**Children and Young People with Disability Australia**

**Annual Report 2019**

# 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 for the National Redress Scheme developed following 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:

* Listening and responding to the voices and experiences of children and young people with disability
* Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community
* Educating national public policy-makers and the broader community about the experiences of children and young people with disability
* Informing children and young people with disability, their families and care givers about their citizenship rights and entitlements
* Celebrating 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

CYDA continues to be a strong voice for children and young people with disability and their families, advocating on a national stage to ensure their rights are upheld, and they are free from violence and abuse.

This year saw the departure of our CEO Stephanie Gotlib after 10 years of dedicated service to CYDA. Stephanie’s contribution has been remarkable over this time. Leading CYDA she influenced national policy debates and action for children and young people with disability and developed a strong body of work in the form of issues papers, research, submissions and reports that are authoritative and accessible. This work has provided a foundation for the organisation’s advocacy work as well as offering valuable resources for members.

Her work on the international stage in contributing to the United Nations and various reports and submissions to policy and legislative reforms in Australia means the organisation is deeply rooted in a human **rights-based** approach

Her strategic approach and deep political nous and contribution means that today CYDA’s reach and influence goes well beyond expectations for a small organisation. This places the organisation in strong stead for the future as the historic Royal Commission into Violence, Abuse, Neglect and Exploitation of Persons with Disability commences. CYDA will continue to be a strong advocate for the rights of children and young people with disability.

After an extensive executive search, our new CEO Mary Sayers was appointed by the Board in June 2019 and commenced in July 2019. Mary joins CYDA following five years as Deputy CEO of the Victorian Council of Social Services and a long history of policy and advocacy for children and young people. She also has family experience of disability, with a son with disability.

In the coming year the CYDA Board will embark on a new strategic planning process as our 2017 – 2020 strategic plan comes to an end. The current strategic plan has served the organisation well, and now is an ideal time for the organisation to be developing a new strategic plan.

I also want to thank all of the CYDA Board Directors for their work and commitment to progressing the rights of children and young people with disability over the last year. This year also saw the resignation of board members Theresa Duncombe (former Chair) and Anne Murphy, and we thank them for their important contribution to the governance of CYDA.

Alan Blackwood

Board Chair

# CYDA Board

**Alan Blackwood (VIC)**

**Chair (May 2019 to present)**

Alan has family experience of disability and has also worked in the sector in a range of advocacy and governance roles with people with disability for over 30 years.

Alan has served on numerous state and national advisory bodies and has previously worked with CYDA on NDIS and education policy.

Alan is a strong supporter of inclusive education and the participation of people with disability in their organisations.

**Theresa Duncombe (NSW)**

**Chair (Resigned May 2019)**

Theresa is a midwife and an advocate in the health system. Theresa has personal 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 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 is currently also involved with the Ministerial Advisory Council of Disability, Telethon Kids Institute Advisory Group and previously was a member of the City of Perth Access and Inclusion Advisory Group.

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 and social inclusion through community events.

**Bronwyn Morkham (VIC)**

An experienced individual and systemic advocate, Dr. Bronwyn Morkham has worked with state and federal governments in systems policy and improvement. She is presently working with state and federal jurisdictions on the systemic and policy reforms needed to implement the National Disability Insurance Scheme, particularly around the scheme’s interactions with other service systems such as health and education.

Bronwyn has served on a number of state and federal advisory bodies and led development of innovative and collaborative practice solutions in systems working with younger people with disability.

**Anne Murphy (VIC) (Resigned May 2019)**

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 currently studying Law 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 advocating for and supporting young people living with a disability. For the past 4 years Jocelyn has been selected as the student representative for the South Australian Ministerial Advisory Committee for Children and Students with Disability.

**Geoffrey Warren (VIC)**

**Secretary**

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.

He has appeared before various national and state boards 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 - Geoffrey Warren (Chair), Theresa Duncombe and Jocelyn Neumueller.

## Policy Committee

Membership - Anne Murphy (Chair) and Grace Mills.

# Board Meeting Attendance

A total of 10 Board Meetings were held during the reporting period.

Alan Blackwood Eligible to attend 1 Attended 1

Theresa Duncombe Eligible to attend 9 Attended 9

Grace Mills Eligible to attend 10 Attended 8

Bronwyn Morkham Eligible to attend 1 Attended 1

Anne Murphy Eligible to attend 9 Attended 7

Jocelyn Neumueller Eligible to attend 10 Attended 9

Geoffrey Warren Eligible to attend 10 Attended 7

# CEO Report

I am extremely proud to have been appointed CEO of Children and Young People with Disability Australia and would like to acknowledge the important contribution made by Stephanie Gotlib over the last 10 years. Her legacy is profound and the organisation is in a strong position for the future because of her work and leading a dedicated and talented staff group.

The policy, legislative, educational and service landscape for children and young people with disability in Australia is set to have a major shake up with the announcement by the Prime Minister on 5th April 2019 of a Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This was announced after years of advocacy by organisations like CYDA and disability advocates.

The Disability Royal Commission has the opportunity to improve the lives of children and young people with disability in the future and protect them from violence, abuse, neglect and exploitation, but also importantly to change community attitudes. We have seen some fundamental shifts in community attitudes resulting from the Royal Commission into Institutional Responses to Child Sexual Abuse and we hope the Royal Commission can provide transformational change into the way the community values and includes people with disability.

The National Disability Insurance Scheme (NDIS) continues to provide opportunities and many implementation challenges for children and young people with disability and their families. CYDA continues to advocate to ensure the NDIS meets its promise, and takes into account the unique developmental and support needs of children and young people. We were pleased to receive an NDIS Information Linkages and Capacity Building Grant to support CYDA members.

One of the most urgent areas for government reform for children and young people with disability is in education. Students with disability continue to be routinely excluded and abused in schools, and segregation of students with disability diminishes their educational outcomes and fundamental human right to inclusion in regular school settings. Of all issues that CYDA receives enquiries from families, the lack of inclusive education is the most common. This is also demonstrated by our 2013 Issues Paper Inclusion in Education: Towards Equality for Students with Disability which is downloaded on average 2,500 times per month from our website. Hence a new and updated resource was commissioned.

The coming year provides significant opportunities for CYDA to advocate strongly for children and young people with disability and their families. I would like to thank our members who are so crucial for a representative organisation and who share with us every day their stories and insights about what needs to change and what is working well. I would also like to thank the Board and staff of CYDA who have made me feel so welcome and all of CYDAs stakeholders who have embraced me in my role and shared their wisdom and knowledge.

Mary Sayers
Chief Executive Officer

# CYDA Staff

Mary Sayers Chief Executive Officer (from July 2019)

Stephanie Gotlib Chief Executive Officer (until April 2019)

Gwenda Cannard Interim Chief Executive Officer (April 2019 – July 2019)

Samantha Cortes Policy Officer (July 2018 – December 2018)

Joanne Ellingworth Business Manager

Darrell Harding Financial Officer

Diane McCarthy Information & Community Liaison
Officer National Redress Scheme (from January 2019)

Robert Pask Policy Adviser

Phebe Shields Information and Policy Support Officer (until August 2018)

# CYDA Membership Summary

## Membership by State

ACT 2.2%

NSW 24.7%

NT 0.6%

VIC 45.9%

QLD 9.8%

SA 9.3%

TAS 3.5%

WA 3.9%

INT .1%

# CYDA Achievements for 2018/19 — 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 Victorian Draft Disability Action Plan, the Queensland Human Rights Bill and the federal inquiry into Lowering the Voting Age, Stronger Outcomes for Families, My Health Record System, Future Employment Services and Job Active inquires.
* Collaboration with other disability representative organisations to produce the Disability Rights Now 2019 Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019 Report.
* Provision of ongoing expertise and advice to the Australian Government on the National Disability Strategy and a joint submission to the Productivity Commissions Review of the National Disability Agreement.
* CYDA is represented on numerous national and state/territory 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.
* Worked collaboratively with youth advocacy organisations and other disability organisations.
* Continued 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 United Nations Convention on the Rights of Persons with Disability (CPRD) 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; The Saturday Paper, ProBono; Disability Support Guide; Talking Disability, The Educator, The Source News.
* Radio and television interviews including: SBS, Channel 9 News, ABC News, Sky News, ABC PM and 2SER.

## 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.
* Maintain contact and collaborate with organisations, collectives and social media forums to progress the rights to an inclusive education.
* Commissioned a new edition of "Towards inclusive education: A necessary process of transformation”.
* Provision of a range of formal submissions including: Policy guidelines and principles for reducing and eliminating restraint and seclusion in Victorian schools and supported schools and Supported School Transport and transition to the NDIS.
* 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**

* Provision of information on the NDIS through social media forums; e-News; CYDA website and CYDA's telephone information service.
* 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.
* Formal submissions to and appeared at related hearings into related inquires including: NDIS ICT Systems and Assistive Technology.
* Participated in meetings, consultation public forums or provided expertise on a range of issues including the ECEI Approach and Hearing Services roundtable
* 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
* Provision of a range of formal submissions including: Royal Commission into Aged Care Quality and Safety Terms of Reference and Australian Government Policy, Program and Legal Response to the redress related recommendations of the Royal Commission into Institutional Responses to Child Sexual Abuse
* 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 and the eSafety and Mental Health Steering Group.
* Continued advocacy for a Royal Commission into abuse and violence of people with disability which was announced in 2019

## 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 secured core funding until 2020 from the Department of Social Services and secured funding for an NDIS Information, Linkages and Capacity (ILC) Building Grant to support families to self-manage their child’s NDIS, and support for the National Redress Scheme
* CYDA membership has remained consistent
* CYDA social media reach has increased
* CYDA has high 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

655 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 1,221; Inclusion in Education: Towards Equality for Students with Disability: Distributed electronic and hard copies 30,207; Belonging and Connection of School Students with Disability: Distributed electronic and hard copies 1,935; Strengthening participation of children and young people with disability in advocacy: Distributed electronic and hard copies 473; Post School Transition: The Experience of Students with Disability: Distributed electronic and hard copies 1,370

## CYDA Website

CYDA'S website is reviewed fortnightly and updated accordingly

Page views and visits steadily increased throughout the year.

Yearly totals - Visits 174,244, page views 208,541.

## E-News

19 e-News were sent to members and subscribers over the year (a total of 51,863 individual emails).

## Social Media

Facebook – Followers as at June 2019 15,965, 890 new likes

Twitter – Followers as at June 2019 4568, 193 new 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

Amaze

Association for Children with a Disability

Australian Council of Social Service

Australian Education Union

Australian Federation of Disability Organisations

Australian Human Rights Commission

Australian Network for Universal Housing Design

Australian Research Alliance for Children and Youth

Brain Injury Australia

Bravehearts

Children’s Commissioners (State and Federal)

Community Resource Unit Ltd

Deaf Australia

Deafness Forum Australia

Department of Social Services

Disability Advocacy Network Australia

Disability Advocacy Resource Unit,

Disabled People's Organisations Australia

Down Syndrome Australia

Disability Discrimination Australia

Disability Discrimination Commissioners (State and Federal),

Disability Institute (University of Melbourne)

Down Syndrome Australia

Education Services Australia

Early Childhood Intervention Australia

Families Australia

Family Advocacy NSW

First Peoples Disability Network

Health and Community Services Union

Heartwell Foundation

Huntingtons Victoria

I-CAN

IHC New Zealand

Imagine More

Inclusion International

Julia Farr Youth

Lifestart

Melbourne Disability Institute

National Disability Insurance Agency

National Disability Services

National Ethnic Disability Alliance

National Youth Commission into Youth Employment and Transition

NSW Teachers Federation

Noahs Ark

NSW Ombudsman

Office of the eSafety Commissioner

Parents of Deaf Children

People with Disability Australia

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

Royal Commission into Institutional Responses to Child Sexual Abuse

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

Save the Children

Scope

Speakout

Speech Pathology Australia

Tasmanian Disability Education Reform Lobby

Teachers Federation NSW

Touched by Olivia Foundation

UNICEF

University of New South Wales

VALID

Victorian Council of Social Services

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. Dan Tehan MP – Former Minister for Social Services

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

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

Hon Linda Burney MP - Former Shadow Minister for Social Services

Senator the Hon Sarah Henderson - Former Assistant Minister for Social Services and Disability Services

Hon. Bill Shorten MP- Former Leader of the Opposition

Hon Tanya Plibersek MP - Shadow Minister for Education and Training

Senator Carol Brown - Former Shadow Minister for Disability and Carers

Senator Jordan Steele-John - Disability Right's Spokesperson

Various Members of Parliament

Department of Social Services

Australian Government Department of Education and Training

Australian Human Rights Commission

Disability Discrimination Commissioner - Mr Ben Gauntlett

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:

Australian Electoral Commission Disability Advisory Committee

Commonwealth Ombudsman Best Practice Guide (NDIS Complaints) Working Group

CRPD Shadow Report Working Group Meeting

e-safety and Mental Health Steering Group

Every Child Steering Committee

Improved Assessment Process for Carer Payment and Carer Allowance (DSS Reference Group)

ISC Project Steering Group

National Disability Strategy Reform Steering Group

NDIS Practice Standards Technical Reference Group (DSS Reference Group)

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

Research to Action Guide on the “journey to employment” (NDS Steering Group)

# Feedback

The Government greatly values the important contribution that CYDA makes in advocating for the rights and interests of all children and young people with disability living in Australia. – Parliamentary Secretary to Premier NSW

I recognise the value of CYDA’s work in supporting Western Australian families and I commend CYDA’s work to promote equal opportunity for children and young people with disability. – Sue Ellery MLC Minister for Education and Training WA

I commend the significant work of CYDA in advocating systemically for the rights of children and young people with disability Australia wide. I acknowledge CYDAs contribution to both national and local policy discussions with regard to the National Disability Insurance Scheme and look forward to continuing our positive relationship in 2019. – Hon Stephen Dawson MLC Minister for Disability Service

I would particularly like to acknowledge CYDA’s key achievements over 2018 including consultation, advocacy and provision of information and resources for children and young people with disability and their families, and the collaborative work CYDA has undertaken with government education stakeholders and the National Disability Insurance Scheme. – The Hon James Merlino Minister for Education Victoria

I commend the valuable work CYDA undertakes as the national peak body charged with advocating on behalf of children and young people with disability across the country. I note particularly your organisations focus on the critical area of education, as well as the National Disability Scheme. – Queensland Department of Communities, Disability services and Seniors

Thank you for all you do to support children and young people with disability and their families. – Dr Helen Nugent AO Chairman National Disability Insurance Agency

# 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.

* Jonathan Moore SC
* Clifton Hill/North Fitzroy Community Bank
* Young Academics Learning Centre, Canterbury
* St John’s Lutheran School, Eudunda
* Niche Logistics

# Financial Snapshot

## 2018 – 2019 Results

Total Revenue………………………………………………………….…$422,138

Total Expenditure…………………………………………………….…$400,620

Result – Surplus…………………………………………..……….….…$21,518

Total Members Equity, 2017 – 2018……………………….....$108,591

Total Members Equity, 2018 – 2019………………………..…$130,109

## Income 2018-2019

Department of Social Services 94%

Donations 0.6%

Memberships 2.5%

Interest received 0.5%

Other income 2.6%

## Expenditure

Consultancy 0.2%

Operating expenses 24%

Office expenses 11%

Employment expenses 64.8%

# Children and Young People with Disability Australia

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