

Submission to the Disability Inclusion Bill 04/10/2023

Thank you for the opportunity to make a submission to the Disability Inclusion Bill.

This ACD Tas submission focuses on the Tasmanian service system landscape and:

- ACD Tas's unique role within it alongside the parents and carers for effectively engaging with services and influencing needed social change;
- the need for government collaboration and governance improvements that recognise the valuable role of parents and carers and bring about timely access to appropriate, competent and relevant services to children with high and complex needs;
- the need to plan for and continuously improve service systems that are inclusive and incorporate the disability needs of children and their families;
- the need to strengthen service provision and safeguarding mechanisms for children with disability.

ABOUT ACD TAS

The Association for Children with Disability (Tas) Inc. is a Tasmanian Family Organisation known as ACD Tas. Incorporated in 1998, ACD Tas is a peer-led not-for-profit organisation that provides information, advocacy, consultation and training, case coordination and peer support. Our mission is to provide community leadership and quality support options that improve participation and life outcomes. Our vision is that people with disability, their families and carers have equal opportunity to reach their potential and lead fulfilling lives.

ACD Tas is the only state-wide family disability specialist provider that focuses on assisting and empowering families with children with any type of disability and/or chronic health condition to achieve positive life outcomes. ACD Tas was established in December 1997 by a group of 11 parents with children with disability, who recognised the need for a state-wide advocacy organisation in Tasmania to support families. The organisation was incorporated in 1998, and the parent community of practice volunteered their time to provide information, support and referral services to families, while they sought funding for family advocacy to gain improved social inclusion outcomes for children with disability.

Since gaining our first funding for advocacy in 2000, ACD Tas has continually developed our model for working with families and our quality family assistance options in direct response to the needs identified by family stakeholders. ACD Tas's overarching purpose, to work for continual progress towards a more inclusive society through the reduction and elimination of barriers to inclusion experienced by children and young people with disability and their families and carers. To learn more about our goals and objectives and how we achieve them please refer to our 2022-2026 strategic map. <https://acdtas.com.au/governance/strategic-map/>

Our 2021/2022 annual report includes more detailed information about our work alongside families and children and young people with disability. <https://acdtas.com.au/governance/annual-report/>

PROFESSIONALISM AND LIVED EXPERIENCE

ACD Tas offers a range of services for families, parents and carers, and youth with disability delivered by professional staff, who are in many cases youth, parent, carer and family peers, working out of regional offices in Devonport, Launceston, and Hobart and home offices across Tasmania.

Daily we engage with and work for more than 250 parents and carers and children and young people with disability (newborn to 25 years old) who require information, advocacy and peer support, including up to 195 participants of the NDIS as a registered provider of Support Coordination. ACD Tas registered to provide the Support Coordination administrative role and function in 2013. We understood from our advocacy work and issue data since 2000 that inclusion and participation outcomes of children with high support needs and complex disability across many environments in Tasmania are poor, and that an expert family service for informing and building the capacity of young people with disability and parents and carers of children with disability to effectively engage with the scheme, its planning process, their plans and community and mainstream services was needed.

The ACD Tas programs are strength based and our support model focuses on empowering families to achieve self-defined goals for the direct benefit of their child/ren with disability and their family as a whole. We work with a fundamental principle that the rights and interests of the child or young person with disability are upheld at all times. Our approach is guided by our Working with Families Model and Family Centred Practice principles and theoretical underpinnings from the Eco systemic theory (Bronfenbrenner), Self Actualisation theory (Maslow and Rogers) and the Resilience theory (Garmezy). ACD Tas staff receive ongoing training and support to continually develop their knowledge, skills and practice for assisting and empowering families. All ACD Tas service areas and staff work to prevent issues arising wherever possible and bring about timely access to appropriate and relevant services and rightful outcomes for children with disability alongside parents and carers.

The importance of family support to the health and wellbeing of individuals with disability is well recognised, and the empowerment of parents as well as the empowerment of those with disability are significant contributors to outcomes (Daly et al, 2015; Dunst & Trivette, 2009; Dunst, Trivette & Hamby, 2007), particularly in relation to capacity building (Dempsey, 1995; Dempsey & Keen, 2008). Empowerment has been defined as ‘a process by which families access knowledge, skills, and resources that enable them to gain positive control over their own lives as well as improve the quality of their lifestyles’ (Singh, 1995, p.13). Importantly, empowerment has been linked to self-efficacy, that is, one’s beliefs about their own capacity to execute an action in order to produce a desired result (Dunst & Trivette, 2009), a sense of control over one’s environment, access to resources, and personal action (Dempsey & Dunst, 2004).

Accordingly, the family-centred approach has been recognised as one of the most important considerations for service providers here in Australia, and around the world (Moore & Larkin, 2005). Research has shown that some of the most important aspects of a family-centred approach are that families are respected, they have choice and control over the supports received, they are able to develop partnerships and collaborations with service providers (Dempsey & Keen, 2008). Importantly, they have also been shown to strengthen and enhance family and individual functioning (Espe-Sherwindt, 2008), and social inclusion (Daly et al., 2015). Still, studies that attempt to understand the needs of such services, and that measure outcomes for parents and children have been limited in number and scope (Bailey, Raspa, & Fox, 2012; Espe-Sherwindt, 2008).

The families ACD Tas works alongside face particular challenges in relation to accessing services, and also require a nuanced approach to support that includes the strengthening of intra-family and external relationships, open and clear communication, and long-term relational support (Howard, Blakemore, Johnston, Taylor & Dibley, 2015). As the prevalence rate of disability in Tasmania is higher than any other state or territory (25.2 per cent of the population according to the Australian Bureau of Statistics, 2015), many of the ACD Tas clients and those linked with the

MyTime program we operate are likely to experience impacts associated with multiple disability and/or disabling conditions and include more than one member with disability.

They are therefore more likely to suffer from socioeconomic disadvantage and have lower levels of education than those with disability in major cities (McPhedran, 2011). Importantly, they are also more likely to engage with their community.

In addition to being skilled and experienced professionals, a majority of ACD Tas' Board members are parents or family carers of children and adults with disability. This peer-led approach is embedded in our Constitution and governance and operational policies and practice. Our constitution lays out ACD Tas's basic objectives. ACD Tas have well-established links with the grass roots community and we have grown and developed our operations, often through co-design, alongside our family stakeholders and in direct response to their needs and those of children and young people with disability.

KNOWLEDGE, RESPONSIBILITY AND INFLUENCE

ACD Tas continues to use the information we receive in our work to highlight issues of concern and to advocate on behalf of and in the best interests of children and young people with disability with high support and complex needs who experience some of the most challenging circumstances. Many Tasmanian children and young people live with a number of disabilities and have complex needs and cannot gain access to appropriate and relevant services.

The ACD Tas has over time earned its place as an ethical and influential industry leader and is regularly called upon to assist community and government understanding of Tasmanian families with children with disability and their experiences and to recommend solutions for improving outcomes. As such we have become the organisation and repository for the community and government to share their relevant information and resources with families. Our collaborations with parents and carers and youth with disability, disability advocacy organisations and peak bodies, the general community, and relevant government agencies are many and are testament of ACD Tas's reputation among key stakeholders as a knowledgeable influencer for improved social inclusion outcomes and promoter and protector of the equal human rights of children with disability.

Our experiences alongside our primary family stakeholders inform this submission.

Disability Inclusion Bill consultation – Practical and political risks

There is a great deal of Disability related Federal and State Government activity, across a range of disability related legislative and service provision responsibilities, preceding the long awaited of the Disability Royal Commission final report and recommendations. With respect to the proposed Disability Inclusion Bill, it is useful to recall and reflect on the purpose and focus of the Disability Royal Commission, which has been somewhat unusual in that its scope extended to and has been supported by the States and Territories of Australia when investigating:

- preventing and better protecting people with disability from experiencing violence, abuse, neglect and exploitation
- achieving best practice in reporting, investigating and responding to violence, abuse, neglect and exploitation of people with disability
- promoting a more inclusive society that supports people with disability to be independent and live free from violence, abuse, neglect and exploitation.

It should not come as any surprise that those who live with disability, those who care and support them, as well as the Australian community hold expectations of the need for profound change in the way those who live with disability are treated. People with disability have had basic right denied, been marginalised, excluded and harmed throughout history and despite the development of legislation and other protections.

The following ABC media article examples community concerns - Sat 23 Sep 2023 at 7:26pm - Without change, the trauma of the disability royal commission will have all been for nothing: <https://www.abc.net.au/news/2023-09-24/disability-royal-commission-change-analysis/102789440>

Senator Steele-John hopes to see a specific disability ministry established.

"We need a coordinated response not only to the royal commission recommendations, but to all of the events and policy areas that impact disabled people," he says.

In its current draft form the Disability Inclusion Bill makes provision for new roles, consultation processes and even investigative bodies, but lacks clarity regarding the key focus and responsibilities of those roles, particularly when it comes to State based responsibilities and the ability to hold to account those who are responsible for ensuring genuine and profound reforms for areas of already existing responsibility, backed by existing International, National and State legislative protections.

In rushing the Disability Inclusion Bill there is a very real probability that a chance for significant and meaningful human rights and inclusion improvements will be missed, along with an associated disability and general community backlash, given the appalling revelations, events and circumstances already unearthed by the Disability Royal Commission.

With the short timelines associated with the draft Disability Inclusion Bill, those living with disability may perceive the Disability Inclusion Bill as not inclusive and inadequate to drive and ensure real change in the circumstance where the work done thus far by the Disability Royal Commission has already established an urgent need for change.

State Government role and responsibility with respect to children living with disability

There are many existing International, National and State legislation frameworks relating to people living with Disability, but there are also specific International, National and State legislation frameworks relating to children and in particular children living with disability, that directly intersect with core Tasmanian State Government responsibilities, including education, health, child safety and youth justice.

Despite existing legislative protections children living with disability remain some of the most vulnerable people in the community. Issues reported to the state government by ACD Tas and other Tasmanian advocacy services annually, matters raised in the Disability Royal Commission (hearings, Issues Papers, Interim Report, Progress Reports, Roundtables and research), regular Tasmanian media reports of children with disability not being able to access specialists, being restricted or excluded from education, having inadequate care and supports from local and community services or in State Care, being overly represented in the youth justice system etc. demonstrate that inclusion outcomes continue to worsen. The design and implementation of the NDIS having an influence on this by disrupting or leading to the cessation of many necessary and established disability supports and specialist services for children living with disability.

The draft Disability Inclusion Bill currently lacks a clear focus to ensure all new roles, bodies and processes (including action planning) first and foremost focus on existing State responsibilities and assessing and filling the gaps that currently exist in essential services and systems that are relevant to meeting the needs of children living with disability and their parents and carers. This work is vital for the inclusion of children with disability to prevent exacerbating known risks to children with disability and restrictive practises from being applied in the first place. For example, it is commonly known that public outpatient paediatric assessments for children and young people have months and even years long waiting lists, and that private psychologists have long waiting lists or closed books. The following ABC news media article provides information on these concerns:

[Calls for more paediatricians as shortage leaves 3,300 Tasmanian children on wait list - ABC News](#)

Shared responsibilities

Of late there have been statements made by Federal Government Ministers and others in decision making positions about the development and reform of the NDIS. In particular, it has been made clear that the intent is to further restrict NDIS access where state government has responsibilities, such as in education and health.

The Disability Inclusion Bill should be clear that the Bill applies where there are shared responsibilities. In particular, the Disability Inclusion Bill should provide a means to ensure uniformity of disability standards, practices and protections. For example, restrictive practices affect people with disability who not only access NDIS disability support services but the services of education, health, police, and youth justice, all of which are core Tasmanian State Government responsibilities.

It is also unclear how the Disability Inclusion Bill 2023 is to interface with, inform, and in key areas provide the means to drive change with respect to already existing legislation and roles, which evidence provided to the Disability Royal Commission reveals historically has failed to protect those living with disability. In some respects, existing legislative frameworks and practices, for example the Personal Information Protection Act 2004, can shield and restrict transparency when complaints are made by people living with disability, despite this not being their intended purpose.

The Disability Inclusion Bill 2023 should be the cornerstone to drive real and required change, but in its current draft form requires far more work to consider how it can meaningfully do so.

Feedback to the summary questions on the Disability Inclusion Bill 2023

Part 1: Preliminary

1. Do the objects, principles and definitions in the Act better reflect human rights and inclusion?

The objectives and principles appear sound and require strengthening to incorporate Conventions and Acts that guide best practice in working in the best interests of a child. This would mean the inclusion and reference to the United Nations Rights of the Child and demonstration of differentiation between adult rights and children's rights and recognition of parental and legal guardian roles and rights. Article one of the Rights of the Child is clear - *For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.* ACD Tas supports the rights of all children to be nurtured to reach their potential as they grow and develop. Whilst it is valuable to note the principles in support of self-determination, individual autonomy and decision making for developing youth and adults with disability, it is also important to recognise the vital role that parents and guardians of children with disability have in their child's growth, development, and upholding their rights for later achievement of autonomy, and skills of resilience, self-advocacy and independent living. In this way we recommend that the bill recognises the rights and duties of parents and legal guardians, or other individuals legally responsible for children and makes reference to appropriate legislation and other administrative measures. The bill should define the rights of a child, parents and legal guardians separately and distinctly to the rights of a child's families, carers and other significant persons.

As is required by associated Federal legislation, "regulating the use of restrictive practices by disability services providers" relates to disability service providers, and aligns with Federal NDIS legislative requirements, that cite State provisions. What is missing, is that the same obligation and oversight is equally stated and applied to all areas of State responsibilities.

Part 2: Disability Inclusion Planning

2. Will the Disability Inclusion Planning requirements contribute to the advancement of human rights and inclusion?

Disability Inclusion Plans are a sound approach, in principle. To be successful within all service systems, inclusion planning must at first be tied to a set of relevant standards and guiding documentation with clear expectations about legal requirements for complying with the standards and the penalties for not doing so.

In addition, effective Disability Inclusion Planning requires a commitment to appropriate consultation, and genuine consultation requires time and resources, with adequate lead times that value people's time, expertise and lived experience, particularly when the core cohort are those people living with disability. Where clear standards and guidelines are in place that link to a Bill (e.g., The Disability Discrimination Act 1992, The Disability Standards for Education 2005 and guidelines for use and understanding the standards), as well as an ethical service leader with sufficient funding for skilled and knowledgeable human resources for plan development, consultancy, compulsory training, monitoring, review and continuous improvement activity, an Inclusion plan is more likely to be effective and lead to positive work force practice changes and inclusion and participation outcomes. However, where one of the afore mentioned elements is not present in support of inclusive planning and implementation, significant barriers can prevent plan success and inclusive outcomes. For example, service leaders who hold beliefs and attitudes that people with disability should not be equally included. It is proven that when a service leader holds this attitude that human rights will not be upheld or advanced and that harm is likely to occur.

Education is provided as an example because the Disability Standards for Education have been in place for 18 years and the goal for the genuine inclusion and participation of students with disability is yet to be achieved. The Tasmanian Department of Education had an Inclusion policy in 2002 and a goal to close down all Special schools. In 2005 this goal seemed likely to be achieved and by 2010 the Department again had waiting lists for children to attend Special Schools.

Ethical leadership is an essential factor in the success of any inclusion plan implementation and the inclusion outcomes experienced by people with disability accessing and engaging with mainstream and specialist services. Ethical leaders lead by example and drive social change, they believe in the equal rights of all people and are therefore more likely to oversee the effective development of plans and staff and have clear expectations for plan implementation and the resources, training and supportive policies and procedures, and operational and strategic plan requirements needed to reach the inclusive objective.

At the present time, the rushed legislative timelines of the Disability Inclusion Bill preclude ensuring the information and recommendations of the Disability Royal Commission, and related legislation, such as the Federal Disability Services and Inclusion Bill 2023, are properly considered, reflected, and inform the Tasmanian Disability Inclusion Bill and frame Disability Inclusion Planning requirements to direct real and required change.

Resourcing for planning and enabling service leaders to harness the knowledge of people with lived experience, representative groups and state funded Advocacy services would clearly strengthen the Act and improve the likelihood of genuine inclusive plans and steps toward the advancement of human rights through inclusive practice. When people who have no prior knowledge or experience of disability collaborate, problem solve and co-design with people with disability and their parents and carers, progressively and naturally their understanding develops and more equitable and inclusive outcomes result and over time increase.

Part 3: Disability Inclusion Advisory Council

3. Are there any changes you would make to the proposed functions or the structure of the Disability Inclusion Advisory Council?

There are clear and direct legislative and Tasmanian State Government service provision responsibilities for children living with disability. That responsibility, focus, and means to collect and reflect accurate information relating to children living with disability, as a means to drive real and required change, is not reflected in the proposed functions or the structure of the Disability Inclusion Advisory Council. Recognition and respect should be afforded to parents, carers and guardians in this role as they are often the first to identify the needs of their child, access services to promote their child's development, recognise and inform of service gaps, innovate and develop solutions where social inclusion barriers are present, advocate and inform services and systems, and uphold rights and inclusion based principles on a daily basis.

The Advisory Council should welcome membership of parents and carers of children with disability and be explicit in its acknowledgement of the vital role that parents, carers and guardians have in achieving positive social inclusion outcomes for children with disability, when they seek to act in the best interests of their child/ren, and are able to gain timely access to appropriate and relevant services.

Part 4: Tasmanian Disability Inclusion Commissioner

4. Are the proposed functions and powers of the Disability Inclusion Commissioner sufficient to promote inclusion and improve quality and safeguarding protections?

To ensure a clear focus, transparency and genuine accountability, the proposed functions and powers of the Disability Inclusion Commissioner should first and foremost be directed to core provisions of Tasmanian State Government responsibilities, as the means to promote inclusion and improve quality and safeguarding protections, while also complimenting National legislative requirements.

When it comes to children living with disability it would be informative and aid transparency for the Disability Inclusion Commissioner to have a mandated responsibility to monitor and annually report on State entities against many indicators, for example:

- the rate of restricted attendance or expulsion of children with disability from schools
- outpatient paediatric waiting lists
- the impact of children with complex disability and support needs presenting at hospitals
- the adequacy of disability related supports in State Care and similar in youth justice

While it is very important the Disability Inclusion Commissioner have wide and autonomous investigative powers, it is also important that independently investigating and monitoring day to day areas and progress of State and combined state and federal Government responsibilities is mandatory. The Commissioner must have the powers to educate and enforce change as well as to hold disability service and state and federal mainstream services and systems to account where there are failings.

The research and data collected by the Disability Inclusion Commissioner should be made accessible to the public. The Disability Inclusion Commissioner should have resourcing to consult regularly with Advocacy groups to strengthen the Bill and improve the likelihood of improved safety and social inclusion advancement in Tasmania.

Part 5: Disability Services Standards

5. Is it important to retain a requirement for all providers to follow the National Standards for Disability Services and is it clear who these standards apply to?

While this requirement for disability services is covered by the National Standards, it is helpful and useful to ensure uniform practice and standards as a State reflection of national legislative requirements. In order for social change to occur service leaders must have access to disability standards that will apply across all service types, mainstream and specialist. Services must also have access to guides that assist them to interpret the standards and make them applicable in an operational sense.

Part 6: Senior Practitioner, Part 7: Regulation of Restrictive Practices, Part 8: Appointed Program Officers and Part 9: Independent Persons

6. Will the authorisation of restrictive practices process, and roles and functions of the Senior Practitioner, Appointed Program Officers and independent persons provide better quality, protections and safeguards for people with disability?

It is unclear how the Senior Practitioner's role in determining restrictive practices, interacts with parental rights to determine medical treatment of their child. It cannot be assumed that all children taking medication to restrict behaviours (e.g., Risperidone) will have a behaviour support plan as parent-administered medication is not

considered a restrictive practice in this context. This is an area that also intersects with schools demanding children be medicated and associated with that, restricting school attendance.

It is also unclear to what extent paediatricians and child psychiatrists been consulted on this aspect of the Disability Inclusion Bill.

The Senior Practitioner is also described as evaluating the "quality of behaviour support plans containing restrictive practices" (Consultation Overview Paper, p. 17). It is unclear what the Senior Practitioner is required to do with respect to Behaviour Support Plans that have not been formulated or fall short of quality.

As safeguarding is a key aspect of the proposed Bill it is recommended that consideration is made to the relevance of the Child and Youth Safe Organisations Bill 2022, the Child and Youth Safe Standards, the Reportable Conduct scheme and the role of the Independent Regulator.

Part 10: Funding

7. Are the conditions for the Minister to fund activities in relation to the objects of this Act clear?

The importance of advocacy in assisting those living with disability to navigate and engage effectively with complex systems and processes, and to support them to uphold their rights, is noted by the Disability Royal Commission. Provision being made for advocacy funding within the Disability Inclusion Bill is crucial and most welcome. Clear or stated aims and parameters for advocacy would strengthen the Bill. At a minimum, given the importance of advocacy for upholding human rights and furthering inclusion outcomes alongside those living with disability, it is recommended that the Minister provide funding for advocacy that gives effect to the core stated objectives, including protections, of the Disability Inclusion Bill and applicable recommendations in the final Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability report.

Part 11: Authorised Officers

8. Do you think the role, functions and provisions made for Authorised Officers are clear?

Part 12: Appeals, Part 13: Offences and Part 14: Miscellaneous

9. Are there any provisions made in Parts 12-14 that require further clarification?

While it is anticipated as a given, it should be stated that Advisory Council members hold registrations to work with vulnerable people, including WWVP (Children) police and NDIS checks.

10. If you have any other comments, suggestions, or concerns about the Bill please let us know.

It is recommended the development of the Disability Inclusion Bill take into consideration and act as a mechanism of review and reform for other key related legislation, for example the Personal Information Protection Act 2004, which itself seems to be out of step with best practice in other jurisdictions.

In summary, we understand and appreciate the need for a new Act to establish the new Disability Inclusion Commissioner and set parameters for restrictive practice safeguarding and inclusive practice expectations for disability and state funded services. Our primary concern about the draft Disability Inclusion Bill is that it requires more work and consideration to fulfill its valuable objectives. The Disability Royal Commission has now released its report and informed of substantial service system failings and significant harm to many living with disability across Australia, and the proposed Bill is a vital mechanism for preventing, ceasing and acting upon abuse and neglect in the Tasmanian community and within the different services and settings that people with disability use.

Taking a bit more time to strengthen the Act, including mechanisms that are relevant and explicit that will support the achievement of the human rights objectives in the Act will set the agenda for success. This Act will be a vital legislative tool for relevant standards, inclusion frameworks, Inclusion plans, policies and procedures, and advocacy, complaints and compliance mechanisms to be linked. There are many factors that impact on and influence social inclusion outcomes, and in the absence of an Australian Human Rights Act that affirms Australia's legal commitment

to uphold, promote and protect the human rights of all people, the Disability Inclusion Bill and its focus on preventing exclusion and unsafe behaviour management practises will be an important instrument. We hope that the Bill will be the impetus to move Tasmania one step closer to people with disability, their families and carers having equal opportunity to reach their potential and lead fulfilling lives.

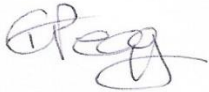
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A handwritten signature in black ink, appearing to read 'C Pegg', written in a cursive style.

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Please contact ACD Tas if you would like more information.