



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

**The Tasmanian State Government
Leading Australia For An Inclusive Society**

Contact: Caroline Pegg – Chief Executive Officer
GPO box 730, Hobart 7001
PH: 0400 623 120
cpegg@acdtas.com.au

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The following additional information has been provided with this submission:

Appendix A: Cost-Benefit-Analysis-of-Australian-independent-disability-advocacy-agencies-2017

Executive Summary

Thank you for the opportunity to make a submission to the 2018/2019 State Budget Community Consultation. This submission will importantly discuss independent advocacy as a valuable community resource in Tasmania that requires continued funding for sustained effort toward an inclusive society for people with disability and their parents and carers. It will also highlight gaps that are present and may remain, following the full roll out of the National Disability Insurance Scheme (NDIS), in mainstream and universal services and where Tasmanian citizens and communities expect a general standard to be provided for children and families.

The key areas for discussion and recommendations are:

- Advocacy
- Child Safety
- Family Support
- Health
- Education

The Association for Children with Disability supports the Tasmanian State Governments vision for the future: *a fully inclusive and participatory society in which people with disability are valued and respected as equal and contributing members of the community.*

The Association for Children with Disability (Tas.) Inc. (known as ACD) is a state-wide not for profit organisation that works alongside Tasmanian families with children and young people aged 0-25 years. Incorporated in 1998, ACD developed its support programs and advocacy reach in direct response to the issues and needs of family stakeholders, clients and members. ACD has offices and staff based in Hobart, Devonport and Newstead and employs 15 staff (9 FTE's).

ACD provides community leadership and quality family support options in Tasmania with a focus on empowerment, issue prevention and influencing continual improvement in societal outcomes for people with disability and their families and carers. ACD provides Information, Advocacy, Training and Consultancy, Case Coordination and Peer Support Networks across Tasmania. In 2016/2017 ACD had 4172 service users.

ACD has been involved with the NDIS since it was called DisabilityCare, and was the first funded Family Advocacy organisation in Australia to register with the NDIS to supply Support Coordination. Regular interaction with the scheme and parents and carers and young participants with complex disability across the community has resulted in ACD gaining vital expertise in this system, and understanding its limitations and possibilities.

The NDIS has significantly improved a person with life-long disability and their families' financial capacity to purchase needed services, supports and equipment and technology. However, the NDIS is a huge social reform that may take many years to realise its full potential for people with disability. Across Tasmania there is considerable workforce and community development work needed to raise disability awareness and ensure choice, readiness and availability of a range of regular and quality services and supports.

ACD as a state funded family service takes a cooperative approach across the Tasmanian community to promoting and protecting the human rights of people with disability and their families and carers. We look forward to continual progress being made toward a more inclusive society and to the reduction and elimination of inclusion barriers experienced by those with disability and their families and carers.

Independent Advocacy in Tasmania

GAP - Beyond July 1, 2019 there is no commitment from the State Government to fund Independent Advocacy in Tasmania for people with disability and their parents and carers.

Australian and Tasmanian Governance supporting documents

National Disability Strategy 2010-2020

2.11 Support independent advocacy to protect the rights of people with disability.

The Tasmanian Disability Framework for Action 2013-2017

1.1.1 Support people with disability, their families and carers to build and strengthen supportive networks that will assist people with disability create an enduring link with the community.

2.1.1 Promote awareness and acceptance of the rights of people with disability.

2.3.3 Support independent advocacy to protect the rights of people with disability.

2.3.4 Enable people with disability to exercise their rights through self-advocacy and through appropriate complaints, review and appeal mechanisms.

SYNOPSIS: *Independent advocacy and the National Disability Insurance Scheme - "Most families and individuals cannot adequately prepare for the risk and financial impact of significant disability. The costs of lifetime care can be so substantial that the risks and costs need to be pooled" (Productivity Commission 2011:2).*

The Productivity Commission concluded that Advocacy should lie outside the NDIS. This was due to the potential conflict of interest that would arise were the NDIS to fund Advocacy bodies whose role was to challenge the disability system overseen by the NDIS. The Productivity Commission recommended that the then funding arrangements through FaHCSIA and various state and territory governments should continue - Productivity Commission 2011:26. (Cost-Benefit-Analysis-of-Australian-independent-disability-advocacy-agencies-2017).

The Tasmanian State Government committed its Disability Program Advocacy funding to the Commonwealth Government in its bilateral agreement between the Commonwealth and Tasmania, Transition to a National Disability Insurance Scheme.

Advocacy for children and young people with disability and their families is 100% state funded in Tasmania to July 2019. The Department of Social Services funds Advocacy through its National Disability Advocacy Program (NDAP) and has extended funding to its current funded organisations, in Tasmania; Advocacy Tasmania and Speak Out Advocacy, until 2020. The Tasmanian Government through its Disability and Community Services agency and DPaC has successfully funded, worked and collaborated with Tasmanian Advocacy services and their memberships for many years. As a result Tasmania is considered nationally to have mature leadership, with successive State Governments making ongoing progress toward the goal of an inclusive society by ensuring that vulnerable citizens have a local representative voice, and are listened to and respected.

Tasmanians are now at risk of losing this local representative voice because the future of Advocacy in Tasmania is uncertain.

ACD Independent Advocacy in 2016/2017

ACD is the only Tasmanian State Government funded Independent Advocacy service that specialises in Advocacy to families with children and young people with any type of disability or disabling condition. In the 2016/2017 financial year, ACD's advocates responded to 236 referrals

from parents and carers requiring Independent Advocacy and support to resolve 434 primary issues affecting children with disability.

ACD Staff worked to bring about assisted outcomes and successfully closed 183 cases during a 12 month period working alongside family members, and in collaboration with key stakeholders across the community. At point of access, thirty two percent (32%) of families and carers who self-referred to ACD Independent Advocacy were assessed by staff (using ACD's impact and urgency matrix) as presenting with primary issues with high urgency (need for immediate response) and high impact (serious issues of risk evident) ratings. This compared to 20% in 2015/2016 and reflects increasing emotional distress and effect on families and carers with children with complex disability and high support requirements.

During and after the NDIS roll out

The demand for independent Advocacy since the introduction of the NDIS steadily increased (ACD 2016/2017 data shows 56 referrals compared to 32 in 2015/2016 for NDIS issue resolution and assistance) as people with disability and their parents and carers grappled with and learned to adapt to a new system and its processes. The Tasmanian Advocacy organisations have regularly met with the NDIA to discuss concerns and share ideas for system improvement since 2014.

A recent survey shows that around a quarter of people with disability and their carers feel they get less support and their life is worse under the NDIS. (Cost-Benefit-Analysis-of-Australian-independent-disability-advocacy-agencies-2017).

[\(http://www.everyaustraliancounts.com.au/ndis-report-card/\)](http://www.everyaustraliancounts.com.au/ndis-report-card/).

Carers Australia – Tas. - A report on: “The impact of the NDIS on Carers in Tasmania - The Picture So Far” – October 2017, demonstrates that about 50% of participant parents and carers are struggling with the system and believe that it has not improved their circumstances.

Independent Advocacy - the benefits to Tasmania

Ongoing commitment for funding of Advocacy by the State Government will ensure a separation, a level of independence, from the Australian Government that governs the NDIS. This will importantly ensure the voice of vulnerable Tasmanians with disability and their parents and carers and highlight any unintended impacts of the NDIS and other services and systems.

Many of the Tasmanians that Independent Advocates work alongside are yet to be diagnosed or have disabling conditions (e.g. people who experience the impacts from Trauma, Anxiety, Depression, ADHD, Conduct Disorder, Asperger's, Brain injury, mild intellectual disability etc.) that may not meet the NDIS criteria for access. These vulnerable Tasmanians with disability frequently fall through service cracks and present complex challenges to the community when accessing mainstream and universal services and systems; often requiring Advocacy for across system issue resolution and successfully navigation.

There are many benefits to State funded Independent Advocacy (as demonstrated fully in the Cost-Benefit-Analysis-of-Australian-independent-disability-advocacy-agencies-2017) and in summary;

- ☐ Reduced costs for governments (resources freed for their next best use); and
- ☐ More productive employment for people with disability; and
- ☐ Better educational outcomes for people with disability; and
- ☐ Better health outcomes for people with disability; and
- ☐ Better child protection outcomes for people with disability.

Additionally Independent Advocacy captures state based issues, concerns and service and support gaps effecting Tasmanian people with disability and their families and carers, providing a reliable litmus test for State Government to assess inclusion and participation progress and prioritise areas for reform and initiative development.

Independent Advocacy organisations are regularly involved in community and government consultations and network meetings and report to and liaise with all levels of government and across the community; utilising their membership and expert knowledge of their primary stakeholder and evidence of barriers to inclusion, to prioritise community development projects that aim to improve societal outcomes.

In 2016/2017 ACD Advocates predominantly worked alongside parents and carers and their children as they connected with the Education, Housing, Child Safety, Transport, Justice, Health and NDIS systems.

RECOMMENDATIONS – INDEPENDENT ADVOCACY

- 1.1 Recurrent state funding provision for the Association for Children with Disability (Tas.) Inc., Advocacy Tasmania and Speak Out Advocacy to provide Individual Advocacy to meet the additional Advocacy demand arising from the National Disability Insurance Scheme implementation issues. (Estimated additional cost for 2017/18 - \$345,000 - \$115,000 to each provider; out- years \$330,000 plus indexation).
- 1.2 A commitment for recurrent state funding provision at current levels plus indexation for the Association for Children with Disability (Tas) Inc., Advocacy Tasmania and Speak Out Advocacy to provide Individual Advocacy from 2019-2022).

CHILD SAFETY

GAP – Independent Advocacy to effectively ensure the wellbeing of children and young people with disability who are under the care and protection of Child Safety.

GAP - Independent Advocacy service availability to take referral from the Children’s Advice and Referral Alliance (CARA).

State Government reforms and initiatives

- Tasmanian Child and Youth Wellbeing Framework
- Strong Families Safe Kids Project

SYNOPSIS: It is universally recognised that a significant percentage of children under Child Safety’s care and protection have diagnosed or undiagnosed disability and many other children suffer from the disabling effects of abuse and neglect. These children are under-represented in Advocacy.

The societal norm is that Parents or legal guardians are expected to protect children’s rights and to speak on their behalf. ACD independent advocacy exists on the basis of knowledge that some Parents, Carers, Guardians or Responsible Adults, cannot; do not; can but require additional information, or need assistance to fulfil this vital role.

Currently families that do not have any natural or sufficient supports and who are no longer able to manage to care for their child with complex disability, are required to enter the Child Safety system voluntarily. These families often report unreasonable treatment as the system is not designed for these exceptional circumstances, and instead to prevent the abuse and neglect of

children. It is hoped that the NDIS and the State Governments Tasmanian Child and Youth Wellbeing Framework major initiatives once fully implemented will prevent these exceptional circumstances from arising.

ACD is excited about the Strong Families, Safe Kids project and plan and particularly the Governments' clear objectives to; place the well-being of children at the centre of services; ensure participation, and to provide better support for children and families. ACD advocacy aligns closely with these principles and our model of practice aims to build family resilience and capacity whilst providing an independent safe guard for a child with disability or disabling condition with their health and well-being (best interests) at the centre at all times.

RECOMMENDATION – CHILD SAFETY

2.1 Recurrent funding provision for the Association for Children with Disability (Tas) Inc., to provide Individual Advocacy (safeguards) to children with disability or disabling conditions who are under the guardianship of Child Safety, and to Parents and Carers with children with disability or disabling conditions that require assistance and intervention with issue resolution and across system or service navigation (Estimated additional cost for 2018/2019 - \$115,000; out-years \$115,000 plus indexation).

FAMILY SUPPORT

GAP: Family centred practice case management to assist in the event of family crisis or complex situations.

State Government reforms and initiatives

The Tasmanian Carer Policy 2016 and the Carers Action Plan – Supporting the work of Tasmanian carers

SYNOPSIS: The State Government and the National Disability Insurance Scheme (NDIS) do not currently fund a model of family centred practice case management for children and adolescents with disability and their families.

When a family is in crisis their main goal tends to be survival, therefore making the professional approach of a Case Manager essential to assisting them through the crisis period; assessing and addressing immediate needs before moving on to essential planning for the future. Serious challenges and incidents reported to ACD by parents and carers mainly occur for children with disability during adolescence. The NDIS is available to this age group but their funded model of complex Case Management (Specialist Coordination of Support) is time limited and goal based and does not support a holistic or family centred approach or provide a commitment to supply sufficient funds for a Participant in the event of crisis.

The NDIS has recognised the benefits of the family centred practice approach with families with children aged 0-6yrs eligible to access support from the NDIS Early Childhood - Early Intervention Model (ECEI) by July 2018. Ideally this approach should be extended to families in crisis, i.e. when a family member with disability exhibits challenging behaviours that have the potential to cause physical harm.

ACD is representing families to the NDIA locally and through Tasmanian Senators for the NDIS to meet this long standing service gap area in Tasmania. Currently the NDIS position is that the Tasmanian Community should supply crisis response and management. We are also waiting to

discover if the Safe Home Safe Families Model and Case Management will apply to families suffering from violent behaviour at home from their child or adolescent with complex disability.

GAP: Crisis response, including access to temporary accommodation or respite, and home outreach by suitably trained and skilled staff.

SYNOPSIS: Currently Tasmanian families do not have any immediate and appropriate options in the event of a crisis that involves a child or adolescent with disability exhibiting challenging behaviour that causes harm to family members.

Tasmania does not have a sufficiently trained and expert workforce to respond to these events. Tasmania has a shortage of crisis accommodation and respite options.

OakPossability, a Tasmanian disability service provider reports that it is working to fill this gap and has designed a fit for purpose model in collaboration with Architects, Designers and Psychologists. They have to date been unable to source a capital grant for building funds.

Education providers demonstrate significant challenges in providing a regular education and suitable environment for children with significant disability who exhibit challenging behaviour that may cause harm. This adds further vulnerability to the family and can contribute to increasing risk of family crisis and breakdown.

The NDIS funds Accommodation and Respite support for some Participants but crisis accommodation and respite options are not readily available in Tasmania. There is no NDIS funding available for outreach in the event of crisis.

Families experiencing challenging behaviour that causes harm in their home and in the community are currently not able to access family violence crisis support options (with the exception of counselling services) as they are funded only to provide assistance in cases of partner or spouse violence. Families report that the current mainstream and universal crisis support options are not appropriate for providing support to those experiencing violence in the home from a child or adolescent with complex disability, and that these options would only be used in an absolute emergency. The current crisis options for the community are governed by, criminal or youth justice (Police), abuse and neglect (Child Safety) and medical frameworks (Ambulance and Hospitals).

RECOMMENDATIONS – FAMILY SUPPORT

3.1 A whole of government framework that recognises and supports Tasmanians effected by different kinds of family violence. (We await the implementation of the Safe Home Safe Families Model to find out if it will be appropriate and apply to families experiencing violence at home from a child or adolescent with complex disability.)

3.2 Recurrent funding provision for a community outreach behaviour intervention service for children and adolescents with disability.

3.3 State Government Consultation with OakPossability and review of the design and objective of a fit for purpose secure respite and accommodation option.

HEALTH

GAP: Timely Assessment and Early Intervention therapies and services

State Government reforms and initiatives

One State, One Health System, Better Outcomes – Changing the health system to make it focus more on the needs of patients.

Rethink Mental Health: Better Mental Health and Wellbeing – Changing the mental health system to strengthen understanding of mental health issues; help prevention and early intervention; improve care and support for people with mental illness; and improve the way that the parts of Tasmania's mental health system work together.

SYNOPSIS: Tasmania has a shortage of allied health practitioners and family centred intervention programs. The benefits of targeted early intervention are well documented. The Tasmanian Early Childhood Intervention Services (ECIS's) are important and well respected family centred practice services providing assistance to families with children with disability or developmental delay from 0 through to school age.

Tasmania has a long standing issue with sufficient supply of a range of allied health practitioners to deliver timely assessment and recommended therapies and evidence based interventions. The Tasmanian Health system is difficult to navigate and TADS (Tasmanian Autism Diagnostic Services) and Health and Allied Health assessment and reporting often take months to access and complete, delaying vital early intervention therapies.

Once diagnosis is gained families with children aged 0-6yrs can access early intervention services after referral from an approved health practitioner from a number of Government funded sources, i.e. ECIS; St Giles; Education; Medicare; Better start. From 1 July 2018 the NDIS will make available Early Childhood Early Education services.

It is hoped that the NDIS will act as an incentive to those Tasmanians studying or qualified in Speech Pathologists, Occupational Therapists, Physiotherapists and Psychologists to return home.

RECOMMENDATIONS - HEALTH

4.1 Recurrent funding provision beyond 2020 for the Early Childhood Intervention Services state-wide.

4.2 Continued focus on increasing Allied Health and Specialist Health practitioners in the North and North West of Tasmania.

GAP: Behaviour Assessment, Management and Training Services

SYNOPSIS: Tasmania does not have a multi-disciplinary team available for face to face response and behaviour management. There is a shortage of relevant Allied Health and Health practitioners, and practitioners rarely provide outreach to a person's home. Individual behaviour assessments and training for support staff usually take months to complete and waiting lists are long. Family distress, high staff turn-over due to injury, and increasing insurance premiums for service providers act as barriers to the consistent implementation of behaviour management strategies. Staff training rarely takes place in environmental context, e.g. where the violence is mainly occurring. Where a number of systems are involved (e.g. Education, Health, Human Services, NDIS), collaboration for agreement on management and treatment is often difficult to achieve.

There are various funded sources available in Tasmania through, Disability Services (DAAT will cease to be funded in July 2018), DoE, the NDIS, and Medicare Health Plans. All of these options are however not immediately accessible.

RECOMMENDATION - HEALTH

4.3 Recurrent funding provision for two (2) secure centre based temporary accommodation and respite options staffed by a multi-disciplinary team who have the capacity to provide community outreach in the event of a crisis where a person with disability is exhibiting challenging behaviour that causes harm.

GAP: Comprehensive medical and psychological health and medication review and management

SYNOPSIS: Tasmania does not have a secure hospital unit for adolescents who exhibit serious challenging behaviour. The Tasmanian health system is not resourced to provide post hospital paediatric and multidisciplinary response to adolescents with developmental and behavioural issues. Child and adolescent Paediatricians and Psychiatrists are not readily available in all regions of Tasmania.

Management of chronic conditions including developmental and behavioural issues, and preventative medicine makes up the bulk of paediatric healthcare presentations. Currently when adolescents are hospitalised they share a ward with babies and young children.

Tasmanians are often forced to travel to Victoria to access required sub-specialists and to undergo treatment and review and change of medication.

The feasibility of travelling with an adolescent with behaviour issues and the cost, in time taken from other family members and work, are prohibitive factors to many for accessing the services they desperately require. Families report managing violent behaviour in the home to the best of their ability.

This information was supplied to the State Government by Tasmanian Health Practitioners in 2015 in response to the State Government Green Paper - Delivering Safe and Sustainable Clinical Services 2014. ACD is pleased that the State Government is working to fill this gap by providing Child Adolescent Mental Health inpatient services in the Launceston and Hobart hospitals.

RECOMMENDATION - HEALTH

4.4 Continued work to develop and sufficiently resource secure child and adolescent mental health inpatient services and Paediatric and Psychiatric Specialists.

EDUCATION

GAP: Models of education and environments that provide for students with disability who exhibit complex or potentially harmful behaviours.

GAP: Human and financial resources to provide for timely Psychological assessment and intensive but short-term therapy or intervention to meet the needs of a student with disability.

GAP: Disability awareness and experienced and skilled Teachers and Support Teachers.

State Government reforms and initiatives

Improved Support for Students with Disability - Providing \$12 million to make schools more inclusive for students with disability.

SYNOPSIS: ACD referrals in 2016/2017 demonstrated continuing demand for Advocacy from parents and carers needing assistance to work alongside them to resolve Education concerns for their children. Education issues formed 30% of primary issues this year on behalf of children with disability aged 6-18yrs.

There is ongoing progress in education inclusion of students with disability and this year brought positive news with a drop in referral requests for Advocates to attend Individual Education Planning meetings; demonstrating a growing confidence in Education planning work and increased collaboration with parents and carers.

Education provider challenges continued to be evidenced for education supply to children with complex disability and challenging behaviour, resulting in no or low education outcomes and imposed part time enrolment, e-learn, or distance or home education.

Parents and carers reported being unable to work full time or part time as a direct result of their child not receiving a full time education and no alternative services and supports being offered.

Parents report increasing financial distress as the cost of living rises.

Where complex cases arose school Principals reported that under resourcing was a barrier to meeting student needs. For example, Psychology assessment and reporting is required by the Department of Education to gain additional funding in most cases and long delays are evident, often leading to family distress.

Principals reported Industrial and red tape issues preventing the use of disability expert education staff with Allied Health (Psychology, Speech Pathologists, OT's) qualifications, for teaching, Learning Support or Management roles and functions.

Where family distress was evident due to a long term experience with education exclusion of their child and systemic issues. Some parents and carers reported feeling like a 'problem parent' because they continued to expect a school and/or the Education Department to address the presenting barriers to their child receiving an education.

After 10 years of Advocating for Individual Funding in Education ACD looks forward alongside families and carers to the State Governments' application of needs based funding for students. Like the NDIS this may take additional resources and some years to effect positive change but this is a significant milestone toward achieving the State Governments' vision for inclusion and participation of people with disability in Tasmania.

RECOMMENDATIONS - EDUCATION

5.1. Review the process for funding students with disability in Tasmania and where possible remove red tape, enabling more hands on involvement by school Psychologists and Allied Health Professionals with disability skills and expertise.

5.2 Resource research, trial and funding of different education models for the successful inclusion and participation of children with disability that present as a challenge in conventional classroom environments.

5.3 Funding provision for Professional Development for Education Leaders in Collaborative Team Building and Working in Family Partnership.

5.4 Recognise and promote best practice examples and standards of excellence in delivery of education and support to students with disability and share good news stories (de-identified) and learnings across the education sector and the general community.

5.5 Funding provision for compulsory Professional Development for all Teachers, Support Teachers and Teacher Aides on Inclusion and Participation of students with disability and diverse needs and everyday application and assessment.

5.6 Funding provision for disability data collation and analysis for informing planning and practice, evidencing professional development needs and innovating in the development of systems, processes and practice for educational improvements for students with disability.