



Children and Young People
with Disability Australia

Annual Report 2018





Children and Young People with Disability Australia

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, community organisation that was incorporated as a Company Limited by Guarantee in November 2009.

CYDA provides a link between the direct experiences of children and young people with disability to the Australian Government and other key stakeholders through:

- Participation and representation of children and young people with disability
- Development and dissemination of expert advice
- Implementation of high impact national advocacy campaigns to positively influence policy, practice and attitudes of the Australian Government, key stakeholders and the wider community
- Delivery of strategic projects that support the Australian Government to reform its policy and practice
- Partnership approach with its membership, non-government, government and other stakeholders

CYDA receives its core funding from the Department of Social Services (DSS). In addition, CYDA has received project funding from DSS regarding the work of the Royal Commission into Institutional Responses to Child Sexual Abuse.

Vision

CYDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

Purpose

CYDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia as individuals, members of a family and their community.

Role

CYDA has the mandate to advocate for children and young people with disability living in Australia and undertakes the following to achieve its purpose:

- **Listen and respond** to the voices and experiences of children and young people with disability
- **Advocate** for children and young people with disability for equal opportunities, participation and inclusion in the Australian community
- **Educate** national public policy-makers and the broader community about the experiences of children and young people with disability
- **Inform** children and young people with disability, their families and care givers about their citizenship rights and entitlements
- **Celebrate** the successes and achievements of children and young people with disability

Guiding Principles

The work of CYDA is guided by the following principles:

- **Fundamental rights:** the rights and interests of children and young people with disability are CYDA's highest priority consistent with Australia's obligations under the United Nations Conventions on the Rights of the Child and the Rights of Persons with Disabilities
- **Having a childhood:** children with disability are children first and foremost and have a right to all aspects of childhood that children without disability are afforded
- **Participating in decision making:** children and young people with disability have the right to participate, in whatever capacity, in decisions that impact on their lives
- **An inclusive approach:** children and young people with all types of disability, from all cultural and religious backgrounds, living with all types of families and in all geographic locations are supported by the work of CYDA
- **Valuing families and care givers:** for the contributions made by families and care givers to support the rights and interests of children and young people with disability
- **Working in partnerships:** CYDA works collaboratively with relevant government, non-government, private sector agencies and the broader community to promote the rights and interests of children and young people with disability
- **Being accountable:** CYDA operates accountably, effectively and ethically as the national peak body charged with the mandate of advocating for children and young people with disability

Chair's report

2018 has seen so many changes across the disability sector. My own son and family, along with so many others, has welcomed the opportunities and changes that the National Disability Insurance Scheme (NDIS) has brought. We recognise that there are immense challenges in the implementation of such an enormous and complex reform process. CYDA has a central role to provide feedback and advocacy regarding the NDIS.

CYDA has a critical role in ensuring that the direct experience of children and young people with disability continues to inform public policy in Australia. Education remains a core focus in the work of CYDA as the right to an inclusive education is still not afforded to many children with disability in Australia. A quality education is essential and fundamental to creating positive futures for ALL children.

This year has seen CYDA participate and provide formal submissions to a wide range of inquiries and other initiatives including education, My Health Record, employment and the NDIS. It was also very exciting to support a delegation to attend the CRPD Conference of State Parties at the United Nations in New York, including two young people with disability. This was one of the highlights of the year and I thank all who attended.

Stephanie, our CEO, has led the systemic advocacy undertaken by CYDA. Along with the other Directors of CYDA I feel fortunate that we have had the opportunity to work alongside Stephanie and the dedicated CYDA staff to bring a wide range of lived experience and voice to the issues that are important to children and young people with disability.

I also want to thank all of the CYDA Board for their work and commitment to progressing the rights of children and young people with disability. I particularly thank Sean Rapley, who recently resigned, for his contribution over the last 4 years.

I look forward to working with you all in 2019.

Theresa Duncombe
Chair

CYDA Board



Theresa Duncombe (NSW)
Chair

Theresa is a midwife and an advocate in the health system. Theresa has experience of disability, with one of her two sons having disability. She has significant experience in a range of community

organisations including Kalparin, Association for Children with Disability New South Wales and My Choice Matters NSW.

Theresa is driven by a strong belief in fairness and equity. She is committed to securing the future of inclusive education for students with disability.



Grace Mills (WA)

Grace Mills 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 including Youth

Disability Advocacy network (YDAN), Diverse Leadership WA and VisAbility.

Grace believes that the inclusion of young people with disability into the community is crucial for increasing the level of participation and recognition of abilities, particularly in areas such as education and employment.

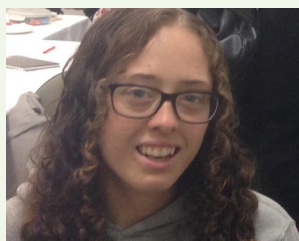


Anne Murphy (VIC)

Anne has two teenage sons. Her youngest son has a disability. Anne's professional background is in medical research and biotechnology. From 2010 to 2012 she worked for CYDA as an Information & Policy Support Officer. She currently volunteers with CYDA, her sons'

schools, and within the Angelman community.

Anne is extremely committed to progressing the rights of children and young people with disability, with particular interest in education, communication and inclusion.



Jocelyn Neumueller (SA)

Jocelyn is a student with lived experience of disability. She has completed a Bachelor of Medical Science at Flinders University while pursuing her sporting ambitions of achieving a podium position at the Paralympics.

Outside of her study, Jocelyn is involved with a number of organisations including Julia Farr Youth. In 2016 Jocelyn was also selected as the student representative for the South Australian Ministerial Advisory Committee for Children and Students with Disability.



Sean Rapley (NSW)
Secretary

Sean is a Principal at an engineering consultancy firm. He has a passion for developing opportunities for people and empowering people to reach their full potential. Over Sean's career, he has developed skills in people management, business development and business planning. Sean has

a son aged nine who has led him to advocate for inclusive education and communities.

Sean was a member of the Touched by Olivia Foundation family of Community Drivers and with the Illawarra community he helped develop Luke's Place, an inclusive play space in NSW.



Geoffrey Warren (VIC)

Geoffrey has 50 years of teaching experience which includes 35 years as a principal. He has degrees and diplomas in Arts, Economics, Politics and Educational Administration. In 2012 he was the winner of the National Disability Award for Excellence in Improving Education Outcomes.

Geoffrey has appeared before various national and state inquiries in support of student needs. He is an articulate and strong advocate for children and young people with disability. He believes schools are greatly enriched through the inclusion of students with disability.

Committees

FINANCE AND RISK MANAGEMENT COMMITTEE

Membership

- Sean Rapley (Chair)
- Theresa Duncombe
- Geoffrey Warren

POLICY COMMITTEE

Membership

- Anne Murphy (Chair)
- Theresa Duncombe
- Grace Mills
- Jocelyn Neumueller

Board Meeting Attendance

A total of 9 Board Meetings were held during the reporting period.

BOARD MEMBER	ELIGIBLE TO ATTEND	ATTENDED
Theresa Duncombe	9	7
Grace Mills	9	9
Anne Murphy	9	9
Jocelyn Neumueller	9	5
Sean Rapley	9	8
Geoffrey Warren	9	4

CEO Report

This year marks my tenth year working with CYDA. Over that time I have seen and participated in vast changes and reform in the lives of children and young people with disability. Obviously, the National Disability Insurance Scheme is a significant change with many people benefitting from increased supports which enable access to a range of opportunities and experiences. Aside from the NDIS, I also believe there is a stronger and louder voice of and for people with disability progressing opportunities, human rights and equal citizenship.

We are also starting to see a change in community attitudes regarding disability. There is a growing understanding that disability is a positive aspect of diversity that strengthens our community. The medical and charity models of disability are starting to fade. It feels to me progress is being made. Slow progress, but change is definitely afoot.

There is still fundamental reform required in education. Experience of an inclusive education for students with disability is still as rare as winning the lottery. In fact students with disability often have poor educational experiences and outcomes. Some experience great harm through educational experiences though exclusion, discrimination and low expectations.

I am determined that in the future we must see the progressive realisation of the right to an inclusive education in Australia. I know professionally and personally of the relentless advocacy still required to ensure children with disability are afforded rights and opportunities to access education. It shouldn't be this hard and there shouldn't be the need to compromise, in any regard, to participate in a quality and inclusive education system. Next year CYDA will lead a national campaign to

progress education reform for students with disability. I am confident that many across Australia will unite with us not only to demand reform but help articulate and deliver the reform needed. We must ensure that children and young people are afforded educational rights and further recognised and valued as learners in schools across the country.

CYDA continues to advocate strongly for a stand-alone Royal Commission into violence, abuse and neglect of people with disability. Violence and abuse is a common experience for children with disability. This is just wrong. I read with shame recently a statistic released from the Australian Bureau of Statistics that 43% of young people with disability aged 18 to 25 years reported experiencing sexual harassment. In the CYDA National Education Survey, 55% of students with disability stated they experienced bullying at school in the last year. A Royal Commission is vital so we recognise, understand and acknowledge why abuse and violence is so prevalent in the lives of children and young people with disability and stop it from occurring in the future.

So 2019 will be another busy year for CYDA where we will continue to relentlessly advocate for the rights of children and young people with disability.

As I do every year, I take this opportunity to thank the CYDA operational team and Board for their work and commitment to progressing the rights of children and young people with disability. I thank all the children, young people and families that CYDA represents for sharing your experience and knowledge. I continue to learn so much. After 10 years, I still think I have the best job in the world.

Stephanie Gotlib
Chief Executive Officer



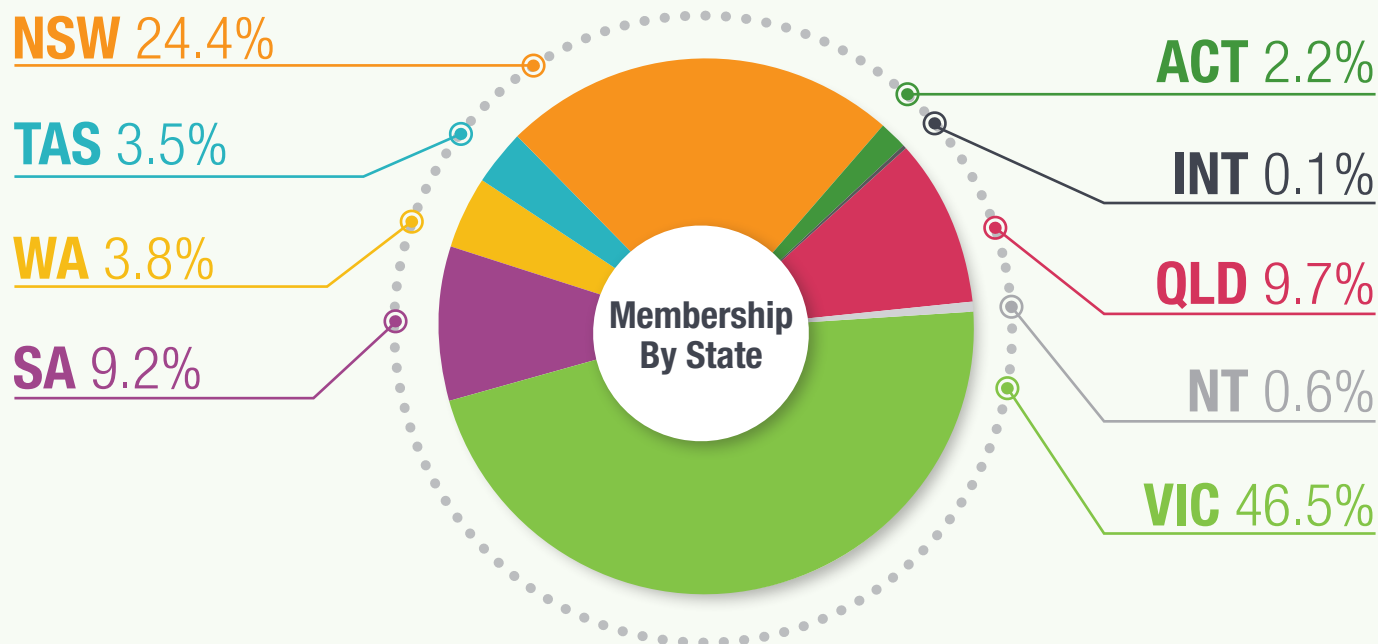
CYDA STAFF

Stephanie Gotlib	Chief Executive Officer
Fleur Beaupert	Policy Officer
Joanne Ellingworth	Business Manager*
Darrell Harding	Financial Officer*
Erin Hill	Administration Assistant*
Robert Pask	Policy Adviser*
Phebe Shields	Information and Policy Support Officer*

Pictured: Stephanie Gotlib, Robert Pask, Joanne Ellingworth, Samantha Cortes (from left to right)

*Part time/Casual

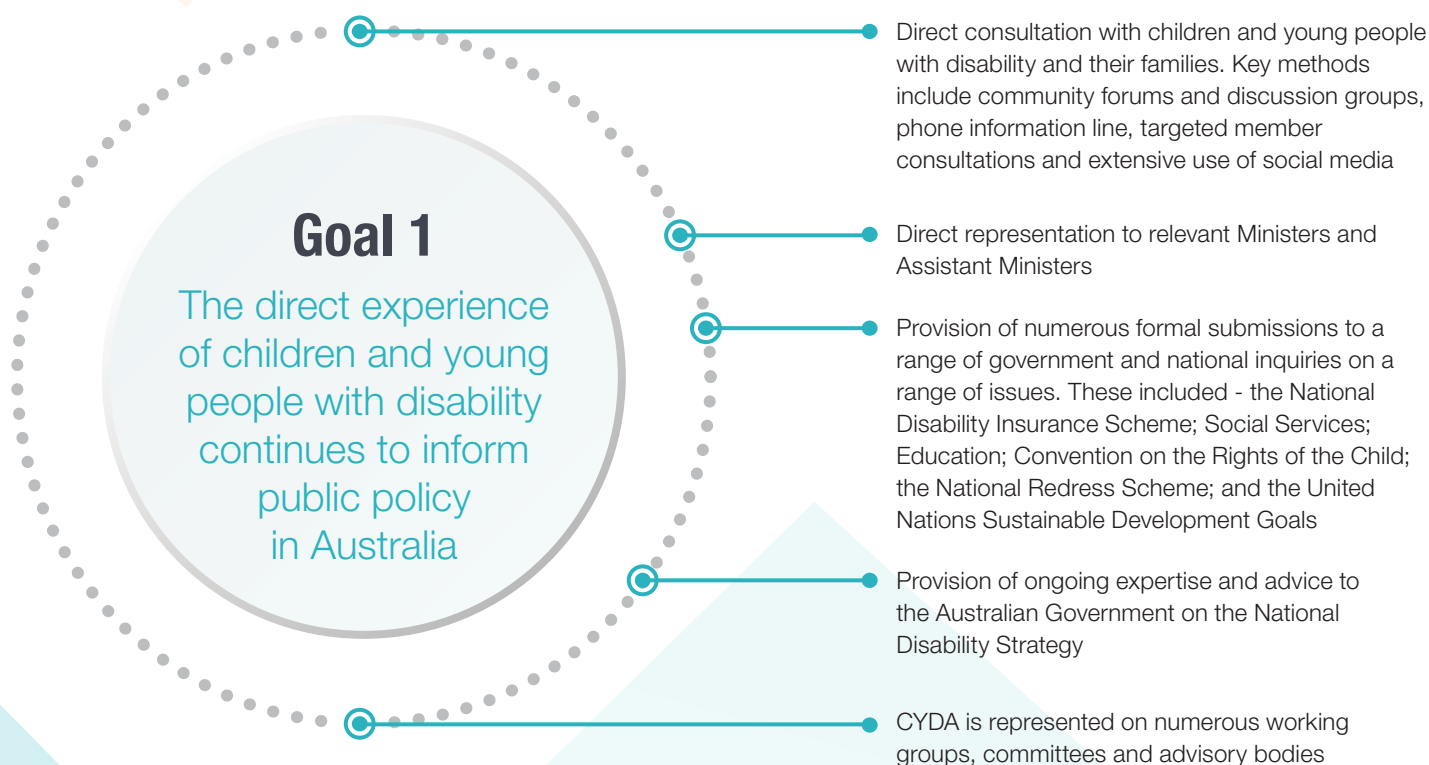
CYDA Membership Summary





CYDA Achievements 2017/18

An Overview



Goal 2

Participation and inclusion of children and young people with disability is promoted and advanced by their national body

Key Actions

- Continued representation and participation of young people with disability on the CYDA Board
- Hosted a national round table forum for young people with disability
- CYDA attended the United Nations CRPD Conference of State Parties in New York. The delegation included 2 young people with disability
- Worked collaboratively with youth advocacy organisations and other disability organisations
- Continual advocacy for the participation and inclusion of children and young people in advisory and consultation processes
- Collaborative Partner of the National Youth Commission
- Member of the Childs Rights Taskforce and the CRPD Shadow Report Working Group

Goal 3

Recognition that children and young people with disability strengthen and enrich families and the community

Key Actions

Direct representation to Ministers, Assistant Ministers and Members of Parliament

Provision of a range of resources and information which is rights and strength based

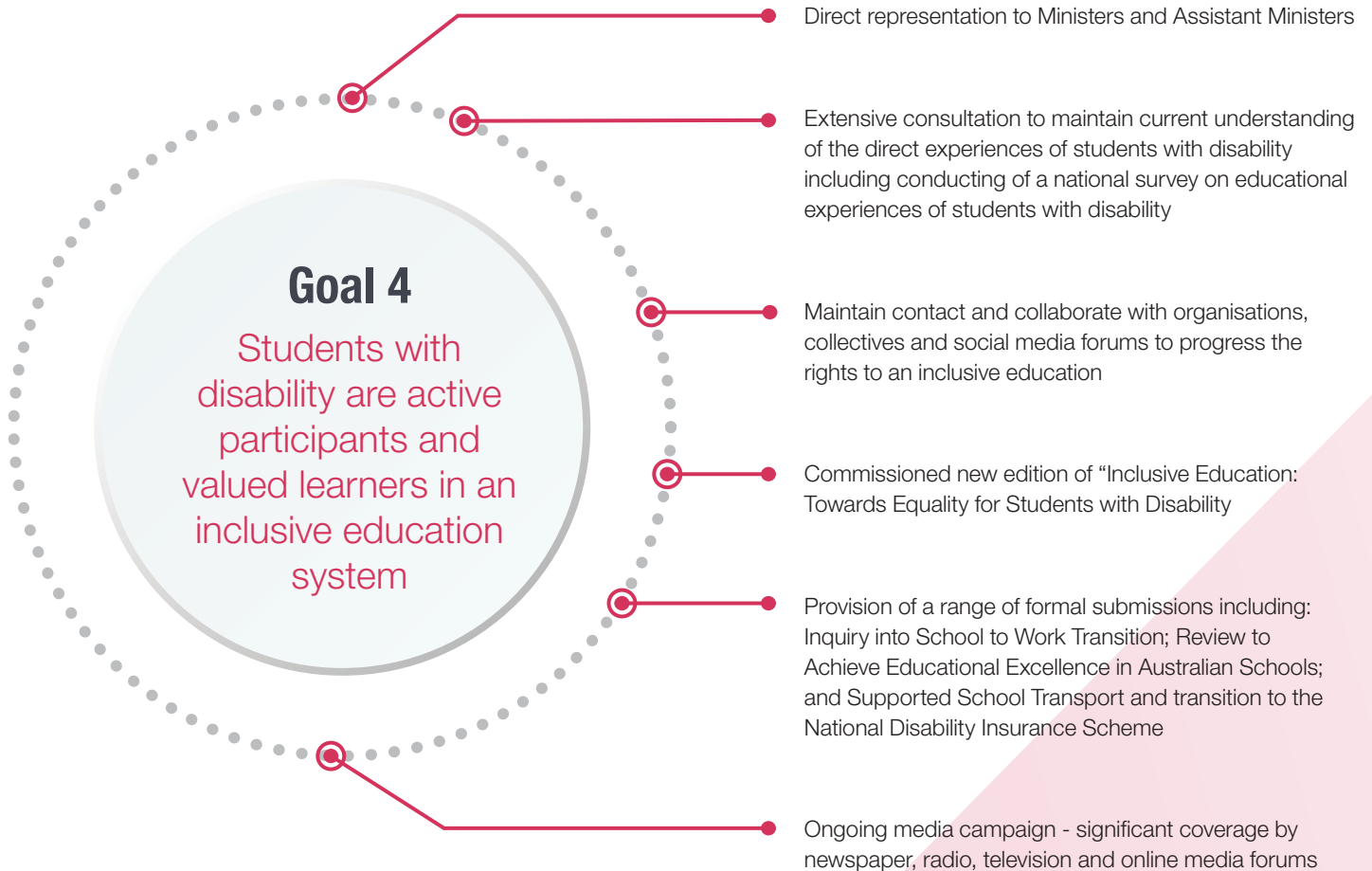
Maintenance of high profile and informative social media to encourage and promote strength based understanding and messaging regarding children and young people with disability

Other media used to promote disability as a positive aspect of a diverse community:

- Print and online articles quoting CYDA including: Courier Mail; The Age; ProBono; Disability Support Guide; The Educator; The Canberra Times; The Australian Education Reporter; The Sunday Mail; The Australian; The Daily Telegraph
- Radio and television interviews including: ABC3; ABC News and 7.30 Report; 2ER; Casey Radio

Member of the Australian Government National Disability Awards Judging Panel. Extensive promotion of awards and attended the rewards ceremony

Key Actions



Key Actions

Goal 5

The specific needs and context of children and young people with disability are embedded within the ongoing development of the National Disability Insurance Scheme

- Direct Representation to relevant Ministers, Assistant Ministers, Members of Parliament, Department of Social Services, NDIS Board, NDIS Independent Advisory Council and the National Disability Insurance Agency
- Provision of information on the NDIS through social media forums; e-bulletins; CYDA website and CYDA's telephone information service
- Formal submissions to and appeared at related hearings into related inquiries including: Productivity Commission Inquiry into NDIS Costs; NDIS Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017; Provision of Services under the NDIS Early Childhood Early Intervention Approach; and the Inquiry into the Medicare Levy Amendment (NDIS Funding) Bill 2017
- Participated in meetings, consultation public forums or provided expertise on a range of issues including: ECIA best practice; participant experience; Quality and Safeguards; NDIS practice standards; NDIS code of conduct and NDIS training
- Regular participation and input to the NDIS CEO Forum

Goal 6

Children and young people with disability do not experience abuse and violence in any context

Key Actions

Ongoing advocacy and representation to government, community and media

Providing information, support and systemic advocacy regarding the Royal Commission into Institutional Responses to Child Sexual Abuse and the National Redress Scheme; meetings and advocacy with an extensive range of services who provide support and counselling to children who have experienced sexual abuse, regular participation in network meetings of services funded to provide support regarding the work of this Royal Commission and the National Redress Scheme

Member of related advisory and collaborative groups including: Vic/Tas Royal Commission Support Services Group; Speak Up and Be Safe from Abuse and the Australian Human Rights Commission Child Safe Consumer Advocacy Advisory Group

Continued advocacy for a Royal Commission into abuse and violence of people with disability

Goal 7

CYDA's governance and operational resources reflect the value it brings in representing the rights and interests of children and young people with disability

Key Actions

● CYDA obtained ongoing funding until 2020 from the Department of Social Services

● A large organisational membership of 5,300 members was maintained

● CYDA social media reach has increased

● CYDA has a constant demand for information, expertise and advocacy from children and young people with disability, families, Governments, Departments, organisations, media and other stakeholders

● CYDA Board and Committee convene regularly

Other Information

Publication Distribution: CYDA Issue Papers

1,427

Enabling & Protecting:

Proactive Approaches to Addressing the Abuse and Neglect of Children and Young People with Disability

Distributed electronic and hard copies

21,344

Inclusion in Education:

Towards Equality for Students with Disability

Distributed electronic and hard copies

1,467

Belonging and Connection

of School Students with Disability

Distributed electronic and hard copies

333

Strengthening Participation

of children and young people with disability in advocacy

Distributed electronic and hard copies

2,149

Post School Transition:

The Experience of Students with Disability

Distributed electronic and hard copies

284

Royal Commission Information Booklet

Distributed electronic and hard copies

**Telephone
Information Service**

781 calls were received by CYDA

CYDA Website

CYDA'S website is reviewed fortnightly and updated accordingly. Page views and visits steadily increased throughout the year.

Yearly totals

141,249 Visits

171,115 Page Views

e-Bulletins

19 e-Bulletins were sent to members and subscribers over the year

A total of **34,973** individual emails

Social Media

1,181 new Facebook likes

455 new Twitter followers

Respresentation

Participation in meetings and collaborative work with national disability sector organisations and key state and territory organisations and stakeholders including:

Advocate for Children and
Young People NSW
All Means All
Association for Children with a Disability
Aussie Deaf Kids
Australian Council of Social Service
Australian Dietetics Association
Australian Education Union
Australian Federation of
Disability Organisations
Australian Human Rights Commission
Australian Network for Universal
Housing Design
Autism Hub Qld
Autistic Family Collective Association
Blind Citizens Australia
Body Safety Australia
Brain Injury Australia
Castan Centre
Children's Commissioners
(State and Federal)
Community Resource Unit
Deaf Australia
Deafness Forum Australia
Department of Social Services
Disability Advocacy Network Australia
Disability Advocacy Resource Unit
Disability Discrimination Commissioners
(State and Federal)

Disability Discrimination Legal Service VIC
Disability Employment Australia
Disability Institute (University of Melbourne)
Disabled People's Organisations Australia
Down Syndrome Australia
Early Childhood Intervention Australia
Every Australian Counts
Families Australia
Family Advocacy
First Peoples Disability Network
Heartwell Foundation
Huntingtons Victoria
I-CAN
IHC New Zealand
Imagine More
Julia Farr Youth
Lifestart
Mental Health Australia
National Disability Insurance Agency
National Disability Services
National Ethnic Disability Alliance
NEDA
Noahs Ark
NSW Council of Intellectual Disability
NSW Ombudsman
NSW Teachers Federation
OT Australia
Parents of Deaf Children

Parents Victoria
People with Disability Australia
Richmond Football Club
Royal Commission into Institutional
Responses to Child Sexual Abuse
Save the Children
Scope
Speakout
Speech Pathology Australia
Tasmanian Disability Education
Reform Lobby
Teachers Federation NSW
The Association for Children
with a Disability (Tas) Inc.
Touched by Olivia Foundation
Unicef
United Nations
University of South Australia
VALID
Victorian Disability Commissioner
Victorian Ombudsman
Women with Disabilities Australia
Women with Disabilities Victoria
Young People in Nursing Homes
National Alliance
Youth Disability Advocacy Network
Youth Disability Advocacy Service
Youth Network of Tasmania

Representation to Australian government departments and relevant ministers, including:

Hon. Christian Porter MP - Minister for Social Services

Hon. Jane Prentice MP- Assistant Minister for Social Services and Disability Services

Hon. Dr David Gillespie MP - Assistant Minister for Children and Families

Hon. Bill Shorten MP- Leader of the Opposition

Hon Jenny Macklin MP - Former Shadow Minister for Families and Social Services

Hon Tanya Plibersek MP - Shadow Minister for Education and Training

Senator Carol Brown - Shadow Minister for Disability and Carers

Senator Rachel Siewert - Chair of Community Affairs References Committee

Senator Jordan Steele-John - Disability Right's Spokesperson
Various Members of Parliament

Department of Social Services

Australian Government Department of Education and Training

Queensland Department of Education and Training

Department of Education and Training Victoria

Department of Education NSW

Participation in advisory committees and national forums on key issues of relevance to children and young people with disability, including:

ACOSS Community Sector Policy Network Group and CEO Forum

Australian Human Rights Child Safe Consumer Advocacy Advisory Group

Australian Electoral Commission Disability Advisory Committee

Australian Human Rights Commission Expert Advisory Group on violence against people with disability in institutional settings

Australian Network for Universal House Design

Children and Family Campaign Steering Committee
(Hosted by Benevolent Society)

Child Rights Taskforce

Coalition on Safety and Wellbeing of Australia's Children

Convention on the Rights of Persons with Disabilities Shadow Report Working Group

National Disability Strategy Reform Steering Group

National Youth Commission – Collaborative Partner

NDIS CEO Forum

NSW Child Safety Organisations Steering Committee

Project Steering Committee for People with Disability
Australia's Royal Commission into Institutional Responses to Child Sexual Abuse Project

Scope Project Advisory Group - Speak up and Be Safe from Abuse

University of NSW - Expert panel on disability policy reform

Feedback

I commend CYDA's vision for children and young people with disability to be afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals are respected.

Michael Hogan Director-General, Department of Communities Child Safety and Community Services QLD

Congratulations on all your efforts – both children's services and disability services are moving to a rights based approach

Human Rights Learning Centre VIC

It's good to see CYDA's involvement within Australia and international. Like event at the UN and advertising for other organizations like first people NZ, also the support that you show the younger generation on how to be able to defend themselves.

Member

I want to say a big thank you to you, as well as CYDA as a whole, for all your support over the last 12 months. It's been a rollercoaster ride with regards to the issue of support for children with a disability, and for education as a whole. We can only hope that next year brings positive change.

Member

CYDA does a great job. I feel I can depend on CYDA to contribute to 'the bigger picture' with a strong voice in the interests of disabled people. I feel CYDA has a grip on the issues and if I call, they will have someone there who knows what I am talking about. I like that CYDA get information in time for the political cycle.

Member

Your work with young people and their families is imperative to many of the reforms occurring in the education system and the roll-out of the National Disability Insurance Scheme. Through your organisation's advocacy, you have made a significant contribution to government policy and services for children and young people with disability.

Hon Grace Grace MP, Minister for Education QLD

It's people like yourself and Julie who bring hope to realise there is light and goodness in life for humankind. Thank you greatly.

Member

A huge thank you for all the important work that you do for the rights of children and young people with disability and let's hope 2018 is a year of positive change and progress – we look forward to working with you to make that happen!

Member

As suggested by you
I have had a look at
your website. It is
comprehensive and clear.
I am very impressed by
your work.

Member

Thanks, Stephanie.
You are a champ!

Member

I commend you and your
team on the dedication
and commitment shown to
your advocacy, support and
representation of children and
young people with disability.

**David Clements,
Interim Commissioner
for Children and Young
People TAS**

I really look forward to working with you to
support and empower children and young
people living with disabilities.

**Hon Katrine Hildyard MP,
Minister for Disabilities SA**

I appreciate the positive working relationship
I have had with Children and Young People
with Disability Australia. Your commitment to
supporting and advocating for some of the
most vulnerable people is commendable.

Thank you for your advice and advocacy and
genuine input to improve our education system.

**Hon Kate Jones MP, former Minister
for Education QLD**

Keep up the
excellent work you
are doing in the
advocacy space.

Member

Thank You

CYDA would like to thank the
following organisations and
businesses for their financial or
in-kind support. We also thank
those members and supporters
of our organisation who have
made individual donations
throughout the year.

Clifton Hill/North Fitzroy Community Bank

Niche Logistics

John Birrell

Jonathan Moore SC

Next Step Financial Strategies

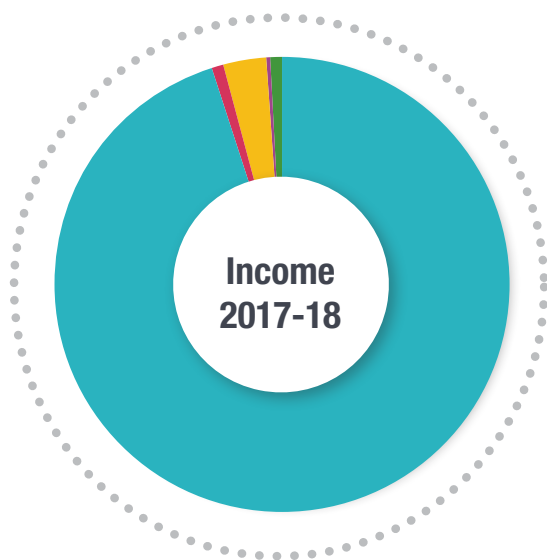
Todd A Bailey Builders



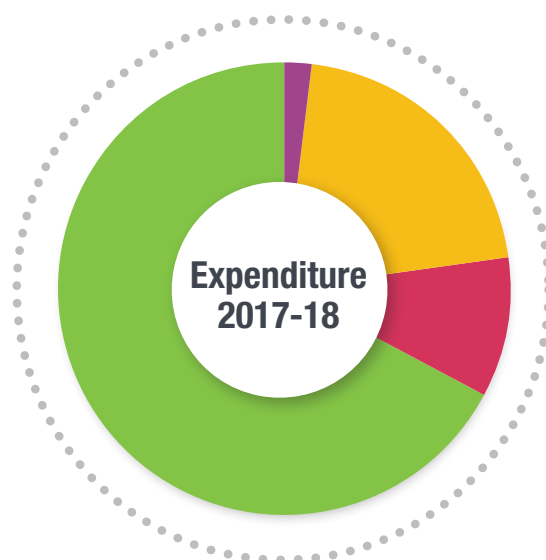
Financial Snapshot 2017 – 2018 Results

Full financial reports available on the CYDA website — www.cyda.org.au

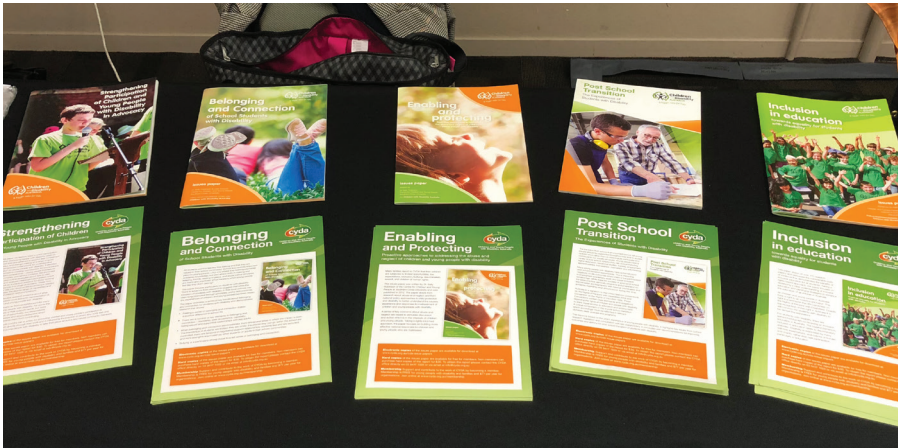
Total Revenue	\$447,360
Total Expenditure	\$440,009
Result – Surplus	\$7,351
Total Members Equity – 2016 – 2017	\$101,241
Total Members Equity – 2017 – 2018	\$108,591



Department of Social Services 95%
Memberships 3%
Donations 1%
Other income 0.62%
Interest received 0.38%



Employment expenses 67%
Operating expenses 21%
Office expenses 10%
Consultancy 2%





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