**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 and 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.

**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.

**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.

**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.

**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.

**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 and Geoffrey Warren.

## Policy Committee

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

# Board Meeting Attendance

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

Theresa Duncombe Eligible to attend 9 Attended 7

Grace Mills Eligible to attend 9 Attended 9

Anne Murphy Eligible to attend 9 Attended 9

Jocelyn Neumueller Eligible to attend 9 Attended 5

Sean Rapley Eligible to attend 9 Attended 8

Geoffrey Warren Eligible to attend 9 Attended 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 Statistic 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 (Part time/casual)

Darrell Harding Financial Officer (Part time/casual)

Erin Hill Administration Assistant (Part time/casual)

Robert Pask Policy Adviser (Part time/casual)

Phebe Shields Information and Policy Support Officer (Part time/casual)

# CYDA Membership Summary

MEMBERSHIP BY STATE

ACT 2.2%

NSW 24.4%

NT 0.6%

VIC 46.5%

QLD 9.7%

SA 9.2%

TAS 3.5%

WA 3.8%

INT .1%

# CYDA Achievements for 2017/18 — an Overview

## GOAL 1 The direct experience of children and young people with disability continues to inform public policy in Australia.

Key Actions

* Direct consultation with children and young people with disability and their families. Key methods include community forums and discussion groups, phone information line, targeted member consultations and extensive use of social media\
* Direct representation to relevant Ministers and Assistant Ministers
* Provision of numerous formal submissions to a range of government and national inquiries on a range of issues. These included - the National Disability Insurance Scheme; Social Services; Education; Convention on the Rights of the Child; the National Redress Scheme; and the United Nations Sustainable Development Goals
* Provision of ongoing expertise and advice to the Australian Government on the National Disability Strategy
* CYDA is represented on numerous working groups, committees and advisory bodies

## 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

## GOAL 4 Students with disability are active participants and valued learners in an inclusive education system

Key Actions

* Direct representation to Ministers and Assistant Ministers
* Extensive consultation to maintain current understanding of the direct experiences of students with disability including conducting of a national survey on educational experiences of students with disability
* Maintain contact and collaborate with organisations, collectives and social media forums to progress the rights to an inclusive education
* Commissioned new edition of “Inclusive Education: Towards Equality for Students with Disability
* Provision of a range of formal submissions including: Inquiry into School to Work Transition; Review to Achieve Educational Excellence in Australian Schools; and Supported School Transport and transition to the National Disability Insurance Scheme
* Ongoing media campaign - significant coverage by newspaper, radio, television and online media forums

## 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

Key Actions

* 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 inquires 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

## Telephone Information Service

781 calls were received by CYDA

## Publication Distribution

CYDA Issue Papers - Enabling & Protecting: Proactive Approaches to Addressing the Abuse and Neglect of Children and Young People with Disability: Distributed electronic and hard copies 1 427; Inclusion in Education: Towards Equality for Students with Disability: Distributed electronic and hard copies 21 344; Belonging and Connection of School Students with Disability: Distributed electronic and hard copies 1 467; Strengthening participation of children and young people with disability in advocacy: Distributed electronic and hard copies 333; Post School Transition: The Experience of Students with Disability: Distributed electronic and hard copies 2 149

Royal Commission Information Booklet: Distributed electronic and hard copies 284

## CYDA Website

CYDA'S website is reviewed fortnightly and updated accordingly

Page views and visits steadily increased throughout the year.

Yearly totals - Visits 141 249, page views 171 115.

## E-Bulletins

19 e-Bulletins were sent to members and subscribers over the year (a total of 34 973 individual emails).

## Social Media

Facebook - A total of 1 181 new likes

Twitter - A total of 455 new followers

# Respresentation

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

Association for Children with a Disability

All Means All

Australian Council of Social Service

Advocate for Children and Young People NSW

Aussie Deaf Kids

Australian Education Union

Australian Federation of Disability Organisations

Australian Network for Universal Housing Design

Australian Dietetics Association

Australian Education Union

Australian Human Rights Commission

Autism Hub Qld

Autistic Family Collective Association

Body Safety Australia

Blind Citizens Australia

Brain Injury Australia

Children’s Commissioners (State and Federal)

Community Resource Unit

Disability Advocacy Network Australia

Disability Advocacy Resource Unit

Deaf Australia

Deafness Forum Australia

Disability Employment Australia

Down Syndrome Australia

Disability Discrimination Commissioners (State and Federal)

Castan Centre

Department of Social Services

Disability Discrimination Legal Service VIC

Disability Institute (University of Melbourne)

Down Syndrome Australia

Disabled People’s Organisations Australia

Early Childhood Intervention Australia

Every Australian Counts

Family Advocacy

Families Australia

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

NSW Council of Intellectual Disability

NSW Teachers Federation

Noahs Ark

NSW Ombudsman

OT Australia

Parents of Deaf Children

Parents Victoria

Parents of Deaf Children

People with Disability Australia

The Association for Children with a Disability (Tas) Inc.

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

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

Youth Disability Advocacy Network

Youth Disability Advocacy Service

Young People in Nursing Homes National Alliance

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

NDIS CEO Forum

National Disability Strategy Reform Steering Group

National Youth Commission – Collaborative Partner

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 Commission for Children and Young People Tasmania

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

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

## Income 2017-2018

Department of Social Services 95%

Donations 1%

Memberships 3%

Interest received .38%

Other income .62%

## Expenditure

Consultancy 2%

Operating expenses 21%

Office expenses 10%

Employment expenses 67%

# Children and Young People with Disability Australia

20 Derby Street, Collingwood, VIC 3066.

PO Box 172, Clifton Hill VIC 3068.

Phone 03 9417 1025 or 1800 222 660 (regional or interstate)

Email info@cyda.org.au

Web www.cyda.org.au

ABN 42 140 529 273

Facebook www.facebook.com/CDISAUS

Twitter @CDA39

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