

Children and Young People with Disability Australia (CYDA) Annual Report July 2021 to June 2022



### **Thank You**

Thank you to the children and young people with disability who have engaged with CYDA and shared your lived experience, expertise and time. We appreciate all that you do to support our work and to create a more equitable, inclusive and accessible community for all.

#### Thank You to all our Funders









- 1. The Lynne Quayle Charitable Trust, managed by Equity Trustees
- 2. The John Saville Eastwood Trust, managed by Equity Trustees

#### **Acknowledgement**

Children and Young People with Disability Australia (CYDA) 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. We pay our respects to Elders past, present and future. This is, was, and always will be Aboriginal land.



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### **About Us**



Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA is a not-for-profit community 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.

#### **Our 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 co-design 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.

## **Chair & CEO Report**







The 2021–22 year was one where CYDA consolidated operations following a period of growth and had enormous impact and reach in policy, advocacy and youth empowerment and leadership development.

CYDA has seen two cohorts of national young leaders complete the program. The format of the Young Leaders Program is co-designed with young people and covers content including Wisdom Weekends, Deep Dives, Structured Networking sessions and individual mentoring. The program provides professional development opportunities, personal reflection activities and networking opportunities to build leadership skills and advocacy pathways for young leaders.

The National Young Leaders Program has seen strong outcomes during this period with most participants securing work and meeting their leadership goals. Many have engaged in a wide range of other leadership opportunities, like giving evidence for parliamentary inquiries and the Disability Royal Commission where issues like discrimination, abuse, and neglect are being examined. Through their involvement in boards and youth advisory groups for other organisations, the National Young Leaders Program participants will be leading changes in community attitudes and aspirations about young people with disability.

The National Youth Disability Summit was co-designed by a group of 10 young people with disability from around Australia, with the event held in July 2022. The Summit Co-Design Committee identified three themes for the Summit; education; advocacy; and medical systems, diagnosis and emotional fatigue of disability. The planning and facilitation of the virtual event was supported by the entire CYDA team and culminated in a successful, well-organised, and well-attended event. Throughout this year, the CYDA community continued to experience significant impacts from the COVID-19 pandemic. CYDA supported young people to take control through continuing to advocate for the consideration of children and young people with disability in decision making during the pandemic. The report Locked out: Vaccination Discrimination for Children and Young People with Disability found there were significant barriers to vaccinations. This is despite children and young people with disability being one of the most 'at-risk' groups in the population for adverse effects of the virus.

During this reporting period, CYDA provided sector leadership to advocate against the proposed National Disability Insurance Scheme (NDIS) independent assessments. In July 2021, the Australian Government announced they would not proceed with the proposed independent assessments but would instead commence a process of co-design to determine the most appropriate alternative. This outcome demonstrates how CYDA's systemic advocacy leads to the creation of more equitable life pathways and opportunities for young people with disability. Throughout 2021 and 2022, CYDA have continued to drive inclusion through discussions with the NDIA to inform the codesign process and ensure young people are well represented.

## **Chair & CEO Report**



The Board had a very productive year, and would like to thank the outgoing board members, Jocelyn Neumueller, Grace Mills (Deputy Chair) and Julie Maylian. With the graduation of CYDA's Inaugural Youth Council, members were invited to express their interest in joining CYDA's Board. It is anticipated youth members will join the Board in late 2022. In August 2022, the Board also farewelled Mary Sayers, the Chief Executive Officer when she resigned after three years in this role. Mary oversaw significant growth and achievements for CYDA and was instrumental in leading the CYDA vision of ensuring children and young people with disability are valued and living empowered lives with equality of opportunity. She also achieved substantial revenue growth so CYDA could continue to support outcomes for children and young people with disability across Australia.

In October 2022, the Board welcomed Skye Kakoschke-Moore to the Chief Executive Officer role. Skye joins CYDA with a background in disability advocacy, human rights and politics. She looks forward to further growing CYDA's impact, sustainability and leadership opportunities for children and young people with disability.

Matthew Hill Chair

Mary Sayers
Chief Executive Officer







Matthew Hill (Vic) Chair Appointed October 2019

Matthew is a senior executive with more than 15 years of 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.



Grace Mills (WA) Deputy Chair Resigned June 2022

Grace is a young person with disability who has been involved with the disability sector in Western Australia since 2013. She has experience in a range of community organisations, beginning with Youth Disability Advocacy Network (YDAN), Diverse Leadership WA and VisAbility. She later joined the City of Perth Access & Inclusion Advisory Group and did volunteering with Essential Personnel to foster young people living with disability to follow their passions and career goals through their Employment Buddy Program. She has been a member of the Ministerial Advisory Council on Disability for WA and the Telethon Kids Institute Youth Advisory Group in her quest for equity and inclusion for young people with disability being involved in policy and research work.

Grace is involved with the Australian Inclusion Group, Inclusion Solutions, Disability Assembly WA, Department of Health Disability Health Network Executive Advisory Group, the NDIA Independent Advisory Council Home & Living Terms of Reference Group and has a love of martial arts and music.

Grace believes that the inclusion of young people with disability in the community in all areas of life, from education to employment and building strong social networks, is key to a thriving and welcoming society.





#### Pamela Williams (Vic) Secretary Appointed August 2021

Pam is a senior executive with experience in government and consulting.

She has had leadership roles in operational service delivery, emergency management, strategic policy and planning and research, audit and evaluation. Pam has worked on the policy and provision of state government community and disability services. She has also undertaken board director roles in a community housing association, tenancy support group, and local community organisations.

Pam has family experience of disability and is keen to support the work of CYDA in promoting the rights of children and young people with disability.



## Timothy Lachlan (Qld) Appointed December 2020

Timothy is a young person and the first Australian to land a wheelchair backflip. He is neurodivergent and lives with Hypermobile Ehlers-Danlos Syndrome, Hypotonia and Spina Bifida Occulta. Timothy is a fourth-year Occupational Therapy (OT) student who is passionate about Wheelchair Moto-Cross (WCMX), fabrication and advocating for access and inclusion.

Tim's passion for helping others is what led him to become a member of the Co-design Committee for the 2020 National Youth Disability Summit and go on to start his own business fabricating affordable, high-quality disability equipment.



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

Lara is an equity practitioner and mother of two boys. She has worked in higher education for over14 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 over 13 years' experience in the insurance and property industries. In his role 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. In addition to this, Andrew regularly sits on executive steering committees and operational boards.

Personally, and most importantly, Andrew is a father to two boys and has experience disability reform in Tasmania. 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 of CYDA from November 2014 to December 2016 before she resigned to concentrate on

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.



Julie Mavlian (NSW) Resigned May 2022

Julie is a mother of four children including a young person with disability.

Julie is a learning and support teacher at a NSW public school. She has a Masters in Special Education and has worked with students in a variety of educational settings from preschool through to adult for more than 30 years.

Julie is a passionate advocate who has worked proactively for the rights and needs of children and young people with disability.





#### Jocelyn Neumueller (SA) Resigned December 2021

Jocelyn is a young person that is passionate about sport and the opportunities it offers. She lives with disability and since 2014 has been involved with committees and organisations in the disability and sporting sectors at both state and national levels. As a Paralympian and world champion, she is passionate about being an active and engaging role model and advocate for people to live the life they love through committee and board participation, advocacy, mentoring and actively engaging in the community. She believes that everyone should get the chance to participate, perform and connect regardless of physical or intellectual ability.

Having a background and degree in medical science, Jocelyn is completing a law and legal practice degree alongside disability advocacy. Jocelyn has contributed to several community and government boards and committees over the years.

#### **Committees**

Finance and Risk Management Committee Membership Pamela Williams (Chair), Andrew Dean, Matthew Hill, Timothy Lachlan and Jocelyn Neumueller.

#### **Policy Committee Membership**

Grace Mills (Chair), Kristen Desmond, Lara Maia-Pike and Julie Mavlian.

#### **Meeting Attendance**

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

| <b>Board Member</b> | Eligible to attend | Attended |
|---------------------|--------------------|----------|
| Andrew Dean         | 4                  | 2        |
| Kristen Desmond     | 4                  | 4        |
| Matthew Hill        | 8                  | 8        |
| Timothy Lachlan     | 8                  | 7        |
| Lara Maia-Pike      | 8                  | 8        |
| Julie Mavlian       | 7                  | 5        |
| Grace Mills         | 8                  | 8        |
| Jocelyn Neumueller  | 4                  | 1        |
| Pamela Williams     | 6                  | 6        |

### **CYDA Staff**



The period 2021-22 has been a year of continual growth for CYDA as an organisation. This has resulted in a significant increase in the number of staff members joining the team.

To provide a high level of support to staff, and to create strong internal knowledge systems, CYDA introduced four work teams, supported by team managers. This restructure has enabled CYDA to attract discipline-specific staff and to allow individuals to utilise their strengths as part of the broader organisational vision.

| Husna Amani          | Youth Project Support Officer* (from June 2022)                 |
|----------------------|---|
| Kay Barnard          | Youth Connection and Opportunities Officer* (from June 2022)    |
| Naomi Chainey        | Communications and Media Adviser* (from June 2022)              |
| Madeleine Clarke     | Youth Programs Coordinator*                                     |
| Kim Collinson        | Inclusion Support Officer* (from October 2021)                  |
| Miranda Cross        | Senior Policy Officer   |
| Alana Doyle          | NDIS Capacity Building Coordinator (until October 2021)         |
| Claire Dunton        | Social Media Officer* (until June 2022)                         |
| Joanne Ellingworth   | Business Manager*   |
| Liz Hudson           | Policy and Research Manager (from November 2021)                |
| Shae Hunter          | Policy Officer* (from June 2022)                                |
| Skye Kakoschke-Moore | Chief Executive Officer (from October 2022)                     |
| Maeve Kennedy        | Policy and Programs Manager (until October 2021)                |
| Amy Marks            | Youth Connection and Development Officer* (until February 2022) |
| Jason McCurry        | Youth Leadership and Development Coordinator*                   |
| Jess Mitchell        | Youth Storytelling and Development Officer* (until August 2021) |
| Daniel Munter        | Youth Programs Manager (from March 2022)                        |
| Brendon Pinto        | Youth Trainee* (until January 2022)                             |
| Sarah Priest         | Communications and Media Adviser*                               |
| Ewen Rawet           | Policy Engagement Officer* (from August 2021)                   |
| Sonia Regan          | NDIS Capacity Building Coordinator* (January 2022-June 2022)    |
|                      | Community Impact Manager* (from July 2022)                      |
| Tasha Ritchie        | Youth Programs Manager (until January 2022)                     |
| Jess Rosenthal       | Administration Officer* (from June 2022)                        |
| Mary Sayers          | Chief Executive Officer (until August 2022)                     |
| Sue Tape             | Project Coordinator – Inclusive Education*                      |
| Terry Wesselink      | Community Impact Manager (November 2021 to May 2022)            |
| Kelly Wilson         | Acting Community Impact Manager* (until January 2022)           |

<sup>\*</sup>Part time/casual

CYDA would like to acknowledge the 2021–22 Youth Council members and their contributions to the organisation as casual employees. CYDA also recognises the support provided by volunteers, including in the support of administration tasks and office operations.

### CYDA 2021-22

### The Year in Review



#### **Key Stats and Facts**

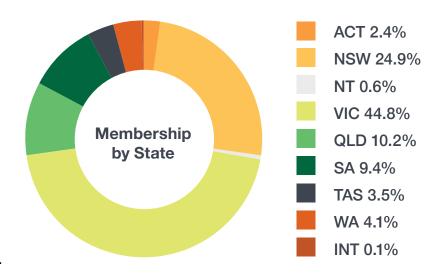
#### Membership



#### **Phone Support**



were received by CYDA for phone information services.



#### **CYDA** in Action



**Submissions** 

in response to government inquiries



Webinars

conducted as part of the Inclusive Education in Australia Project



Forums Held

Disability Royal Commission engagement



(including **85.3%** new visitors)



sent to members and subscribers over the year (a total of **80,158** individual emails)











#### **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**

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.

 A total of 11 webinars across six topics were designed and developed for delivery from January to June 2022. There was significant interest in the webinars with over 400 registrations for the four webinars held in May and June 2022.

- A pool of 11 young people recruited as cofacilitators to support the design and delivery of the webinars. Each webinar included the stories, tips and voices of three young people. Young people were supported with briefings, accessibility features and prompting questions to develop their stories and input for each topic. This included sharing their memories, their favourite things, and their advice for families and educators. Young people shared their experience and insights as part of the live webinar. The initiative developed individual skills such as self-advocacy, presentation and storytelling. The webinars also provided clear and purposeful advice for families and caregivers.
- Young people were supported by CYDA to build their capacity in the ongoing development of communications skills, support network and organisational capacity building.
- Case studies and youth resources were developed in partnership with young people to promote inclusion in education across CYDA and partner organisations.



#### **Drive Inclusion**



#### Australian Coalition of 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. CYDA chairs and co-convenes ACIE with partner organisation, All Means All.

The ACIE Roadmap – Driving Change: A Roadmap for Achieving Inclusive Education, provided a clear framework for CYDA's advocacy including:

- featuring in education recommendations in the Pre-Budget Submission and CYDA's 2022 Election Platform
- as a platform to outline student voice and to drive an inclusive education in Australia.

#### **Disability Standards for Education –** Resources for Students, Families and **Caregivers**

CYDA was contracted by the Federal Department of Education to co-design and develop resources to support young people with disability and their carers to understand and navigate the Disability Standards for Education (DSE).

 CYDA worked diligently to co-design and develop a range of further resources identified as important by community groups to understand and engage with the DSE. CYDA engaged in a four-session round of co-design meetings with three subgroups, to develop ranges for general, CALD communities and First Nations individuals.

- Resources were co-designed with three specialist community groups, including supports from National Ethnic Disability Alliance, Inclusion Australia, and First People Disability Network to co-design resources for their representative audiences.
- CYDA has completed development of the resources, with Tranche 1 set for distribution in mid-late 2022.
- Tranche 2 resources have been submitted to the Department of Education, with further revision work to completed before distribution in 2023.

#### **Digital Access and Inclusion: A Guide** to Digitally Inclusive and Accessible Co-design, Consultations and Events

CYDA was approached by Foundation for Young Australians to develop a digital inclusion and accessibility guide for event planning and development. The guide was developed to upskill the youth sector to maximise engagement when working with the intersectionality of youth and disability. The guide was designed to provide a reference for young people with disability to host their own peer-led spaces.

- The project facilitated co-design opportunities with multiple stakeholders, including young people with disability.
- Even before it is published, the guide has gathered significant interest from senior leaders across the child and youth sector, with significant interest from the National Office for Child Safety.
- The guide is planned for release at the end of 2022. It will be made publicly available on CYDA's website and will be promoted widely through our networks. It will be updated as techniques and methodology evolve.

### **Drive Inclusion**



#### **Policy Submissions and Reports**

Submission to the National Disability Advocacy Framework 2022-2025 Consultation

Clearing the Roadblocks: Promoting Equitable Pathways and Opportunities - CYDA's 2022 Election Platform

Submission to the Quality Initial Teacher Education Review

Report – Locked out: Vaccination Discrimination for Children and Young People with Disability



#### Partnerships, Collaboration and Representation

| Group  | Convenor  |
|--|---|
| Disability Strategy Reference Group                        | NSW Department of Education                               |
| Disability Inclusion Reference Group                       | Department of Education (Victoria)                        |
| Disability Standards for Education Peaks<br>Groups         | Department of Education, Skills and Employment            |
| National Advisory Group                                    | Playgroup Australia                                       |
| Thrive by Five Early Childhood Education and Care campaign | Thrive by Five – Mindaroo Foundation                      |
| Australian Coalition for Inclusive Education               | CYDA chairs, convenes and provides secretariat services   |
| Students with Disability Working Group                     | Australian Curriculum, Assessment and Reporting Authority |
| National Disability Coordination officers                  | National Disability Coordination officers                 |
| Students with Disability Loading Review – Expert Panel     | Price Waterhouse Coopers                                  |
| Disability Employment Services Reform<br>Reference Group   | Department of Social Services                             |
| Income Support and Employment Services<br>Network          | Australian Council of Social Service                      |

#### **Drive Inclusion**



#### Case Study 1

Xander (he/him) is a 15-year-old high school student with disability and a proud member of the LGBTQIAP+ Community. Xander is passionate about advocating for all people with a disability, especially his peers, within the education system. Xander was supported by CYDA to co-host the webinars Inclusion in Early Childhood: When and Where Do We Start? and Early Intervention and Inclusion -Can We Do Both?.

Feedback from attendees was positive about Xander's involvement:

"The young people who spoke were eloquent and insightful. Thank you for providing the platform for us to hear their thoughts on such an important issue."

At CYDA's invitation, Xander also led the development of a tip sheet regarding early intervention for families of young children and contributed to an article in the Learning Difficulties Australia magazine.

"I wanted to let you know that these opportunities have really helped me in many ways. Working with CYDA has helped me value myself more and have the opportunity to be heard. So thank you."

(Xander, student)



### 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**

# Research: The Impact of COVID-19 on Post-School Transitions for Young People with Disability

CYDA partnered with researchers from the University of Melbourne and the University of New South Wales to identify the additional challenges young people with disability face as they finish school and transition to work or higher education.

- The research was co-designed with young researchers who were employed by CYDA.
- The findings highlighted the importance of an individualised approach to support during school and supported transition to postschool options.
- The published report will be used as a platform for CYDA and other organisations to advocate for improved approaches to post-school planning for young people with disability.



#### **Growing Up Making Decisions Project**

CYDA partnered with University of New South Wales and Inclusion Australia to investigate how children and young people with cognitive disability are supported to make decisions about important aspects of their life.

The research aimed to learn how children and young people make decisions, and what helps them make those decisions.

A community researcher, with lived experience as a young person with disability, held individual interviews over Zoom with children, young people and parents and caregivers. Nine young people with cognitive disability, aged 14 to 25 years and six parents, participated in the study.

The responses were collated and summarised by the research team and published in a report, released in 2022.

The research then looked at what improvements could be made. The report identified:

- how systems such as education, health, NDIS, and out-of-home care could be improved so that young people have the opportunity and support to be part of the decision-making process
- more information should be provided about rights – to young people with cognitive impairments and their families and society more broadly
- more information and resources should be provided to young people, their families and services about supporting young people to build capacity in decision making
- programs are needed to support young people build capacity in decision making

   including specific areas such as leaving out-of-home care, NDIS planning, moving to adult health care, leaving school, finding employment, moving out of home.

### Create Equitable Life Pathways and Opportunities



The results were also presented by the community researcher at the Virtual Disability Conference 2022: Raising Expectations.

#### In Control Our Way Project

In 2020, a series of resources were developed to build the capacity of families and caregivers to self manage their child's NDIS plan. In 2021, these resources were shared, and planning commenced to develop a strategy for distribution, promotion and ongoing updates.

The series of resources are available on the CYDA website and are accessed by parents and caregivers seeking support implementing their child's plan. These resources will be updated in the financial year 2022–23 to ensure the most up-to-date NDIS information is included.

By supporting families and caregivers to understand and implement their child's plan, the project aims to create positive experiences for children and young people and ensure the NDIS supports the best possible life path.

#### **COVID-19 Vaccine Ambassador Project**

The Department of Health (Victoria) provided funding to engage communities, parents, caregivers to support the COVID-19 vaccination program for those aged five to 11 years. With a strong network of families with children at potential increased risks associated with COVID-19, CYDA was able to develop a social media campaign to:

- promote and increase awareness of the vaccination program
- increase circulation of trusted, credible vaccine information
- enhance culturally-appropriate and accessible engagement
- dispel myths and address community concerns and
- increase health literacy.

CYDA also facilitated a webinar targeting families of young children who were interested in further information about the vaccination program.

### Research Project: The Impact of COVID-19 on Post-School Transitions

CYDA partnered with University of New South Wales and the University of Melbourne to explore the experiences of young people with disability transitioning from secondary school in 2020 or 2021 and explores whether the COVID-pandemic has had a significant impact in the post-school transition period.

The research was co-produced between two academics and two young people with disability who were co-researchers employed by CYDA.

The research found that students with disability have not only had their education interrupted, but the pandemic has reinforced the existing inequality they face in their education.

#### **LivedX Youth Advocacy**

LivedX has been designed by and for young people with disability. Co-design with young people was integral to this project and consequently LivedX was steered by a working group of the Youth Council.

A series of seven consultations, referred to as LivedX, provided opportunity for 63 young people from across Australia to share their insights, experiences and ideas for a future that embraces young people with disability and enables them to thrive.

The project, a component of CYDA's Our Voices Our Visions: Youth Advocacy Project, was funded by the Youth Advocacy Support Grant from the Australian Department of Education, Skills and Employment.

### Create Equitable Life Pathways and Opportunities



There were seven sessions held in 2021 covering a range of topics that young people deemed important to them. These consultations have been synthesised into a series of five papers, to be published in late 2022.

- Tertiary Education and Learning
- Financial Security and Employment
- Healthcare Settings for LGBTQIA+ Youth with Disability
- Community Spaces for LGBTQIA+ Youth with Disability
- Inclusion and Decision Making

Once published, the LivedX papers will be used to advance CYDA's systemic advocacy.

#### **Policy Submissions and Reports**

Submission to the Consultation of the New Disability Employment Support Model

Submission to the National Disability Insurance Agency's Support for Decision Making Consultation

Submission to the Review of the Disability Support Pension Impairment Tables

Submission to the Inquiry into the Purpose, Intent and Adequacy of the Disability **Support Pension** 

Submission to the Social Security Legislation Amendment (Streamlined Participation Requirements and Other Measures) Bill 2021 [Provisions]

Report - How Did COVID-19 Impact Post-School Transitions for Young People with Disability and How Can These Be Better Supported?

#### Partnerships, Collaboration and Representation

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

### Create Equitable Life Pathways and Opportunities

#### Case Study 2

CYDA partnered with the University of New South Wales to undertake the Growing Up and Making Decisions Research Project. The project aimed to understand how young people with cognitive disability and their families can build their capacity to make decisions at various life stages.

Community researcher, Britt (she/her) was involved as a young person with disability. Britt interviewed young people with cognitive disability and their families. Britt facilitated a comfortable environment for them to share their stories and ensured their views were interpreted correctly. Britt's personal experiences provided a valuable insiderperspective.

"I learnt what it took to be an ethical researcher, an interviewer and just how much our voices really do have a chance to be heard. CYDA's support set me up for success from day one and the University of NSW empowered me."

(Britt, community researcher)

From the research findings, a practical resource for young people and their families will be created and released in late 2022.





To achieve this goal, CYDA will:

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

#### **Key Achievements**

#### **Developing External Communications**

The growth of CYDA and our increasing advocacy work is an opportunity to establish a consolidated and clear communication strategy. During this period, CYDA began this work through:

- development and growth of social media platforms to increase reach and share key advocacy messages, including introducing new platforms such as LinkedIn to reach a more diverse audience
- increased staffing resources to support an organisational approach to communications
- commencement of planning for an impact strategy and data dashboard to measure impact across the community.

#### **Education Community Attitudes Project**

CYDA, as part of the Australian Coalition for Inclusive Education (ACIE), managed a project to investigate community attitudes towards inclusive education.

The project included:

- background desktop research looking at Australian and global evidence, in support or otherwise of the case for inclusive education
- stakeholder interviews, and online focus groups conducted with teachers and families.

Key findings from this project confirmed the need for active student voice and continued engagement with education stakeholders. CYDA's Inclusion in Early Childhood webinar series designed subsequently, ensured the voice of young people, their experiences, and related support for educators was prominent and focused on the need to openly discuss community attitudes.

#### **Developing the Voices of Young Leaders Through Co-design and Paid Opportunities**

CYDA is deeply committed to ensuring that the voices of young people with disability are accounted for and valued in decision making. CYDA plays a key role in promoting the voices of young people by modelling ways young people can influence policy and change in the community. In 2021-22, CYDA has engaged young people through:

- CYDA's Youth Council: a group of 12 young people with disability were given paid working opportunities to support CYDA's decision making, engagement methodologies and representation at community events.
- Media Opportunities: CYDA has supported many young-disabled people to be involved in media opportunities, including mainstream news, articles and podcasts.
- Advocacy: CYDA has supported a range of young people with disability to be involved in consultations, co-design and advocacy opportunities to be decision makers and have their lived experience heard as part of government, community and organisational initiatives. CYDA's expertise in youth disability engagement has been recognised across Australia with an increased number of requests for support with initiatives that champion lived experience.



### Lead Changes in Community Attitudes and Aspirations

#### Partnerships, Collaboration and Representation

| Group  | Convenor                                       |
|--|--|
| Disability Sector Consultative Committee                           | NDIS Quality and Safeguarding Commission       |
| Complaints Function Advisory Committee                             | NDIS Quality and Safeguarding Commission       |
| CEO Forum  | National Disability Insurance Agency           |
| Co-design Advisory Group   | National Disability Insurance Agency           |
| NDIS Joint Advocacy and Co-design                                  | Disability Representative Organisations (DROs) |
| NDIS Systemic Advocacy Working Group                               | Public Interest Advocacy Centre (PIAC)         |
| Child Youth and Families Reference Group                           | NDIS Independent Advisory Council              |
| Information Gathering for Access and Planning – Steering Committee | National Disability Insurance Agency           |
| Employment Briefing  | National Disability Insurance Agency           |

#### Case Study 3

In December 2021, the In Control My Way working group invited the then NDIS Minister, Senator the Hon. Linda Reynolds CSC to attend a meeting. A group of five young people with disability discussed their key challenges with the NDIS, including specific challenges faced by young people to access and utilise the scheme.

The Minister responded positively, highlighting the need for youth representation on the advisory panels of the NDIA. The group followed the meeting by writing a formal letter to the government reiterating their concerns and the agreements from the Minister.

Young people valued the opportunity to be involved in the discussion.

"I really enjoyed and appreciated the opportunity to talk to the Minister. I feel like I am making tangible change for myself and others in the disabled community. And I feel like I've been given the opportunity to have a voice when it comes to issues that matter."

(ANON., working group participant)

Although there was a change in government a few months later, there has been a noticeable shift in the willingness to include young people in decision making with the NDIS, and more broadly across government.

### 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**

### National Youth Disability Summit 2022: Our Stories, Our Future

CYDA's second annual National Youth Disability Summit was delivered in July 2022. The Summit was co-designed with the National Summit Co-Design Committee. It was a three-day flagship event to connect a diverse range of participants, including young people with disability, professionals from a variety of sectors, and government officials. Two of the three days were for young people only. This created a safe space for young people to engage with the content, grow their knowledge and create connections.

The Summit engaged a diverse range of speakers and leaders in the sector, including Dr Ben Gauntlett (Disability Discrimination Commissioner), members of parliament the Hon. Amanda Rishworth MP and the Hon. Jason Clare MP, Dr Dinesh Palipana, and Elise Muller.

The themes for the Summit were chosen by the Co-design Committee and included; education, advocacy, medical systems, diagnosis and emotional fatigue of disability.

CYDA partnered with Inclusion Australia and Deaf Australia in the planning process for the Summit to provide stronger accessibility and inclusion for attendees.

The Summit was hosted during NAIDOC week, and included significant focus on Indigenous culture, speakers such as Damian Griffiths, Elise Muller and Gi Brown, and topics to champion celebration of Indigenous culture and the intersection with youth and disability.

#### **National Summit Co-design Committee**

CYDA formed a National Summit Co-Design Committee to support the design and delivery of the National Youth Disability Summit for 2022.

The National Summit Co-Design Committee provided eight young people with disability with seven months of leadership and decision-making opportunities to create a youth-led, co-designed national event. All members of the National Summit Co-Design Committee received opportunities for further development and training such as media training, understanding how to utilise a budget, event management, and knowledge of Indigenous cultural competency.

Members of the committee reported the opportunity to be involved was significantly rewarding and engaging and supported their own personal goals.

### National Youth Disability Leadership Program

CYDA's National Youth Disability Leadership Program (or Young Leaders Program) is a six-to-12-month-fully-online leadership program for young people with disability aged 18 to 25 years. It is funded by the Information, Linkages and Capacity Building (ILC) Program from the Department of Social Services (DSS).

CYDA delivered the second program between August 2021 to May 2022 which saw nine young leaders graduate. The program provided an opportunity for young people to develop skills, knowledge and be introduced to a network of engaged young people and sector leaders.

### Support Young People to Take Control



The program covered topics such as identity and values, community, systems change and self care. Deep Dive sessions were introduced to the program. These were co-designed by young people and focused on disability rights, leading and managing a team, building a profile and networking.

The program invited high-profile guest speakers to attend, including politicians, actors, disability advocates, paralympians and media personalities. Guest speakers were identified by the cohort of young people and invited to attend by CYDA. Young Leader graduates were offered professional mentoring for 12 months following the program. Mentors were external to CYDA and matched to the aspirations of the young person.

#### In Control My Way Project

In Control My Way is an individual capacitybuilding project, funded by an Information Linkages and Capacity Building grant. The project is designed to develop resources to support young people to take control of their NDIS planning and implementation, to increase their choice, control and autonomy.

Five young people with disability who have experience with the NDIS formed a co-design group and were supported by a project coordinator. A total of 21 meetings were held to conceptualise and co-design the project (September 2021 to June 2022). As a result of the co-design process young people have identified key areas of information and support that is required and will develop resources that are accessible, youth-friendly and relevant for young people with disability. The co-design group met with then NDIS Minister, Senator the Hon. Linda Reynolds CSC (December 2021) to discuss the NDIS and to advocate for a stronger voice in the further development of the scheme.

Staff changes led to inconsistent engagement in the progression of the project, however it is anticipated that the resources will be finalised in early 2023.

#### **CYDA Web**

CYDA Web is an online platform to build youth engagement and support young people with disability to identify and participate in opportunities across the country. The project has been in continual development, culminating in CYDA's The Platform page on Instagram, and a growing email list. The CYDA Web includes external opportunities for young people with a disability, as well as opportunities within CYDA.

CYDA Web directly engages more than 450 young people with disability in range of opportunities, including paid work, co-design opportunities, media, professional development programs and advocacy.

A youth-led newsletter and further content will be introduced in late 2022 to further develop engagement and provide increased opportunities for young people to connect.

#### **Australian Government Election Webinar**

In the leadup to the 2022 Federal Government election, CYDA hosted a webinar to allow young people with disability to directly connect with incumbent politicians - the Hon. Bill Shorten MP (Australian Labor Party), Senator Jordon Steele-John (Australian Greens) and Senator Hollie Hughes (Liberal Party).

Young people with disability were invited to ask the politicians direct questions surrounding pre-election asks and promises, to gain further understanding of where their values align with specific parties.

The event was facilitated by CYDA staff and a young disabled facilitator.

Support Young People to Take Control



#### **Policy Submissions and Reports**

Report: Growing Up Making Decisions Project – Partnership with University of New South Wales and Inclusion Australia





### Support Young People to Take Control



#### Partnerships, Collaboration and Representation

| Group  | Convenor  |
|--|---|
| Our Voices, Our Way, Our Lives Project<br>Advisory Committee | National Ethnic Disability Alliance   |
| Growing Up Making Decisions                                  | National Disability Research Partnership<br>Project University of New South Wales |
| National Youth Disability Network                            | CYDA convenes   |

#### Case Study 4

The 2022 National Youth Disability Summit was held in July 2022. In recognition of the importance of disability representation and youth engagement, the Summit was co-designed "by young people with disability. for young people with disability".

With the increase of youth engagement in the disability sector and the growth of disability representation, CYDA acknowledged it is more important than ever to have spaces like the CYDA Youth Summit for young people with disability to share and learn from each other. The co-design process was deliberately incorporated from the start and is a testament to the Summit's authenticity.

"To meet the challenges facing children and young people, it is important to draw on the innovation of disabled youth, staff, partnerships and the resolve of the Australian."

(ANON., Summit participant)

The 2022 Summit facilitated youth-autonomous conversations including an 'open day' focusing on collaboration with the wider community to strengthen allyship. The event was free and held online. There was also significant consideration given to accessibility features, including Auslan interpreters, closed captions and image descriptions. These elements enabled the event to be truly accessible, regardless of geography and access requirements.

CYDA continues to respond to calls for genuine disabled youth representation in our programs with clarity, scale and impact.

#### **National Youth Disability Summit** 2022 Snapshot





People attended one or more sessions





Attendee rated the Summit (on a scale of 1-10)

Comments posted by attendees

### 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 (Disability Royal Commission)

Since the Disability Royal Commission commenced, CYDA has been funded by the Department of Social Services to provide systemic advocacy and support children and young people with disability, and their families, to engage with the Royal Commission.

In 2021–22 CYDA partnered with Your Story Disability Legal Support and Blue Knot national counselling service to hold two virtual forums to provide guidance on how to prepare a submission to the Disability Royal Commission. These sessions were focussed on supporting parents and caregivers of children with disability on how to engage

children in the Royal Commission.

In addition to this, CYDA has provided five submissions to the Disability Royal Commission to highlight the intersectionality of violence, abuse, neglect and exploitation with service systems and process:

- Parliamentary Joint Committee on Human Rights inquiry into the Religious Discrimination Bill and related bills
- Department of Social Services consultation of the New Disability Employment Support Model
- A joint submission: Institutional Neglect and the Disability Transport Standards
- Clearing the Roadblocks: Promoting Equitable Pathways and Opportunities: CYDA's 2022 Election Platform
- Disability Royal Commission's issues paper: The Impact of and Responses to the Omicron Wave of the COVID-19 Pandemic for People with Disability.

CYDA supported two young people to give evidence at the Disability Royal Commission public hearings which examined the experience of children and young people with disability with different education settings.

CYDA CEO, Mary Sayers, gave evidence at the Public Hearing on Education, highlighting issues related to segregated education environments for children and young people.



### Call Out Discrimination, Abuse and Neglect



#### **Child Safe Organisation Project**

CYDA received funding from the National Office of Child Safety to make recommendations on what resources would support organisations to:

- understand and implement the National Principles for Child Safe Organisations
- ensure the safety of children and young people with disability.

CYDA will host a series of consultations with key stakeholders, including young people with disability in the latter half of 2022.

#### Measuring the Impact of the Government's Approach to COVID-19 (Omicron wave)

In May 2022, CYDA distributed a short survey throughout the youth network, to gain insights into how children and young people were impacted by the changing policies and community attitudes regarding COVID-19 management.

The survey was further supported by an internal staff forum, capturing the perspectives of CYDA staff, the majority of whom have personal and/or family experience of disability.

The findings were presented in a formal submission to the Disability Royal Commission. The submission detailed how inappropriate policies and community attitudes such as the 'let-it-rip' approach, leads to significant risk of harm for children and young people with disability. CYDA urged government to take steps to improve responses, at all levels of government, to implement targeted actions for children and young people with disability.



#### **Policy Submissions and Reports**

Submission to the DRC Workbook for Preparing a Submission in Support of Your Child

Submission to the Disability Royal Commission's Issues Paper: The Impact of and Responses to the Omicron Wave of the COVID-19 Pandemic for People with Disability

Submission to the Successor Plan to the National Framework for Protecting Australia's Children 2009-2020

Report – Endorsement of ARACY Covid Report to Disability Royal Commission



### Call Out Discrimination, Abuse and Neglect

### Partnerships, Collaboration and Representation

| Group   | Convenor   |
|---|--|
| Child Safe Sectors Leadership Group   | Attorney General's Department  |
| Respectful Relationships Reference Panel  | Department of Education, Skills and Employment                                   |
| Respectful Relationships Priority Cohort<br>Working Group                                       | Department of Education, Skills and Employment/Social Research Centre            |
| Young People with Disability and Violence at Home Project                                       | University of Melbourne  |
| Advisory Group for National Strategy to<br>Prevent and Respond to Child Sexual Abuse            | Attorney General's Department  |
| National Coalition Steering Group   | Families Australia for National Framework for<br>Protecting Australia's Children |
| COVID-19 Working Group  | Department of Education (Victoria)   |
| COVID-19 Disability Communications Working Group  | Department of Health   |
| Disability and Health Sector Consultation Committee (DHSCC)                                     | Department of Health   |
| Disability Representative Organisations (DRO) Disability Royal Commission (DRC) Sector meetings | CYDA convenes  |
| Disability Royal Commission (DRC) Disability<br>Representative Organisations (DRO) meetings     | Disability Royal Commission  |

## Call Out Discrimination, Abuse and Neglect



#### **Case Study 5**

CYDA has a strong commitment to supporting and empowering children and young people, particularly in relation to self expression and personal safety. Throughout each youth engagement activity, CYDA use a range of strategies to ensure young people are safe from harm, discrimination and risk.

Engagement facilitators are supported by an internally-appointed safety and wellbeing officer, who is available for young people to contact if they feel unsafe, uncomfortable or distressed at any time. Safety and wellbeing officers manage risks to young people at every point of their engagement with CYDA.

Facilitated sessions are tailored to ensure they are accessible and do create a sense of safety and support for young people. Staff and young people are expected to abide by a code of conduct, ensuring all young people know and understand acceptable behaviours.

CYDA are committed to being a child-safe organisation and actively seek feedback from young people to continually improve engagement practices. Young people report this provides them with a safe and inclusive environment to begin their advocacy journey.

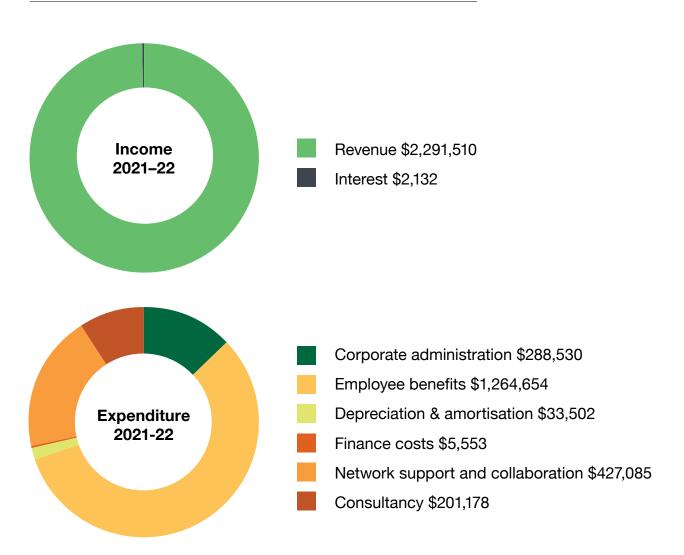


## **Financial Snapshot**



#### 2021-22 Results

| Total Members Equity: 2021–22 | \$423,689   |
|-------------------------------|-------------|
| Total Members Equity: 2020–21 | \$350,549   |
| Result: Surplus               | \$73,140    |
| Total Expenditure             | \$2,220,502 |
| Total Revenue                 | \$2,293,642 |
|                               |             |



### The Year Ahead





I am very fortunate to be joining CYDA following Mary Sayer's passionate and careful stewardship of the organisation over a period of evolution and growth.

The coming year brings many opportunities for children and young people with disability and CYDA, including responding to the final report of the Disability Royal Commission and the Independent Review of the NDIS. The extension of funding by the Department of Social Services will allow us to continue to run important initiatives like our Youth Council, our annual Youth Summits and our Young Leaders Program. We will continue to partner with government departments and research bodies to ensure high quality and accessible resources are created for young people with disability and their families. We also look forward to working collaboratively with other organisations in the sector to further enhance our impact. Discussions about the development of our next Strategy will also commence and will provide us with the opportunity to make sure CYDA continues to ensure children and young people with disability are valued and living empowered lives with equality of opportunity.

Skye Kakoschke-Moore CEO from October 2022



### 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 2021 to June 2022.

CYDA thanks all the young people who have been deeply involved in CYDA's work including the inaugural Youth Council, the National Summit Co-design Committee, the Australian Coalition for Education Youth Working Group, and the ongoing contributions provided to CYDA projects.

CYDA would also like to thank:

Professor Helen Dickinson and Dr Sophie Yates (Public Service Research Group, University of New South Wales, Canberra) and Dr Catherine Smith (University of Melbourne) for their support in producing the following reports:

- Locked out: Vaccination Discrimination for Children and Young People with Disability
- How Did COVID-19 Impact Post-School Transitions for Young People with Disability and How Can These Be Better Supported?

Samantha Loff from Herbert Smith Freehills for their in-kind legal support

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Once again CYDA would like to acknowledge volunteer, Adam Dickson, for his work in collecting and delivering the mail to the CYDA office.







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