging young people with disability in a meaningful and authentic way. Our voices in policy reform are highly valued by our national partners to ensure decisions are made in the best interests of young Australians.

Strategic Goal 2 - Create equitable life pathways and opportunities

## Policy submissions

* National Disability Advocacy Framework 2022 to 2025 consultation (July 2022)
* Senate Inquiry into work and care (September 2022)
* Joint submission on disability and higher education (November 2022)
* Department of Social Services consultation: Strategy Guides for Australia’s Disability Strategy (December 2022)
* CYDA Pre-Budget submission 2023/24 (January 2023)
* A new act to replace the *Disability Services Act 1986*: A joint submission from Disability Representative Organisations (February 2023)
* Quality Framework for the Disability Employment Services program (February 2023)
* Early Years Strategy discussion paper (April 2023)
* Inquiry into Early Childhood Education and Care (May 2023)
* LivedX-What young people want:
* To understand the lived experiences and perspectives of young people with disability across a range of issues, CYDA hosted consultations and one-on-one interviews. These consultations were codesigned by a working group of young disabled people and were synthesised into a series of five papers in December 2022:
* LivedX 1: Tertiary education and learning
* LivedX 2: Financial security and employment
* LivedX 3: Healthcare settings for LGBTQIA+ youth with disability
* LivedX 4: Community spaces for LGBTQIA+ youth with disability
* LivedX 5: Inclusion and decision making

The papers are available on CYDA’s website and form the basis for ongoing advocacy for CYDA.

## Partnerships, collaboration and representation

* Towards best-practice access to services for culturally and linguistically diverse people with a disability, convened by the Social Policy Research Centre & the National Ethnic Disability Alliance
* Australian Universal Design for Housing, convened by the Australian Universal Design for Housing

### CYDA in Practice: Investing in children and young people with disability: *their voices and their future*

In January 2023, CYDA issued a pre-budget submission to the Australian Government, calling for a strong investment in children and young people with disability.

“CYDA urges the Australian Government to make bold and targeted investment in children and young people with disability, to maximise individual power and autonomy, and support social inclusion, safety and equality to ensure their rights are upheld and that Australia is truly an inclusive society for all its citizens.”

The submission highlighted five key areas for further investment:

1. Involve and engage children and young people with disability across all government portfolios impacting their lives

2. Adequately resource Australia’s Disability Strategy’s (ADS) key actions and targeted action plans (TAPs)

3. Develop and implement a targeted National Youth Disability Employment Strategy

4. Drive and fund transformational change to ensure inclusive education

5. Ensure the National Disability Insurance Scheme is fit-for-purpose for children and young people

The messages from this submission have informed CYDA’s position on key advocacy areas, including education, employment, safety, and the NDIS.

# Strategic Goal 3

Lead changes in community attitudes and aspirations

To achieve this goal, CYDA will:

* develop the voices of young leaders through codesign and paid opportunities
* change community attitudes about children and young people with disability
* build a network of allies to support social change.

## Key achievements

### The Platform newsletter

The e-newsletter is distributed to more than 400 young people and is supported by a social media platform of the same name.

The newsletter was developed to promote and celebrate young people’s contributions to disability advocacy. The Platform is a combination of youth-lived experiences, connections to important projects and opportunities across Australia, and participation in the disability discourse that is identified as important to disabled young people.

The first edition of the newsletter was shared in January 2023, with 12 editions released from January to June. Topics have included disability pride, community participation, sexual and reproductive health, advocacy in medical spaces and diversity. The newsletter has more than 400 national subscribers.

### Book Review Project

CYDA invited young people with disability to read and review 45 children’s picture books about disability, inclusion, diversity, and identity. The reviews are intended to be shared with teachers, schools, families, and caregivers to facilitate conversations with young children about diversity and inclusion.

A total of 84 young people applied to participate in the project, with 15 young people aged 9 to 26 years selected. The young people represented seven different states and territories and were supported by family members when required.

Young people were given the opportunity to build peer networks through reviewing up to 45 children’s books to identify positive characters and stories related to disability and inclusion.

Young people produced creative reviews of each book in a variety of formats to share with teachers, schools, families and caregivers, promoting inclusion and understanding among students.

In June 2023, CYDA began scoping opportunities for sharing the book reviews in places like early childhood settings, school systems, state education departments and with book authors or publishers.

Although the full distribution is in late 2023, the project has attracted interest from early childhood educators, schools, government and the wider community. CYDA was accepted to present the Book Review project at the 2023 Reimagine Australia National Early Childhood Support Conference and the Early Childhood Australia National Conference in late 2023. Audiences will include early childhood workforce, advocates and families.

“ It was also incredibly lovely and personally healing to read these books that would’ve been instrumental in my own upbringing. Being able to share these thoughts, to possibly encourage a shift, a change in the discussions about disability with children and young people ... I don’t know how to articulate how much that means to me.”

Book Reviewer, Young person with disability, June 2023

### Disability Youth Leadership Program: DREAM Employment Network

In January 2023, the Department for Social Services announced CYDA’s successful funding application to implement the DREAM Network. The Network aims to influence community attitudes by bridging the gap between employers and young people with disability seeking employment.

Project planning, including codesign, commenced in May 2023, with the Network set to operate in the 2023/24 financial year.

### Developing the voices of young leaders through codesign and paid opportunities

CYDA continues to be committed to ensuring young people with disability are at the forefront of decision making and communications. We have facilitated opportunities for young people to share their experience as a way to influence change in the community.

* CYDA’s Youth Council: Youth Council members are often invited to support CYDA’s representation on advisory groups or to participate in community events, including virtually or in person
* Media opportunities: CYDA supports a range of young people to share their lived experience via media to highlight key advocacy issues.
* Public platforms: CYDA provides young people with opportunities to develop their advocacy via blogs or videos on topics that are important to them, including education, employment and travel.

### Adolescent Violence in the Home – webinar panel

CYDA was invited to participate in a webinar in partnership with Australia’s National Research Organisation for Women’s Safety (ANROWS). The webinar was part of a launch for research into adolescent violence in the home, advocating for a collaborative service response.

The research shows a high rate of violence among adolescents with disability and ANROWS aimed to highlight the need for trauma-informed, disability-informed service responses. CYDA was invited to participate as a panel member for the webinar. A young person with disability was also identified to participate, supported by CYDA. The webinar was rescheduled to the second half of 2023.

Strategic Goal 3 - Lead changes in community attitudes and aspirations

69% of young people with disability believe CYDA are changing attitudes about children and young people with disability

83% of adults report that CYDA has helped them to have higher expectations of young people with disability.

## Policy submissions

Disability Royal Commission Disability Pride Youth Forum summary report (December 2022)

## CYDA in Practice: Youth Voice: Challenging myths about young people with disability

Emily Unity was a member of CYDA’s Youth Council in 2022/23. They shared their views on ableism in the media and broadly across society. The following is a blog post, written by Emily and shared on CYDA’s website and social media platforms.

“As a disabled young person, it’s heartbreaking to be bombarded by media that perpetuates ableist attitudes and myths. Especially with the recent federal budget, it’s awful to see headlines that paint people like me as a burden to society or a drain on the economy. I am writing this reflection to disrupt the normalised ableist narrative and bust the media myths that perpetuate it.”

Myth: disability supports are ‘tax burdens’ or ‘costs to the healthcare system’.

Fact: Disability supports are an investment in the wellbeing of Australians with disabilities. Many disabled individuals rely on government-funded programs such as the National Disability Insurance Scheme (NDIS) to provide essential services and supports such as healthcare, education, and employment. These services are not a burden but rather a necessary investment in promoting the wellbeing and inclusion of disabled individuals in society. Providing disability supports is not only a matter of social justice, but is also early intervention and prevention, and a way to reduce inequality by ensuring that disabled individuals have the same opportunities as non-disabled people.

Myth: disabled people waste their support resources on ‘junk therapies’.

**Fact:** Disabled people, like everyone else, have the right to make choices about their own health care and wellness. It is also important to note that not all disabilities can be treated with conventional medicine and many disabled people face significant barriers to accessing quality healthcare and may turn to alternative therapies as a last resort. Rather than blaming disabled people for supposedly wasting resources, we should work to ensure that all people, regardless of ability, have access to high-quality, affordable healthcare. We should also respect disabled people’s autonomy and their right to make informed decisions about their own health and wellbeing.

Myth: disabled people are greedy for money and are being over diagnosed to secure more funding.

**Fact:** Disability diagnoses are made based on medical evidence and clinical expertise, not financial gain. In fact, many people with disabilities face significant barriers to getting the support they need, including long wait times for assessments and services, lack of accessible infrastructure, and discrimination in employment and education.

Myth: disabled people are the cause of high costs, not the supports or system.

**Fact:** There are systemic issues that contribute to the high cost of supports like the NDIS. These issues include unnecessary bureaucracy, the lack of accessibility in mainstream services such as health and education, the need for greater investment in early intervention and prevention, and the underfunding of disability services for many years.

Myth: there’s nothing anyone can do to change these myths.

**Fact:** Anyone can speak up and challenge this harmful narrative. I believe that we have a collective responsibility to change the narrative around disability and the NDIS. We need to start talking about the value and worth of people with disabilities and the vital role they play in our society. We need to acknowledge that disability is a natural part of human diversity, and that everyone has the right to live their life to the fullest. We need to demand better representation in the media, and we need to speak out against ableist attitudes and discrimination wherever we see it.

I can’t wait to see a future where disabled people like me are genuinely valued as people, rather than just numbers on a balance sheet.

## Partnerships, collaboration and representation

* Disability Sector Consultative Committee, convened by the NDIS Quality and Safeguarding Commission
* Complaints Function Advisory Committee, convened by the NDIS Quality and Safeguarding Commission
* CEO Forum, convened by the National Disability Insurance Agency
* Codesign Advisory Group, convened by the National Disability Insurance Agency
* NDIS Joint Advocacy and Codesign, convened by the Disability Representative Organisations (DROs)
* NDIS Systemic Advocacy Working Group, convened by the Public Interest Advocacy Centre (PIAC)
* Child Youth and Families Reference Group, convened by the NDIS Independent Advisory Council
* Information Gathering for Access and Planning – Steering Committee, convened by the National Disability Insurance Agency
* Employment Briefing, convened by the National Disability Insurance Agency
* National Disability Research Partnership Strategic Communications Reference Group, convened by the The Social Deck
* NDIS Quality and Safeguarding Commission Research and Practice Steering Group, convened by the NDIS Quality and Safeguarding Commission

Strategic Goal 4 - Support young people to take control

To achieve this goal, CYDA will:

* grow the confidence, leadership capability, and agency of young people
* connect young people with change agents and networks, building an ecosystem
* provide platforms and opportunities for young people to use their expertise to solve problems.

## Key achievements

### In Control Our Way Project

The In Control My Way Project has developed seven resources to support young people to take control of their NDIS planning and implementation, and to increase their choice, control and autonomy.

Five young people with disability who have experience with the NDIS formed a codesign group and were supported by a project coordinator. A total of 19 meetings were held to conceptualise and codesign the project (August 2022 to June 2023). In addition to online meetings, CYDA hosted a codesign workshop for the group to meet in person in Adelaide. The group created audiovisual content for the project, undertook resource development and peer-tested draft resources. Local young people were also invited to share their varied personal experiences of the NDIS to add depth to the resources.

The codesign team gave positive feedback about both the experience of codesign and the resources that they had developed. The project supported capacity building of the codesign team who reported feeling confident that they had developed resources that would support a range of young people.

“Everything in my life relies on NDIS funding…when you don’t have that understanding of your plan or funding it is terrifying because you feel out of control of your own life. Knowing that these resources are out there, I now know how much I would have appreciated to have these.”

The codesign team said they were particularly proud that they had created new resources targeted young people, given most resources focused on older adults. They felt that the resources would better equip young people to manage their services and assume choice and control in their life.

The resources are scheduled for public release in September 2023.

### Youth Council

CYDA’s Youth Council provides young people with disability an opportunity to grow their confidence and leadership with the support of CYDA. Youth Council members are provided with training in governance, codesign and media engagement. These skills provide them with skills to:

* represent CYDA at community events, forums or round-table discussions
* share their lived experience in the media in a way that furthers advocacy and builds their profile
* participate in community leadership and governance opportunities.

In December 2022, CYDA appointed three new Board members, who were former members of CYDA’s Youth Council. This has provided invaluable leadership opportunities for the young people while also adding depth and value to CYDA’s governance.

### National Youth Disability Summit 2023

CYDA delivered our second National Youth Disability Summit in a virtual format in July 2022, hosting more than 500 attendees over three days.

Building on this, CYDA hosted the third Summit in January 2023 as a hybrid event, both online and in person. The event was held in Canberra and had a theme of ‘Our Voices, Our Abilities, Our Future’.

The Summit was codesigned with CYDA’s Youth Council to ensure that the topics were youth-led, and youth-focused. A total of 60 young people with disability participated in the two-day Summit (either in person or virtually), with central topics surrounding inclusive education, diagnosis and self care. Attendees also participated in social and networking activities, including a gala dinner.

Speakers included a range of disabled advocates. Nas Campanella, National Disability Affairs Reporter, spoke about the power of inclusive education for young people with disability. Recognised community advocates, Zoe Simmons and Mali Hermans, shared their lived experience of diagnosis and self care.

Members of parliament from the disability and community sectors were also invited, including Minister for the National Disability Insurance Scheme and Minister for Government Services, The Hon Bill Shorten MP, Minister for the National Disability Scheme and Government Services, The Hon Dr Anne Ally MP, Minister for Youth

Senator The Hon Jordon Steele-John.

Bill Shorten MP, the Minister for Early Childhood Education and Minister for Youth, the Hon Dr Anne Aly MP, and Greens Senator for WA, , the Hon Senator Jordon Steele-John. Young people were given opportunity to speak directly to government ministers and learn more about their portfolios.

The Summit included round-table discussions where Youth Council members facilitated discussions, encouraging young people to share their lived experience, learn from others and build strong peer connections. Attendees reported that they found the Summit meaningful and engaging, both in-person and online.

### National Youth Disability Leadership Program

CYDA’s National Youth Disability Leadership Program (or Young Leaders Program) was delivered as a seven-month program focused on building leadership and disability advocacy skills for young people with disability. The 2022/23 cohort were the third group to complete the program, working hard to develop their skills, build connections with peers and hear from leaders with disability in the general community.

The program addresses a range of topics to build the leadership capacity of individuals including values and goal setting, systems change, advocacy and activism, and disability justice. Young people are given direct access to disability leaders and advocates through presentations and ongoing mentoring.

Ten young people graduated the program in February 2023, representing communities across Australia. Each graduate was paired with a mentor of their choice, to further develop their leadership and advocacy skills over the subsequent 12 months.

### Partnerships, collaboration and representation

CYDA convenes the National Youth Disability Network.

* Our Voices, Our Way, Our Lives Project Advisory Committee, convened by Inclusion Australia
* Growing Up Making Decisions, convened by the National Disability Research Partnership Project University of New South Wales

CYDA in Practice: CYDA at the 16th Conference of State Parties

In June 2023, four members of CYDA’s Youth Council, board member Margherita Dall’Occo-Vaccaro and CEO, Skye Kakoschke-Moore, attended the 16th Conference of State Parties to the Convention on the Rights of Persons with Disabilities (COSP) at the United Nations headquarters in New York.

More than 100 countries were represented at COSP, with CYDA being one of 48 civil society organisations from around the world representing people with disability and their supporters.

Delegates Ashleigh Keating, Charlotte Young, Danny Dickson and Justin Hill delivered speeches, participated in events and built connections with young disabled leaders and organisations from around the world.

Themes for discussion included inclusive education and the underrepresentation of children and young people in decision-making and reforms. CYDA cohosted an event called Children with disabilities: going beyond representation with the Canadian Institute on Disability and Public Policy where common barriers to inclusion were discussed.

CYDA’s attendance at COSP increased awareness among international delegates, as well as those attending from Australia, about CYDA as a national youth representative organisation. CYDA’s presence highlighted how organisations can help to bridge the gap between domestic and international advocacy efforts by young disabled people.

During the conference, delegates asked questions and provided reflections on their own experiences with inclusive education, invisible disability, involvement in politics, employment, neurodiversity and the underrepresentation of young people with disability in decision-making roles.

“Attending the Conference on State Parties helped me to understand the rights of persons with disability from an international point of view on the topic of disability and what countries are doing to advance the rights of those with disabilities. Charlotte and I took part in doing an intervention (speech) on behalf of CYDA where we made the message clear on not leaving children and young people with disability behind, where we had the confidence to speak up and tell the forum not to leave nobody behind.”

Justin Hill, Youth Council member, COSP delegate

Strategic Goal 5 - Call out discrimination, abuse and neglect

To achieve this goal, CYDA will:

* highlight systemic injustices and drive reform
* coordinate action to ensure rights are upheld
* support and empower children and young people, and their families and caregivers, to hold those in power to account.

## Key achievements

### Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

As part of its continuing commitment to engaging children and young people with disability in the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC). CYDA held the following activities:

* Disability Pride Forum: an online forum was held for young people with disability to explore disability pride and how society can better support disability pride to guard against violence, abuse, neglect and exploitation of people with disability. Nine young people attended a 90-minute session, which was recorded and shared as a submission to the DRC.
* *Vision for an Inclusive Australia*: Quest for Inclusion: CYDA hosted an interactive in-person activity with a small group of teenagers to create a vision for an inclusive society. Using gamification methods, the participants used Dungeons and Dragons to tell stories, solve puzzles and tackle challenges to access and inclusion in an engaging fantasy format. The sessions was recorded and summarised with materials forwarded to the DRC as a formal submission.

91% of young people with disability believe CYDA are driving reform by calling out discrimination, abuse and neglect.

Young people feel more safe interacting with CYDA than they do in their broader community.

### Policy submissions

* Disability Royal Commission’s Supported decision-making and guardianship: proposals for reform roundtable paper (August 2022)
* National Inquiry into Long COVID and Repeated COVID infections (November 2022)
* Disability Royal Commission: Targeted Engagement with young people with disability (November 2022)
* Joint submission from Disability Representative Organisations Identified gaps in the scope of work undertaken by the Disability Royal Commission (November 2022)
* Joint Submission to the Disability Royal Commission: Charter of Human Rights\_ (December 2022)
* Disability Royal Commission: Summary of CYDA recommendations to the DRC\_2019- 2022 (December 2022)
* Draft National Stigma and Discrimination Reduction Strategy (February 2023)
* Senate Inquiry into the Extent and Nature of Poverty (February 2023)
* Education Department’s Review of the impact of COVID-19 on school students with disability (April 2023)
* Inquiry Committee into the Provision of and Access to Dental Services in Australia (June 2023)

**Partnerships, collaboration and representation**

CYDA convenes Disability Representative Organisations (DRO) Disability Royal Commission (DRC) Sector Meetings.

* Child Safe Sectors Leadership Group, convened by the Attorney General's office
* Respectful Relationships Reference Panel, convened by the Department of Education, Skills and Employment
* Charter of Human Rights Campaign Advisory Committee, convened by the Human Rights Law Centre
* Advisory Group for National Strategy to Prevent and Respond to Child Sexual Abuse, convened by the Attorney General's office
* National Coalition Steering Group, convened by the Families Australia for National Framework for Protecting Australia’s Children
* Disability and Health Sector Consultation Committee (DHSCC) , convened by the Department of Health
* DRC DRO meetings, convened by the DRC

CYDA in Practice: Community Survey: The impact of ending mandatory self-isolation periods for people with COVID-19 on children and young people with disability.

On Friday 30 September 2022, the Australian National Cabinet announced that the self-isolation period for people testing positive to COVID-19 would cease to be mandatory as of Friday 14 October, 2022. As the national peak representative organisation for children and young people with disability, Children and Young People with Disability Australia (CYDA) undertook a community poll asking how young people with disability and their families would be impacted by this decision.

The poll had 142 respondents.

**6%** were young people with disability between 12 and 17 years old.

**26%** were young people with disability between 18 and 25 years old.

**68%** were parents or caregivers of children or young people with disability.

**88%** of young people with disability, and **81%** of parents and caregivers, **DO NOT** support ending mandatory self-isolation periods for people with COVID-19 at this time.

Common themes emerged from respondents:

* feelings of anger, exhaustion and grief at being forgotten, abandoned or “betrayed” by policy-makers
* lack of trust in the general population to take personal responsibility for COVID19 mitigation in a safe and effective way without a mandate
* frustration that the weight of personal responsibility will fall disproportionately on those most at risk of long-term complications or death from COVID-19
* fear, anxiety or “terror” regarding the increased risk of being exposed to COVID-19 without a mandate in place
* frustration that a change in policy, promoted as an increase in personal freedom, will in practice reduce freedoms and safe access to community for an already marginalised group
* fear around being exposed to support workers with COVID-19 if they are no longer mandated to self-isolate
* fear that children and young people with disability will be at increased risk of exposure to COVID-19 at school.
* fear that parents with pre-existing conditions will be at greater risk of exposure to COVID-19 via their school age children without a mandate to self-isolate in place.

“These are the times that I wish I wasn’t chronically ill or disabled, because the choices that ablebodied people make about massive public health issues like this affect us and limit us from going about our normal days.”

CYDA highlighted the concerns of, and for, children and young people who are mandated to attend school, where remote learning was no longer an option. Children and many young people are generally not in a position to make their own choices about attending public spaces or having contact with non-family members, including in spaces such as childcare or sporting clubs.

In light of the responses and the risk to children and young people, CYDA recommended renewed efforts by the government to consider public health campaigns and to reconsider the cessation of mandatory isolation.

“I am terrified. We will definitely be spending a huge amount of our time at home and only going out when absolutely necessary (therapies and medical appointments).”

CYDA continue to work alongside our community and government to systematically advocate at the national level for the rights and interests of all children and young people with disability living in Australia.

# Financial snapshot

Total revenue: $3,056,653

Total expenditure: $2,735,258

Result: surplus $321,395

Total Members Equity 2021/22: $423,689

Total members equity 2022/23: $745,084

Income 2022/23
Revenue $3,040,557

Interest $16,096

Expenditure 2022/2023
Corporate administration $441,341

Employee benefits $1,591,317

Depreciation & amortisation $34,339

Finance costs $4,408

Network support and collaboration $473,327

Consultancy $190,526

# The year ahead

The year ahead is full of new opportunities for CYDA and the broader disabled community. CYDA CEO Skye and Board Chair Matthew reflect on their vision for the next 12 months.

When one door closes, another one opens. This year several of our longstanding youth leadership and capacity-building projects are set to end, with funding winding down for our Youth Council, Young Leaders Program, and the National Youth Disability Summit.

I believe this presents us with an exciting new opportunity: the chance to explore and embrace different, long-term, and more sustainable funding sources for the vital work we do.

CYDA is uniquely placed to actively contribute to significant reforms impacting the lives and futures of children and young people with disabilities and their families. We’ll continue to fight to ensure the rights of our community are upheld and advanced through the implementation of recommendations by the Disability Royal Commission and NDIS Independent Review.

As the organisations enters the final year of its current Strategic Plan, the board is committed to ensuring the voices of children and young people with disability and their families are central to the design and implementation of the next Strategic Plan. In so doing, we ensure CYDA’s broad mission and direction are directly informed by the needs and concerns of our core community.

We are also further embedding good governance practices at a board level, including regular training, risk management reviews and succession planning.

Thank you

The CYDA team would like to thank the CYDA Board, members, partners, funders and supporters for their contribution to CYDA in the year July 2022 to June 2023.

CYDA thanks children and young people, and their families, across Australia for their contributions to furthering systemic advocacy and creating a more inclusive, equitable future for all. CYDA acknowledges the personal stories that have been shared and values the lived-experience contributions from the whole community.

CYDA would also like to thank our partners, supporters and followers for their ongoing support and trust.

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