

## **Submission to the NDIS Independent Review 2023**

### **1/09/2023**

Thank you for the opportunity to make a submission to the NDIS Independent review.

This ACD Tas submission focuses on the NDIS and 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 NDIS 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 redesign 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.

Our experiences alongside our primary family stakeholders inform this submission.

### **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 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/>  
Appendix C gives a NDIS registered provider perspective on a year of Support Coordination delivery.

## **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 that we would need to become experts in the scheme and use our professional and lived experience knowledge in order to effectively inform and build the capacity of young people with disability and parents and carers of children with disability to engage with the scheme, its planning process, their plans and the community and mainstream services 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 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.

ACD Tas's peer support and fostering social change work has been funded by the state and Australian governments through successful tendering for various grants over the past 15 years. In the past 4 years ACD Tas has received funding through the ILC program. Tier 2 funding (now ILC) was initially conceived as supporting all people with disability to have increased linkages to community supports and to foster social change (Productivity Commission, 2011). Something ACD Tas celebrated, as we knew from experience that empowered parents and carers positively influence needed social changes every day with individuals and within every environment and every service and system they engage with. Empowered parents and carers raise empowered children and young with disability and prepare them to participate in, and contribute to, social and economic life.

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*Recommendation: Maintain tier 2 funding and provide long term grants for tier 2 services that can evidence their work to inform, empower and build the capacity of people with disability and parents and carers of children with disability to foster social change.*

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## **Tasmania and the continuing service gaps facing families and children with high support and complex needs**

The Tasmanian government in agreement with the Australian government transferred almost all of its disability funding to the NDIS. Over a transitional period between 2017 -2019 the state government ceased to provide some vital last resort services; community case management (community options), an interdisciplinary allied health team (Disability Assessment and Advisory Team) for advice, training, assessment, behaviour management and outreach, out of home centre-based respite and sector training funding (Workforce Development Unit).

Since this time, to remind decision makers that more work is still required to fill these service gaps, ACD Tas has often referred to the 2016 KPMG report commissioned by state government – A REVIEW OF DISABILITY SERVICES DELIVERED BY TASMANIAN DEPARTMENT OF HEALTH AND HUMAN SERVICES.

The report and some of its recommendations highlighting the importance of ensuring services for people with disability with complex and specific support needs. The following sections remain relevant today.

*“One of the risks with the transition to full scheme NDIS is that clients may be adversely affected, particularly those with complex and specific support needs. The following recommendations relate to DHHS’s role in effectively and safely managing clients during the transition:*

- 11. That the DHHS comprehensively describe and mitigate the strategic, tactical and operational risks relating to the transition to full scheme NDIS, prior to transitioning clients.*
- 12. That the Tasmanian government works with key stakeholders including the NDIA, Tasmanian Health Service and Primary Health Tasmania to ensure clients with complex and / or specific support needs are not adversely affected by the transition, and to improve the capacity and capability of mainstream services to support them.*
- 13. That the DHHS puts strategies in place to improve collaboration across the private, not-for-profit and public sectors to: ensure clients with complex and specific support needs can access appropriate services; identify service gaps; and increase the likelihood of effective system responses to service gaps.*
- 14. That the DHHS specifically strengthens its regulatory approaches in relation to clients with a dual diagnosis, in recognition that amendments to Tasmanian disability legislation will not negate the Department’s obligations under other legislation.*
- 16. That the DHHS works with key stakeholders to optimise its responsiveness to individual client needs, and supports building capability amongst Tasmanian consumers to undertake self-direction and make informed choices about their support requirements.”*

ACD Tas continues to be involved, alongside individuals and their parents and guardians in consultations, on committees, and through submissions to highlight many areas of issue experienced by children with complex and specific support needs. We work to influence legislation, regulations, policy, standards, service pathway development and service provision. Many of the families ACD Tas advocate alongside and their children require access to several service systems (including the NDIA) at the same time, and experience ongoing risk of harm from service system boundary maintenance, a reluctance or lack of powers to make decisions and take responsibility, and a lack of access to and engagement with timely, coordinated, experienced services equipped to address their fundamental needs.

There are significant gaps in needed services in Tasmania to support children with complex disability needs. The NDIS market and individualised funding model approach has not improved this situation. The associated costs and risks for provision and maintenance of quality services for children with complex needs are high, and many service providers do not offer appropriate options. Although significant requirements of registered providers are legislated in the NDIS Act 2013 and powers to the NDIS Quality and Safeguards Commission to enforce them, the Act does not include any statements, principles, objectives or sections to demonstrate it places any value on NDIS registered providers who

support people with high support and complex needs in order to ensure availability and sustainability of specific needed service types.

In addition to often not having access to appropriate and relevant services, families face ever increasing bureaucratic hurdles and difficult processes within mainstream and specialist services systems that act to prevent their full access and engagement. These individuals and/or services providers more often than not work with a Professional centred and/or Family-allied model, practise.

*Professional centred* – where the Professionals are the experts who determine what the child and family needs and how to meet those needs. Families are expected to rely and depend upon the professional, who is the primary decision-maker.

*Family-allied model*: Professionals view families as being able to implement intervention, but the needs of the child and family and intervention continue to be identified by the professionals.

ACD Tas staff regularly witness the impacts to children with disability and parents and guardians from experiences of poor service delivery practise and attitude, lack of service availability, service system boundary maintenance and service system failures, and works to correct them daily through our service provision. Please refer to Appendix A, and the 2022 ACD Tas submission to the Reforming Tasmania's Youth Justice System Consultation - *A pathway for improving outcomes across the youth justice support continuum*.

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*RECOMMENDATION: In addition to person centred practice, family centred practice training is funded and available for registered disability providers and community and mainstream government provider personnel. Staff learn a model of practise and view families as equal partners. Intervention is individualised, flexible and responsive to the family-identified needs of each child and family. Intervention focuses on strengthening and supporting family functioning. Families are the ultimate decision-makers.*

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## **The National Disability Insurance Scheme**

While the NDIS has significantly improved the financial capacity of people with lifelong disability and their families to purchase needed services, supports and equipment and technology (where available), there is much work to do in the coming years to build Tasmania's capacity to meet these needs, and to ensure that the scheme's implementation issues and bureaucratic processes do not result in an increase of the barriers to those who are the most vulnerable participants within the scheme.

There are many social inclusion barriers being experienced by children and young people with disability and their parents and carers. Please refer to Appendix B, from the ACD Tas annual report - BARRIERS TO ACHIEVING OUTCOMES WITHIN 6 MONTHS OF REFERRAL, AS REPORTED BY ADVOCATES IN 2021/22.

The NDIS Act 2013 and elements within, including its objects and principles are progressive and especially powerful in support of adults with disability in its human rights, equality, equity and social inclusion and participation intent. ACD Tas would like to see the principles strengthened in support of parents, carers and guardians of children with disability, expanding upon or adding new regulations to the Act and giving weight to Principle 4:

(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected; and

(12A) *The relationship between people with disability and their families and carers is to be recognised and respected.*

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**Recommendation:** *The Act should 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.*

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Recognition, respect *and support* 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 the rights and inclusion based principles noted in the NDIS Act on a daily basis.

Following the NDIS full scheme rollout it has been widely reported that some of the NDIS design elements have added excessive pressure to the lives of many of its intended recipients. Whilst the objects and basic principles of the Act are progressive, the provisions and rules (for example the 31 principles related to NDIS planning – Division 1 – Principles relating to plans) are overly complicated. The result for some, an inaccessible and incredibly stressful planning process that is feared and sometimes leads to an insufficient NDIS plan, that leads to a review request and another planning meeting, and/or a plan that cannot be implemented by its recipient for multiple reasons, and sometimes a retraction from the scheme by those who have the most significant disability needs.

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**RECOMMENDATION:** *Continuous simplification of the planning process, with Planners actively involved prior to the plan to determine, and provide where necessary any assistance required for the Participant and/or their Person Responsible/Nominee to engage successfully in the process. This may include follow up after a meeting and prior to plan release to determine if changes are required. This would include the ability for plan recipients to have a contact number for their Planner in order to speak directly with them during the process and without need to phone the contact centre.*

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It is noted that the Act and agency made the following assumptions for the schemes development that has led to problems compounding:

- all people with disability would not need to access the scheme to have their disability specific needs met
- that parents and carers and Participants have sufficient functional literacy to engage with the scheme
- that parents and carers and Participants have ample free time and the capacity to effectively engage with the scheme, their plan, the disability sector and mainstream providers.
- there is or will be a ready, sufficiently funded and ever-growing market of services and skilled human resources that are equipped to supply needed and quality services and support types.
- a one size fits all NDIA and partner approach will be effective to meet the needs of people with disability and their parents and carers across all states and territories.

- states and territories are actively working together to successfully implement the scheme and ensure there are no service gaps.
- an insurance approach is appropriate for funding the disability specific needs of those with life- long disability needs.
- a regulatory framework for providers and Commission will effectively safeguard people with disability and prevent provider abuse and exploitation.
- that community and mainstream services and government agencies are working towards being inclusive or are inclusive and understand their responsibilities and accept them.
- private unregistered providers will work without conflicts of interest and in the best interests of people with disability.
- those who would complain about plan decisions would have the time, the know-how, confidence and capacity to use complaints mechanisms or access an advocate or legal aid service.
- advocacy and legal aid services would be able to meet the NDIS issue demand for service from Participants and parents and carers.
- that the regulatory framework mechanism for safeguarding would spend more time on workforce development than it would on responding to providers complaining about providers.
- that sound financial modelling for unit prices and increases would encourage the development of the disability market and its financial sustainability.
- that constant changes in staff, operational delivery and communications by the agency and partners would not affect the approach on the ground to aid recipient understanding of and engagement with the scheme

ACD Tas supports the report (No. 13) of the Tasmanian Legislative Council's Sub-Committee Inquiry into Disability Services in Tasmania. ACD Tas's own experience working with children and young people with disability and their families and carers confirms the findings of the inquiry that:

- While the introduction of the NDIS has been a positive policy change that has changed the lives of many people living with disability for the better, there remain many Tasmanians living with a disability who are ineligible for the NDIS and who rely on state government supports and services
- For many applicants, carers and service providers, the roles and responsibilities of the Tasmanian Government and Commonwealth Government under the NDIS are confusing and difficult to navigate
- There are significant barriers to participation in the NDIS, including challenges in meeting the eligibility criteria and obtaining a diagnosis, accessing and navigating the system, and a shortage of allied health professionals
- Many state government-funded supports and services have had their funding reduced, removed or altered since the introduction of the NDIS
- The move to individualised support and away from the provision of block funding to organisations has seen many small organisations reduce the services they provide, or close altogether with the result that many Tasmanians are unable to receive necessary support for their disability
- There has been a rapid increase in demand for disability services, and there is a shortage of workers, including direct disability support and allied health professionals such as occupational therapy.

## **The NDIS market approach**

The NDIS added a new layer of challenge for not-for-profits and their ongoing sustainability and service quality development, when it invited private providers (some of whom are not registered by the NDIS) into the disability sector, with the stated aim of creating consumer choice and healthy competition between services. ACD Tas has always held serious concerns about the possible ramifications of this decision, and especially for people with disability with high support and complex needs. With our small and spread-out population already experiencing a lack of timely and availability needed services and skilled and qualified human resources, as well as regular exclusion from many mainstream service systems, we thought it unlikely that private providers would bring changed or improved conditions. For many of the people we represent, over time we have witnessed a retraction in the so

called, 'market', of available and needed service types. Following immense and compounding changes to the scheme since its inception, we have also seen a decrease in not-for-profit providers offering essential service types, an increase in for profit providers seeking higher than industry hourly rates, an increase in recipients and their parents and carers self-managing NDIS plans (increased unpaid work), a general watering down of service quality, and a reduction in transparency, accountability and integrity of conduct.

The Aged Care Royal Commission final report in 2021 found long standing serious issues with private providers and systemic failures, meaning many aged people with high support and complex needs were placed at risk, suffered or came to harm and were exposed to inadequate levels of care, abuse and neglect. As essential service gaps are present and more unregistered private providers enter the scheme we are concerned about the privatisation of the disability sector resulting in similar consequences for many people with disability who have high support and complex needs.

### **Safety, dignity, well-being and equity of people with disability with high and complex needs**

ACD Tas and other advocacy organisations are busy assisting, informing and empowering parents and carers and people with disability, as well as advocating within service systems, defending rights and holding people to account. Advocacy and information organisations are not funded or positioned to safeguard every highly vulnerable child and adult with disability.

In addition to natural safeguards (parents, carers, family, friends) for most children, before the NDIS launched, the safeguards were built into state government disability policy (e.g. the Disability Services Act in Tasmania, with regulations that resulted in no disability provider receiving funds to provide whole of life services to a person with disability), government and not-for-profit disability specialist services (e.g. government services of last resort existed that prioritised assistance to those with high support and complex needs), and mainstream services (e.g. there was disability inclusion planning, across agency agreements and a disability framework for action - although agencies often pushed back on lines of responsibilities it was not to the same degree that is evident now).

Not for profit disability specialist providers had always had an important safeguarding and raising disability awareness role, but now report spending most of their time looking internally at their organisations with a focus on understanding the scheme and keeping up with changes, gaining and training staff, direct service delivery, financial sustainability and funder compliance. The state government previously played a valuable role in not-for-profit disability service and workforce development. A clear gap now, and it is uncertain if there is any plan or work underway to make sure that the not-for-profit disability sector survives and ensures that specific needed services types are available, sustained, and provide quality care for children with disability with high support and complex needs.

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**RECOMMENDATION:** *That the NDIS strengthen the practice in support of the NDIS Act 2013 – Part 2 Objects and Principles: (ga) protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme. This may require funded workforce development and training options, a review of the funding model for some service types to allow block funding, regular monitoring and review of private unregistered providers, increasing advocacy funding and availability to meet demand, and developing and maintaining a community visitors type scheme.*

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Looking more broadly beyond the disability sector, there seems a lack of stakeholders outside the National Disability Insurance Agency (NDIA) and their partners, some ILC funded providers and people with disability, their parents, carers and advocates (incidentally during issue resolution), that are informing and raising NDIS and disability



awareness across mainstream and specialist service systems, to foster social inclusion and to ensure that these services and systems realise their roles and responsibilities in providing services effectively that include all people.

We welcome the state governments' introduction of a Disability Commissioner in Tasmania, Mary Mallet, and look forward to working with her to make progress at a state level.

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***Recommendation:** That the Australian government and NDIA increase work and planning in collaboration with states and territories in support of NDIS Act 2013 – Part 2 Objects and Principles: (h) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability;*

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### **Reforms and the disability sector, government mainstream providers and community working together**

For many family stakeholders we have witnessed a domino effect of issues since the NDIS was launched. We hold serious concerns about the consequences. We know we need to protect the NDIS; it is a much-needed social reform and its legislation stands today to champion the right of people with disability to experience equality and social inclusion in their everyday lives. We know that the NDIS provides vital disability specific services, supports, equipment and modifications to meet the needs of thousands, and some of whom had not had their disability needs met before. We know that the issues are extensive and that the responsibility for resolving them sits with the entire community; each and every level of government and department, business, service and system.

We look forward to the recommendations from the Disability Royal Commission and the NDIS Independent Review and the continuous improvement of the scheme.

ACD Tas remains hopeful of a scheme redesign and reset that starts with empowering the safety, dignity, well-being and equity of people with disability with high support and complex needs, as the priority. A big responsibility for those involved we know, but we believe that the NDIS reform can lead the way, and that if the NDIA, the disability sector, and the state and territory governments mainstream service systems are compelled to work effectively together, to meet the needs of those with the highest need as a priority, that what will follow will be a community and services and systems that are genuinely inclusive and prepared to meet the needs of everyone.

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31 August 2023

## Appendix A

### Submission to the Reforming Tasmania's Youth Justice System - A pathway for improving outcomes across the youth justice support continuum

Thank you for the opportunity to make a submission in response to the Reforming Youth Justice Discussion Paper. The public health approach to youth justice and therapeutic focus on how systems can better support children and young people at risk of entering the youth justice system is to be commended. The Association for Children with Disability (Tasmania) Inc. – ACD Tas., particularly applauds the Discussion Paper's recognition of cognitive disability, trauma and aboriginality as key risk factors, which accurately reflects the demographics of our advocacy clients, including both those at risk and those requiring specific advocacy to engage with the youth justice system.

The ACD Tas submission focuses on two issues that are found in the Discussion Paper:

1. The role of parents and caregivers in accessing services
2. Timely access to appropriate and relevant services

This submission will explore these issues through the lens of the case study of Matthew found on page 18 of the Discussion Paper and will explore the important role that better resourced and connected existing services can play in facilitating early positive outcomes for Matthew and his care givers.

#### About ACD Tas

The Association for Children with Disability (Tas) Inc. is a Tasmanian not-for-profit organisation. ACD Tas is a peer-led family organisation that provides information, advocacy, consultation and training, NDIS support coordination and peer support to families across Tasmania with children with disability.

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.

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 support, including 208 participants of the NDIS. Their experiences inform this submission.

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[11 March 2022](#)

Please contact us if you would like more information.

## CASE STUDY

Matthew lives with his grandmother and biological mother, who has ongoing issues with substance abuse and is often absent for periods of time, during which Matthew's grandmother provides care for him.

Matthew was diagnosed with attention deficit hyperactivity disorder (ADHD) by his paediatrician at age seven and his grandmother struggles to manage his behaviours, while also trying to negotiate the instability that his mother's substance abuse issues create. His grandmother is reluctant to contact the Strong Families Safe Kids Advice and Referral line for assistance due to concerns that Child Safety may remove Matthew from her care.

At age 12, Matthew was referred to the Child and Adolescent Mental Health Service when he started to experience psychotic symptoms, however due to his high support needs, they advised they were unable to provide a service.

From a young age, Matthew had difficulties at school inducing poor concentration, poor attendance, difficulty complying with rules and difficulties interacting with his peers. Matthew was excluded from school at 13 due to increasingly antisocial and aggressive behaviours which resulted in the police being called to the school.

## Missed opportunities

Matthew's grandmother's reluctance to seek assistance, means that parenting support services such as the Intensive Family Engagement Services (IFES) or Integrated Family Support Services (IFSS) are unable to become involved and provide support. Appropriate interventions to manage his significant mental health concerns are unavailable and Matthew's continued disengagement from schooling over many years progressed to him being excluded, resulting in the absence of structure and prosocial routines and activities, as well as issues with literacy and numeracy, impacting upon his capacity to engage in meaningful work or training into the future. The current approach to service provision, exacerbates existing risk factors for offending.

## A different future

Parenting supports utilise an assertive outreach model to engage with Matthew's family, empowering and providing support and advice to his grandmother regarding child development and strategies to assist in managing his ADHD. The service also supports Matthew's mother to access drug rehabilitation services.

Matthew is able to access the new Youth Early Intervention mental health service, established through the reforms to the Child and Adolescent Mental Health Service who provide support in his home, his school and to his family, to assist him to manage his emotion regulation and poor impulse control. With support to manage and respond to Matthew's behaviours, the school is able to implement appropriate learning approaches to keep Matthew engaged.

### 1. The role of parents and caregivers in accessing services

In the case study, Matthew is described as a teenager with diagnosed ADHD who lives with his grandmother, his primary carer, and intermittently his mother who has issues with substance abuse. At 12, Matthew began to experience psychotic symptoms, but CAHMS decided they were unable to intervene due to his high support needs. By age 13 Matthew was excluded from school and it was in this context that he has come in contact with the youth justice system: the police were called to the school because of his poor attention, difficulty complying with rules, and "increasingly antisocial and aggressive behaviours which resulted in the police being called to the school." His grandmother struggles with his behaviour and with his mother's behaviour but is worried about seeking outside support because of fears he will be removed from her care. The case study gives no consideration to the support mechanisms and obligations embedded in the Tasmanian education system, including the possibility of internal psychologist assessment, consultation with Learning Service, or use of Compulsory Conciliation via the Office of the Education Registrar, despite school being the trigger point of Matthew interacting with police.

The case study then characterises the many missed opportunities, key amongst which is Matthew's grandmother's reluctance to seek assistance and missing the opportunities of having the support of an IFFS or IFES worker to

support her. There are three points to make here. First, Matthew's grandmother has not been reluctant to seek all expert support. Matthew was diagnosed with ADHD at the age of seven. This is a paediatric diagnosis which requires assessment. Given his current age Matthew would not have had the benefit as a young child of being assessed for Early Intervention processes and supports, as those did not exist in their current form at that time. While we are hopeful signs of Matthew's ADHD were picked up early, possibly in the first years of school or before, his grandmother's role in seeking assistance should not be discounted. She is likely to have been active in taking him to appointments to get this diagnosis.

Secondly, we recognise that IFFS and IFFES could support the family in some service access areas, but that these services are not equally available throughout Tasmania nor a replacement for timely access to specialist paediatric and mental health support. We regularly see referrals being made to Strong Families Safe Kids and IFFS and IFFES workers put in place as a stop-gap measure because there is no way to access the services these children, young people and their families actually need. In this case, CAHMS would not provide service because of Matthew's behaviours, and it appears that no specialist paediatric reassessment for ADHD and other potentially undiagnosed conditions were considered by the authors of the case study.

Thirdly, Matthew's cognitive disability is ADHD. This is a condition usually responsive to medication and allied psychological supports, neither of which is particularly within the skill set of the IFFES and IFFS workers.

To make a more informed assessment of the role of the family and system in this case study, we need to ask the questions which the case study does not address:

- Did Matthew's grandmother try to access a more recent public outpatients' paediatric appointment to ensure any medication continued to be effective as he entered puberty?
- Were Matthew's psychotic symptoms expressions of ADHD, or its commonly comorbid mental health conditions, such as depression, anxiety and insomnia?
- Are there any other potentially undiagnosed conditions?

ACD Tas advocacy data demonstrates in a number of similar cases to Matthew's, that accessing timely and appropriate services for these issues, as we'll explore in the next section, rarely comes down to caregiver reluctance. The inclusion of this presumption however in the case study is important as it informs us that sometimes judgements by systems and paid professionals who work within them can act as an additional barrier to families continuing to push for access to needed services and supports.

## **2. Timely access to appropriate and relevant services**

"Appropriate mental health interventions to manage his significant mental health concerns are unavailable..." continues Matthew's case study. "The current approach to service provision exacerbates existing risk factors for offending." In Matthew's case, it is clear that his mental health means he is at risk of offending, and at risk to himself and his family. He has been unable to access adolescent mental health services when he needed them most, in part because his cognitive disability undermines his capacity to present himself as a safe and compliant patient. This does not, however, negate his need for urgent support.

The Discussion Paper recognises cognitive disability as a risk factor for young people coming into contact with the criminal justice system (although only statistics are included for intellectual disability). There are a range of cognitive disabilities which emerge more overtly in the teen years, such as Acquired Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and Acquired Brain Injury (ABI), often alongside trauma, anxiety, depression, and other mental health concerns. Children and young people with these conditions may come to the attention of police and the wider youth justice system prior to recognition of their cognitive disabilities. The complexity of these conditions may impede young people's own awareness of their needs. Indeed, some young people come to the attention of police without warrant because they do not respond to police in the manner of their neurotypical peers,

and may seek to flee any confrontation. That said, we acknowledge that the police, like parents and caregivers, are the responders of last resort. When other systems fail, such as the education and mental health systems failed Matthew, it is usually the police or ambulance who parents and caregivers will call.

How is the service system failing these young people? Often problems are recognised along the way, such as Matthew’s ADHD which was diagnosed while he was still in the early years of primary school. However, the system is bedevilled with massive delays which, in the life of a child or young person, undermine early intervention efforts. At ACD Tas we regularly see examples of parents urgently trying to access assessments, such as psychological support, cognitive testing, adolescent psychiatry, and paediatric appointments.

How long are they typically waiting? Indicative wait times for Tasmanian Health Service outpatient paediatric clinics are concerning. Wait lists for urgent developmental and behavioural outpatient clinics can be 20 times the 30 days expectation. For example, in the South of Tasmania the waiting time for children and young people *who have been internally referred* to Paediatric Developmental Behaviour Outpatients is currently 618 days.

Systemic delays, such as this example, mean that while behavioural or developmental concerns may be well recognised in a child or young person – by family members, teachers and schools, and general practitioners – and appropriate paediatric referrals made – they still may not be assessed for up to 24 months. Clearly, such systemic delays leave these children and young people at risk of coming into contact with the police and youth justice system. No matter how good the family and community support, it is no substitute for paediatric, medical, mental health and other therapeutic systems. Left waiting and unsupported, these children and young people are more likely to come to harm, and exhibit their distress through escalating antisocial behaviour, with long term and sometimes lifelong consequences.

#### Tasmanian Health Service - Outpatients Clinics<sup>1</sup>

Indicative waiting time in days <sup>2</sup>			
Clinic Name	Urgent (within 30 days)	Semi-Urgent (within 90 days)	Non-Urgent (within 365 days)
Paediatric Developmental Behavioural (internally referred)	618	189	322
MCH Paediatric Clinic	24	133	659
Paediatric Clinic	37	182	195

Let’s now review Matthew’s situation before he is 7 years old with the view to reshaping the community response by utilising and enhancing existing services and filling existing service gaps, to gain improved outcomes alongside Matthew and his care givers.

<sup>1</sup> Source: Tasmanian Health Service, *Estimated Outpatient Appointment Waiting Times*, [https://www.outpatients.tas.gov.au/clinicians/wait\\_times](https://www.outpatients.tas.gov.au/clinicians/wait_times), accessed 25/01/2022.

<sup>2</sup> This table is indicative only - the data shows the 75th per centile of time waiting for patients as of publication date of data

Existing settings and services	Assistance	What is required	Gaps in systems and services
Early childhood and care setting	If Matthew exhibits behaviours of concern the early education and care setting refers to the Inclusion Support Agency. They work with a trauma informed and family centred approach and provide additional support for Matthew's inclusion at the early childhood and care setting.	<p>Matthew's behaviours are recognized as an early indicator of a disabling condition, and additional support is sought through the Inclusion Support Agency for Matthew to attend the early childhood setting.</p> <p>Six months before Matthew starts school, a key staff person at the Early Childhood and Care setting attends pre-kinder sessions and school care team meetings to inform a successful transition plan and to build the capacity of education staff for working with Matthew.</p> <p>The Inclusion Support Agency ensures the family are fully informed, and as necessary, where issues present links them to specialist advocacy.</p> <p>The Inclusion Support Agency seeks approval from Matthew's mother or grandmother to also refer him to The Early Childhood Early Intervention service supports.</p>	<p>GAPS – There is no guarantee that Matthew will attend an Early Childhood and Care setting or that he will gain the assistance he requires.</p> <p>There is also no guarantee that the Early Childhood and Care setting will seek Inclusion Support if they recognize that Matthew has behaviours of concern. Matthew may be excluded.</p> <p>If Matthew does attend and does gain assistance through the Inclusion Support program, there is no current funding available to facilitate the care settings involvement in his successful transition to education.</p> <p>There is no guarantee that Matthew's family will be connected to a specialist advocacy provider when they experience issues or be supported to navigate and engage with needed complex systems and services.</p>
The Early Childhood Early Intervention service (ECEI).	If Matthew exhibits behaviours of concern and developmental concerns his grandmother and mother can access ECEI and the early childhood approach – who can determine with the	The ECEI service has built an important relationship with Matthew's grandmother. A year before Matthew starts Kindergarten there is a	GAPS – the ECEI service does not fulfill a case management role and functions. There is no guarantee that the information about services used, assessments

	<p>family the right supports to build their capacity and can assess and plan to manage Matthew's behaviours for his successful inclusion in the community and everyday settings.</p> <p>There are many in - doors and referral points to ECEI, including GP's, Child and Family Centres, Community Centres, Neighbourhood Houses, and Specialist services, including advocacy and information services.</p>	<p>transition of information and building of capacity for Matthew's successful inclusion in education. The ECEI worker acts as the case manager and central point of contact with Matthew's Mother and Grandmother and the school and arranges and chairs care team meetings and maintains communication with stakeholders as a transition plan is completed and implemented.</p>	<p>completed, and connections made will be effectively transitioned to a school setting to enable informed decision making.</p> <p>There is no guarantee that Matthew's family will be connected to a specialist advocacy provider when they experience issues or be supported to navigate and engage with needed complex systems and services.</p>
School setting	<p>Matthew may attend pre kinder and then kindergarten sessions at the age of four (4) and when behaviours exhibit may be referred for school psychological assessment for determination of additional school resourcing to assist his inclusion.</p> <p>The teacher is the key contact for the parent and other relevant services.</p>	<p>The school Psychologist completes a cognitive or education assessment and seeks in school resources to assist Matthew's inclusion and develops and monitors a behaviour management plan and strategies. They meet with Matthew's mum and grandma and explain the assessment and recommendations. The teacher works with a trauma informed and family centred approach and develops and monitors an education plan, collaborates closely with Grandmother and Mother, and includes the Psychologists behaviour management strategies to assist Matthew's successful inclusion in education.</p> <p>If an early disability diagnosis is made a Learning Plan is required, to make suitable adjustments and define supports. The development of the</p>	<p>GAPS: Schools rarely provide early assessment for children who exhibit challenging behaviour or sufficient resourcing to meet the early needs of children with ADHD. In the early years, schools rely on the health system to provide assessment, diagnosis and treatment. Successful transition to school can be difficult as schools rarely know who will be teaching a child before they begin school and what resources will be available to them. This means that effective preparation and prevention of issues is not commonplace.</p> <p>Many families are unaware of their role in their child's Learning Plan or that they can have connected relevant services and an advocate to support them in</p>

		<p>Learning Plan can involve a teacher, other more senior school staff, Learning Services and is required to include consultation with the family.</p> <p>A Learning Services Inclusion manager is involved to advise on Matthew's progress and supports, and if necessary to facilitate connection with his grandmother and outside key stakeholders as he participates in education.</p>	<p>ensuring a Learning Plan meets their child's needs.</p> <p>A central and key point of education contact is not available to Matthew's grandmother outside the school he attends, and he will not be overseen as he transitions in his education. He may receive inconsistent assistance or resources and his grandmother may not be recognized as his decision maker.</p> <p>There is no guarantee that Matthew's family will be connected to a specialist advocacy provider when they experience issues or be supported to navigate and engage with needed complex systems and services.</p>
Home	<p>Mathew's mother and grandmother are his care givers. His grandmother provides the most stable parenting. When behaviours exhibit Matthew's grandmother experiences fluctuating capacity to manage this and to assist his engagement and collaborate with services, due to her age, health, her daughters' substance abuse cycle and impacts, other competing family member needs, and a lack of natural supports.</p>	<p>Grandma engages with Matthew's General Practitioner and gains referral to Outpatients Paediatric Developmental Behaviour and receives an appointment in 6 weeks. She gains access to an assessment, a formal diagnosis and a treatment plan and other relevant health, mental health and therapeutic services. The GP liaises and consults with the Paediatric team on progress and their involvement and with the grandma's family centred case manager. Her capacity to manage difficult family circumstances is strengthened as Matthew's behaviour improves as a result of</p>	<p>GAPS: Often services won't engage with kin carers who don't have formal guardianship or allow them to make decisions in the event of an absent parent.</p> <p>Outpatient Paediatrics Services have up to a 2-year waiting period for access and Matthew has been recognised as having a support need but has been left undiagnosed and untreated.</p> <p>There is no family centred practice community or case management service available to grandma and Matthew to oversee progress and facilitate connections with key stakeholders across systems and services.</p>



		<p>receiving well-coordinated and targeted treatment and assistance. At times when her carer capacity wanes and before she experiences distress she can gain family support from a trusted case manager, who has access to brokerage funds and can connect her with needed and trusted outreach supports of her choosing and can act as a point of contact for her with health stakeholders and where other system services and case managers are involved, maintaining progress with her in Mathew's best interests while at all times encouraging and welcoming Matthew's mothers involvement and facilitating referral pathways to gain relevant treatments.</p>	<p>There is no guarantee that Matthew's family will be connected to a specialist advocacy provider when they experience issues or be supported to navigate and engage with needed complex systems and services.</p>
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### Summary of Key Points

- Families do support children and young people at risk of entering the youth justice system, to the best of their ability and often in circumstances where they have no knowledge of, nor appropriate supports for navigating a multitude of complex systems. Families are often the only support system that endures.
- Family reluctance to engage with Safe Families Safe Kids does not mean they are reluctant to seek support. Families want relevant and timely supports, not substitutes for timely and specialised services. Families often know what support their children and young people want, need, and will accept. IFFES and IFFS may provide some supports but be insufficient to address the fundamental needs.
- Systems and paid professionals who work within services can have a negative or a positive impact on the outcomes of young people at risk of or engaged in offending and their care givers. We presume that systems and agencies have the resourcing and want to work and can work together, when often the reality is that there is a lot of time and effort put into boundary maintenance instead of collaboration, especially when people present with a number of co-morbidities and require access to several systems at the same time.
- Risks present and are significantly exacerbated when system and service gaps appear and when there is no continuity of therapeutic services or access to family centred case management.
- The community expectation is that children and young people in crisis and need for assessment and supports will receive it in a timely manner. However, this is not an accurate perception of the service situation in Tasmania.

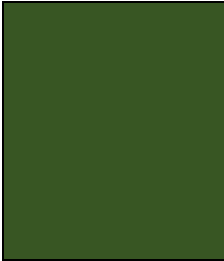
- Families often are not connected to a specialist advocacy provider after years of experiencing issues and not gaining support to navigate and engage with needed complex systems and services.
- It is not commonly known that public outpatient paediatric assessments for children and young people have months long waiting lists, and that private psychologists have long waiting lists or closed books.
- Waiting times and service gaps for public paediatric services exacerbates risks to children and young people and their families.
- Statistics are not publicly available for mental health service gaps for children and young people with cognitive disabilities and comorbid mental health conditions. Reliable statistical indicators are needed to recognise unmet needs in this area, and for urgent attention to remedying this situation.
- Could Matthew have waited 618 days for an appointment with a paediatrician? Should he have been declined mental health support because of the behavioural presentation of his ADHD? Should other education-based options have been fully explored long before escalation to a crisis point and interaction with police?
- Additionally, Strong Families Safe Kids may be perceived by vulnerable families facing significant challenges as a service too close to Child Safety and possible removal of a child. A Parenting support outreach service may be perceived as undermining the parenting role of informal guardians who don't require parenting assistance but rather a family centred practice empowerment approach to service delivery.

**TABLE 2: BARRIERS TO ACHIEVING OUTCOMES WITHIN 6 MONTHS OF REFERRAL, AS REPORTED BY ADVOCATES IN 2021/22 – taken from the ACD Tas 2021/22 annual report**

<p><b>Education</b></p>	<ul style="list-style-type: none"> <li>• The education facility cannot make the necessary adjustments or supply the human resources or alternative education environment to facilitate attendance in full or part-time education</li> <li>• Limited or no education was received, and no other options were provided</li> <li>• Children with disability who exhibit challenging behaviour do not receive an education (either public or private) for extended periods of time and do not have planned pathways for their return – a resource to support school staff and students, particularly neurodiverse children, with disability to re-engage successfully with school would assist</li> <li>• Lack of human resources delays educational assessments and impacts on a student’s receipt of funded supports and, therefore, their participation and/or progress in education</li> <li>• Lack of human resources delays behavioural assessments and management planning and impacts on a student’s engagement in education</li> <li>• Positive behaviour strategies are not consistently implemented – repeated use of part-time attendance and/or suspension leads parents to pursue avenues of complaint and/or move their children to other schools</li> <li>• Families report coercive behaviours from senior education (school) personnel and being fearful of repercussions if they make a complaint, or are experiencing slow complaint-handling processes</li> <li>• Lack of skilled human resources leads to the poor implementation of learning and transition plan strategies and results in poor education attendance and outcomes for children</li> <li>• Insufficient funding is raised by senior education (school) personnel as a reason why schools are unable to support children with education</li> <li>• Advocates are called in to continually solve problems that should not be occurring at the school level – attitude and actions of school principal results in parent feeling bullied and intimidated after raising concerns</li> <li>• Parents requesting advocacy to solve school attitudinal issues and to access supports that their children are entitled to – key school personnel refuse to utilise skilled DoE human resources available</li> <li>• Accessing needed psychological assessments through DoE at the school level is not triaged for priority by a psychologist and lengthy wait times are evident for students who are not prioritised – the process across the DoE needs to be uniform and not dependent on school staff</li> <li>• Restricted attendance is over-used by schools as a strategy when accommodations for children do not exist. Systemic issues due to lack of resources at a mainstream school and no policy to enable schools to tap into support school human resources temporarily results in the student not receiving an education.</li> </ul>
<p><b>Housing system / Stock resource / Financial constraints</b></p>	<ul style="list-style-type: none"> <li>• Public housing is not appropriate or available to meet the needs of families with multiple children with disability and/or those with specific requirements that directly relate to their disability</li> <li>• Public housing is not available and long waiting lists apply – one family has been on a housing waiting list 2.5 years; one family of 5, 2 adults and 3 children with disability reside in a one-bedroom flat</li> <li>• Private housing for rental purposes is not affordable and/or available</li> <li>• Housing stock is not available to safely house children with complex disability and challenging behaviour</li> </ul>

	<ul style="list-style-type: none"> <li>• While advocacy resulted in a Housing Case Manager being appointed for an Aboriginal family, the systemic lack of disability-appropriate public housing meant that the family remained homeless and at risk despite already being on the waitlist for two-and-a-half years</li> </ul>
<b>Health system – No appropriate facility/human resources</b>	<ul style="list-style-type: none"> <li>• Delay in receiving appropriate health care – surgery and regular treatment for children and/or primary carers (COVID impact)</li> <li>• No appropriate inpatient or outpatient options exist for child and adolescent healthcare intervention for child/ren with disability and complex needs and those exhibiting harmful challenging behaviour</li> <li>• Waitlist applies – cannot access timely outreach child psychology assessment and therapy for behaviour management assistance</li> <li>• Waitlist applies – cannot access Tasmanian Autism Diagnostic Service assessment for NDIS access in the north-west</li> <li>• Service retraction – cannot access needed paediatric assessment and treatment as the specialist reports that it is no longer sustainable for him to continue to travel to Tasmania to see patients</li> <li>• Wait time – cannot access timely child psychiatric assessment and treatment</li> <li>• Medical and associated costs prevent completion of assessments and reports required by families to evidence NDIS eligibility</li> <li>• Medical cost gaps prevent families from using Medicare mental health treatment plans and gaining timely associated services</li> </ul>
<b>Service of last resort / community care and support / NDIS / Continuity of support</b>	<ul style="list-style-type: none"> <li>• Cannot gain specialist respite – in-home, centre-based or in the community for child/ren with disability who exhibit challenging behaviours and are excluded from school</li> <li>• Cannot bring a team together to develop an effective community emergency service response plan for families caring for child/ren who exhibit violent challenging behaviour – emergency response or service of last resort does not get activated outside police or emergency medical health services or until children end up being left at hospital emergency</li> <li>• Insufficient NDIS plans – long delays following changes of circumstances and requests for reviews, and therefore access to needed services, supports and equipment</li> <li>• NDIS access requests rejected and insufficient information to dispute the decision provided in correspondence about the reason – a complaint does not shed further light on the situation</li> <li>• Two non-English speaking children with complex disability have a delay in gaining needed services as they transition from ECEI services to the NDIS system – they are not granted sufficient support coordination in their plan to enable effective planning and communication</li> <li>• Youth with challenging behaviour are excluded across all environments and services and cannot access needed or timely medical health, medication reviews or dental checks</li> <li>• Despite identification of risks to children, Child Safety advise they are unable to provide accommodation for a child at risk</li> <li>• NDIS – slow response time for review and change of circumstance requests (up to 3 months), then seemingly automatic denial of requested plan changes</li> <li>• NDIS Quality and Safeguards slow to inform a complainant of the results of service investigation</li> <li>• Domestic and family violence are experienced by some individuals and families, and this tended to obscure the need for a systemic response and reduce the capacity of the individuals to consistently self-advocate and seek support. Parents with a history of trauma make the individual call for advocacy but, due to circumstances, find it difficult over time to maintain engagement in the process although they are experiencing multiple issues, each of which are high priority, and pose intermittent</li> </ul>

	<p>threats to their family life, such as threatening ex-partners, homelessness or unstable housing, mental health (their own or their child’s). The complexity of their circumstances may impede issue-based advocacy because there is a need for issues to be addressed in concert, including case management support, financial support, mental health support, and stable and safe housing.</p>
<p><b>Childcare system / Service gap / skills</b></p>	<ul style="list-style-type: none"> <li>• Vacation care and outside school hours care placements are not available or cannot accommodate the care and support of a child with significant support requirements</li> <li>• Skilled staff are not available in after-school and vacation care settings to enable care of children and for parents to continue to work</li> </ul>
<p><b>Centrelink</b></p>	<ul style="list-style-type: none"> <li>• Long delay in appeal of Disability Support Pension eligibility – family require support to apply for payments, respond to correspondence or to appeal decisions for young person with disability</li> <li>• Time taken to investigate and resolve – domestic violence partner was somehow able to claim a carer’s payment for a child not in their care through a Domestic Violence assistance line at Centrelink</li> </ul>
<p><b>Disability / Community specialist support gap</b></p>	<ul style="list-style-type: none"> <li>• Families who are not gaining timely outcomes for children in the health system interstate and do not have access to advocacy call ACD Tas for information and assistance</li> <li>• No service exists to supply across-system independent lead coordination/case management for families and children and youth with disability with complex situations – insufficient NDIS support coordination hours and poor design of system does not allow reasonable decisions to be made in a timely way</li> <li>• Kinship or foster carers (without formal guardianship) are not able to advocate on behalf of the child/ren in their care (where a legal guardian is required) and cannot access timely needed services and supports</li> <li>• Carers are experiencing serious health issues but cannot be hospitalised as no short-term accommodation services are available to support their child/ren with complex support needs on short notice</li> <li>• Children whose support needs exceed their funding classification as their current diagnosis doesn’t reflect their actual needs – cannot gain sufficient NDIS plans, particularly with fast-changing needs</li> <li>• Disability specialist services are either limited or not available for in-home support in area.</li> <li>• NDIS use ‘not value for money’ as a reason not to proceed with many requests made for specialist supports, without additional information provided for people to be able to dispute the decision – plain language decision justification required but not provided</li> <li>• NDIS design – the complaint system team do not have the authority to rectify acknowledged NDIS mistakes of process when they are made at plan level, sending people through more reviews and complaints processes and preventing access to needed services for children with disability</li> </ul>
<p><b>Family Capacity / Changes to situation</b></p>	<ul style="list-style-type: none"> <li>• A number of families came to advocacy with varied personal resources and capacity to engage in advocacy processes. Some did not have good memories for details, appointments, and general administrative competencies to cope with how modern administrative systems work. Personal capacities should not make such a difference to outcomes when it comes to navigating systems. Other barriers include not having consistent phone credit, literacy, and stable housing, all of which are important for accessing and keeping support documentation.</li> <li>• The family has a distrust in service providers, based on lived experience, and a view that their concerns will not be addressed. Effective communication and collaboration took time to develop trust.</li> <li>• While advocacy resulted in an updated Learning Plan, and escalated review of an NDIS plan, the family did not have the emotional reserves to escalate a formal complaint to the NDIS appeals.</li> </ul>

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- Separated parents did not agree on issues of concern and Family Court orders were later issued, with one parent given custody.
  - People who are not eligible for the NDIS cannot afford access to specialist services and a medical health cost to the family results.
  - After having arranged for urgent TADS assessment in Hobart to progress NDIS registration, the family chose instead to wait until TADS could be undertaken in the north-west.

## Appendix C

### NDIS SUPPORT COORDINATION REPORT taken from the ACD Tas 2021/2022 annual report

Written by Nicole Gates – Statewide Program & Finance Manager

ACD Tas delivered a case coordination program (as registered NDIS Support Coordinators and Specialist Support Coordinators) alongside 195 families and carers and NDIS participants, primarily aged 0–25 years. Some NDIS participants who accessed ACD Tas before turning 25 chose to remain with ACD Tas for this service.

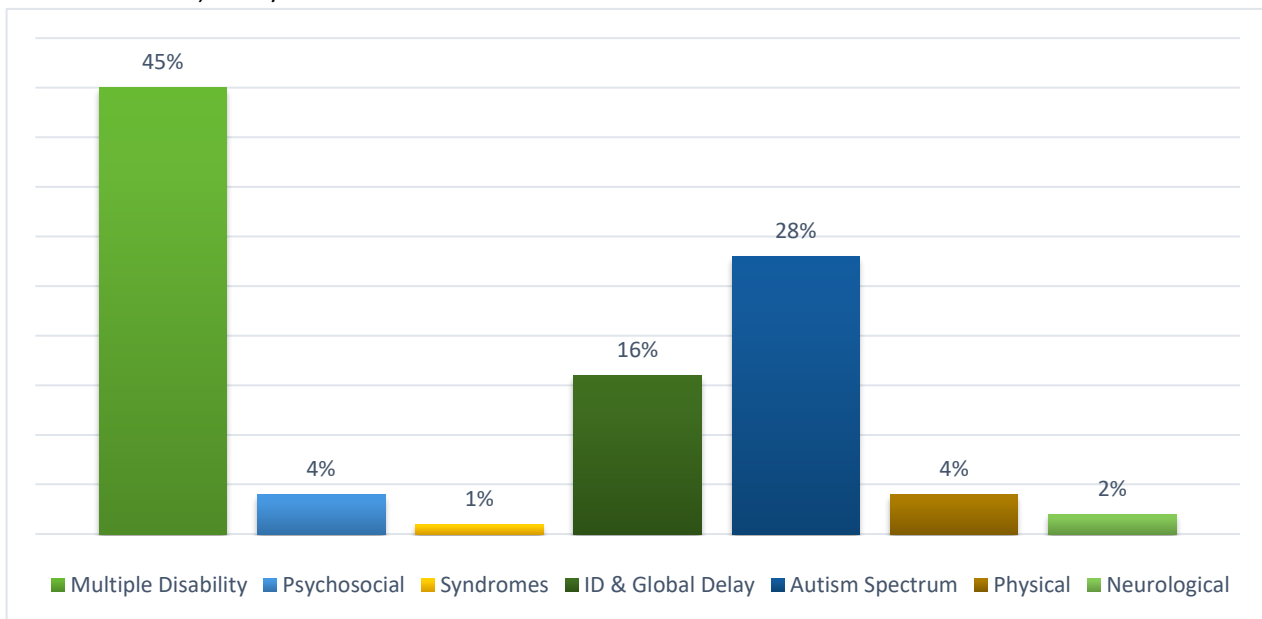
During 2021/22, we had 23 new referrals for support coordination. We had 27 participants cease with our service for reasons such as: building sufficient capacity to navigate without support coordination assistance, choosing an alternative provider when moving to another location, ceasing with the NDIS, or participants not meeting service agreement responsibilities.

We continued to review the time and role functions required to meet the support coordination needs of NDIS participants who, on average, were provided with 0.89 hours per week of funding in their plans. This time was found to be sufficient for those who require basic plan implementation, monitoring and maintenance, and assistance to effectively prepare for their next plan. However, an hour a week was insufficient for those with additional support needs and those who experienced a change in circumstances or a significant life crisis. Among ACD Tas support coordination participants, 86% have significant and complex support needs.

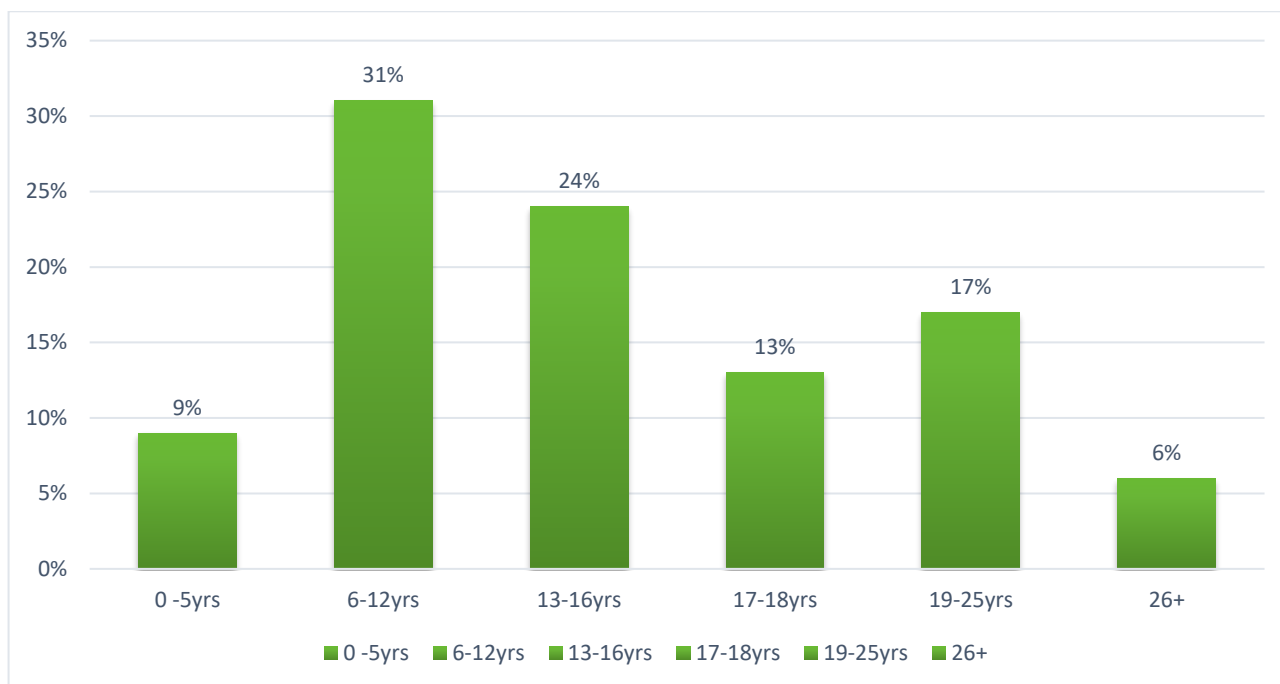
The Support Coordination team completed continuous improvement work this year with a focus on the implementation of the Support Coordination Guidelines which include conflicts of interest, code of conduct, the NDIS Practice Standards, and the role of the NDIS Quality and Safeguards Commission.

ACD Tas said goodbye to two long-term Support Coordinators this year, Jill Simmons and Kim Laffoley. These experienced, knowledgeable staff members will be missed but we wish them well as they transition to retirement. ACD Tas has been focusing on support coordination systems and processes, particularly with recruiting activities, and ensuring that new Support Coordinators are well supported with regular check-ins regarding their confidence with systems, processes and navigation of the NDIS.

FIGURE 8: DISABILITY DIAGNOSIS REGISTER OF CHILDREN AND YOUTH ACCESSING ACD TAS NDIS SUPPORT COORDINATION, 2021/22



**FIGURE 9: CHILD AND YOUTH AGES IN 2021/22 FOR THOSE ACCESSING NDIS SUPPORT COORDINATION**



### **Support coordination activity**

We have built on the work of previous years to facilitate evidenced progression towards participants meeting their identified goals, using their funded hours and building the capacity of participants to make informed decisions on funding use. ACD Tas has implemented a Team Leader structure and this has been working well. Regarding recruitment of staff, we have a greater focus on the specialist qualifications and experiences of applicants in the areas of allied health, out-of-home care and behaviours of concern to ensure staff have appropriate knowledge and experience to support participants in these areas. To attract applicants with specialist skills, we need to be highly competitive and pay wages above the industry average. This is becoming increasingly difficult with no increase to the support coordination hourly rate over the last 3 years and significant increases to award wage costs, superannuation and overheads.

As a group, we have spent time training and upskilling in areas where there had been significant changes to NDIS policy and funding streams. An example is the NDIS Practice Standards and the role Support Coordinators fulfil in relation to Behaviour Support Plans and the NDIS Quality and Safeguards Commission.

ACD Tas Support Coordinators have been developing tools and resources for staff health and wellbeing including time spent at a desk, ergonomic awareness, compassion fatigue and vicarious trauma. This is often encountered when collaborating with complex participants over an extended period of time.

### **ACD Tas support coordination clients**

Many NDIS participants with high and complex needs continue to present with, and experience, several complicating factors including:

- transitional life stages
- loss of residence/home



- entering the criminal justice system
- using services from various systems
- family breakdown
- services or supports being withdrawn by providers or there not being enough capacity available
- exclusion from systems, services, supports and/or groups
- serious behaviours of concern
- a primary carer with more than one child with disability, or who is themselves a person with disability, and/or has a disabling condition or health condition
- the person is isolated (emotionally or geographically), has no natural supports and is experiencing serious primary relationship breakdown.

ACD Tas collaborate with Participants and their relevant guardian or family member who often have varying levels of capacity. Some will increase their knowledge, build capacity and no longer require support coordination. Others will realistically not develop the capacity to understand and use the scheme independently for many years, if at all.

We have had regular feedback from participants and their families with the common themes and challenges across the following areas.

- Desire for a reconnection with the scheme's initial purpose and intent and the reinstatement of trust. 'Sustainability' of the NDIS is an issue of concern, as this at times has been the justification for reducing funding in participants' plans. This increases distress for participants and carers who believe that their funds are not secure and will continue to reduce each year.
- Concern over a policy shift by the NDIS to move to non-face-to-face methods of contact for plan reviews and the confusion of 'check-ins' and the resulting rollover of a participant's plan or an entire new plan.
- Concerns over the number of plans which were either rolled over, unfunded or did not align with the participant's goals negatively impacted on the number of support hours in the participant's plans, with ACD Tas having to use funds for administrative tasks in many cases. The support coordination funding was insufficient to meet the needs and circumstances of the participant.
- Concern about administrative burden – Parents, nominees, and participants report spending many hours collecting evidence, submitting reviews, and attending case conferences. These tasks have drawn them away from their caring role, leisure time and/or paid employment and caused significant stress.
- Concern about the NDIA decision framework – Participants who have not been successful in obtaining an outcome via a review or do not have the time, resources, or emotional energy to appeal a decision in the AAT are losing supports. This can have wide-ranging consequences, including loss of social connections, functional capacity or even bring them serious harm. The NDIA may save money in these circumstances, but at what cost?
- Concern about the quality of provider support – Issues identifying providers who have the appropriate level of skills to do the job and the capacity to take on the participant, especially in allied health therapies, behaviour support and general support workers.

ACD Tas received some of the following compliments and feedback about our incredible Support Coordination team.

*“Working with Pauline regarding some very complex participants, and ACD Tas has worked so well with all of the clients I am jointly connected with. I wanted you to all know how wonderful you all are at ACD Tas and what great work you all do.”*

*"Jess was wonderful dealing with my stress and anger at the NDIS systems on Monday. She was very patient with me and allowed me a safe space to express myself."*

*"You have certainly got a great Support Coordinator in Nick. He has been instrumental for me and my son. No one else has been able to motivate him to achieve the things he has this year."*

*"ACD Tas has been an excellent support for my grandson and has helped him to achieve great progress. The Support Coordinator has helped both of us to understand the NDIS plan and how best to use it and made the entire process easier for us."*

*"Patricia's breadth of knowledge, compassion and understanding of my daughter's situation is such a relief, I don't actually have the words"*

## **Changes to the NDIS**

There were some significant changes to the National Disability Scheme in 2021/22. Minister Reynolds put a pause on Independent Assessments and then scrapped them after an independent inquiry. Minister Shorten's appointment provided some much-needed relief that positive change is on the way.

The NDIA spent \$34.8 million on Administrative Appeals Tribunal (AAT) matters in 2020/21. Of this, over \$17.3 million was paid to private law firms to represent the NDIA at external reviews (an increase from \$13.4 million the year before). In December 2021, the Guardian newspaper revealed a 300% spike in NDIS appeals when compared with the same month-by-month period in the previous year. The Guardian also found that this increase was not proportional to the number of new entrants to the scheme, as the NDIA had claimed. In November 2021, the AAT had 3,084 NDIS cases on hand; by comparison, the AAT had 913 NDIS cases on hand at the same time the previous year. Families tell us that the emotional and economic toll placed on participants, parents and carers to gather information to present as evidence to the NDIS is overwhelming. Support Coordinators are not funded sufficiently to coordinate and assist with the gathering of such information.

There were a number of discussion papers released during the year and the NDIS sought submissions to inform policy and pathways moving forward. ACD Tas has contributed to submissions, but we have found there has been a huge growth in the number of submissions, e.g. 'Have your Say', 'Complete our Survey', 'Contribute to Shaping the Future' sponsored by the NDIA. ACD Tas also undertakes consultations where we can as an NDIS provider, but we would rather use other parts of our service to make sure that participants, family and carers can have their say.

August 2021 saw the release of the draft for the new NDIS Act distributed after the Tune Review. There were 29 recommendations, 19 of which require amendments to the NDIS Act and rules. The community was provided with 4 weeks to comment on it which was short of the Independent Advisory Council's (IAC) recommendation of 8 weeks. July 2022 saw changes to the NDIS Act being legislated. Most importantly, the changes will not affect independent or functional assessments, changes to reasonable and necessary criteria (section 34) or how plan budgeting is calculated.

November 2021 saw the release of the long-awaited Improving Support Coordination for Participants paper. This paper was the result of a review initiated four years ago! There was consultation with the sector by means of a discussion paper. We were hoping for a detailed guide filled with solutions to many of the issues faced by the support coordination cohort; we instead received a structured outline of the role of support coordination that will

certainly be helpful to those who are new to the role and a great resource to support conversations with participants and their families.

December 2021 saw the release of the new Operational Guidelines for Supported Independent Living (SIL). New models such as Individualised Living Options (ILOs) and the ability to be more creative about how a participant chooses their living arrangements is a positive shift in paradigm. This funding model also creates obstacles for providers regarding vacancy management. ACD Tas is confident that this will not be the last of the changes in relation to living options, so perhaps a more positive and workable model is on the horizon.

## **Impacts to support coordination**

Gaps in service provision continue to present an issue for Support Coordinators. In many cases, intense planning and coordination is necessary to overcome barriers and to innovate, influence, problem-solve, and assess and report on risk. If Support Coordinators are to be effective, then they must be supported by sufficient participant plan hours.

Throughout the year, we have had to keep abreast of, and respond to, the ever-changing landscape of our COVID Response Strategy. It has been a difficult time to respond to the needs of the COVID pandemic, assisting participants to stay well informed and safe, facilitating vaccinations and staying up to date with the Pricing Guide addendums. We continue to find reserves with each wave or new strain of COVID and I'm sure it won't be long before we are amid the next COVID outbreak which will again test our Support Coordinators' resilience and fortitude. On the topic of COVID and support coordination, with only two days' notice, the NDIA announced earlier in 2022 that participants could no longer use core funds to pay for support coordination, which was previously a COVID measure. With significant community pressure, this was extended for one month.

There have been no increases to the NDIS support coordination hourly rate for the last 3 years. ACD Tas believes that the current pricing model, insufficient hours in participant plans and high administrative burden, are challenging the support coordination program's sustainability. The rising annual wages have seen increases in the Social, Community, Home Care and Disability Services Industry (SCHADS) award of 1.7% in July 2020, 2.9% in December 2020, 2.5% in July 2021, and again in July 2022 a 4.4% increase. Superannuation has also increased (from 9% to 10.5%) along with other overhead costs such as insurances, rental, IT system support and upgrades, compliance and audit costs as the Consumer Price Index and interest rates are at an all-time high. While the pricing guide was indexed for the disability support worker cost model by 9% in June 2022 to accommodate the increases in SCHADS award and superannuation obligations, the Support Coordination (and Therapy and Plan Management) line item remains unchanged! ACD Tas is continuing to have discussions with the community and agency about this shortfall.

The service provision markets in Tasmania are thin, meaning there is little choice of who a participant engages service with after often waiting for extended periods on waiting lists. Adding to the frustration of long waitlists, some providers are averse to taking on the more complex participants, perhaps because they receive the same hourly rate regardless of complexity. It takes time to get up to speed on the ever-changing systems and implementation of in-house policies and processes. Staff turnover has presented a challenge for them and the participants who feel they cannot get momentum when establishing core or capacity building support.

Staff turnover is not new to the NDIA either. We see a huge variance in the skill set of NDIA workers, especially in the National Call Centre (NCC). This often results in Support Coordinators having significant wait times while our consents are checked, declined, and double-checked, only to be told that they cannot answer the question that they have called to ask. These delays all impact on the usage of support coordination funded hours, which are often inadequate in the first place.

Repeatedly, we hear of the bureaucratic hurdles and difficult processes designed more to keep people out of the scheme, or not easily being able to access or use it. The navigation of existing and ever-changing systems and processes present huge barriers for participants and their families. Coupled with the often longwinded, drawn-out

timeframes for simple administrative errors to be corrected, it only adds to the frustration of Support Coordinators and participants alike. The NDIS continually ask Support Coordinators to provide justification to the NDIS during plan reviews, especially when multiple therapists are involved with a participant. As you can imagine, there are sometimes small overlaps between services. As we are not experts in the allied health field, the questioning of therapists, to provide evidence of need, can often be interpreted as intrusive and unjustifiable by the service providers.

As the bureaucratic overhead increases, the support coordination effort becomes more complex and time-consuming. For example, ACD Tas recently engaged with a family after receiving a request for service with minimal hours funded for support coordination, but we accepted and commenced the exploration work to see how we could best assist. We quickly discovered that the family was from a non-English speaking background and had multiple children with disability. The request for service was relating to only one of the children. The plan had not been implemented, meaning they had not spent any of the plan funding available and were not connected to any supports or services. The Support Coordinator had to coordinate the services of an interpreter for every engagement with the family, with in-person communication being the most effective. After multiple attempts to get a copy of the plan and connect with the family, it was soon discovered that some elements of the funding would be sufficient, but there were insufficient support coordination funding hours to assist and provide the level of connection and service that this family required. The NDIS system had not considered known indicators for a high need for assistance, i.e., non-English speaking and multiple children with disability. The support coordination funding was the only element found to be insufficient, the very thing required for plan implementation. We have been advised that the NDIS will not accept a review for insufficient hours for support coordination.

The barriers that families face create multiple stressors as they try to navigate systems and supports which are often inadequate and that they do not understand, or they may require multiple service systems to interact in an effective manner. Most of the families that ACD Tas support cannot gain the assistance required without significant input from our Support Coordinators.

The challenges of insufficient funding have had an impact on the number of people who require advocacy referral and support. The advocacy services across the state are at capacity, with no increased funding on the horizon which would allow for more human resources to be employed. As previously mentioned, the number of people who are in the review and complaint processes, either within the NDIA or externally at the AAT, is ever-increasing and placing huge demands and extending timeframes for access.

## **Impacts to ACD Tas**

Reductions in funding in terms of hours and hourly rates creates a situation where the funding does not cover the costs of the organisation for administrative work. The unfunded challenges we face include a significant on-the-job training component for Support Coordinators to provide this service. For ACD Tas to meet our obligations, we are required to have professional supervision, attend training sessions about NDIS, including the quality and safeguarding requirements and ongoing changes and improvements, respond to reviews and consultations, digesting and disseminating NDIA communications with stakeholders, keeping up with pricing changes and line items, liaising with other providers to resolve concerns, and other administrative functions.

ACD Tas was recently informed that Tasmania has been selected as the pilot site for the implementation of a new portal/finance system for NDIS providers and participants. There has been a flurry of seminars to attend in a noticeably short timeframe, so providers can be informed of the changes and facilitate the rollout of the pilot, which is going live mid-November. Tasmanian providers will now be running two portals/finance systems simultaneously. Tasmanian providers have not been financially compensated for this change by either a one-off payment or increase in the support coordination hourly rate. It is yet another administrative cost of doing business which is expected to be absorbed.

ACD Tas is torn between not wanting to run down the scheme to families and adding pressure to their already complex lives, and being clear about inadequacies. It is often Support Coordinators who tackle these inadequacies of the scheme. Staff turnover in the sector is on the increase as staff spend more time assisting people to access their plan and deal with administrative burdens rather than implementation and innovation. This ineffective system is left with the Support Coordinator, who is limited in their actions in a fee-for-service world with limitations on funding, and no known formula as to how these amounts are allocated. Many Support Coordinators take on compassion fatigue and experience vicarious trauma. This leads to stress, burnout and resignations from the Support Coordinators across the sector. The collective knowledge base then leaves the sector.

In conclusion, there is much work to do in the coming years to build Tasmania's capacity to meet the needs of children and young people with disability, and to ensure that the NDIS scheme's implementation issues and bureaucratic processes do not increase the barriers to those who are the most vulnerable participants within the scheme. I hope that the Tasmanian Government will be able to use some of the information in my report to influence a simpler, more effective scheme. ACD Tas wishes only to ensure that people with disability and their families, often with a number of comorbidities and complex situations themselves, have the support they require to live a fulfilling and 'ordinary' life. Given that ACD Tas is one of the few peer-led services in the state that works with this cohort of people, this program area is a priority for us. We initially moved into registering and delivering support coordination services to prevent issues from occurring and to build capacity, and to seek better life outcomes for people with disability and their families.

We will continue to work with all levels of government and the community. We are hopeful that Minister Shorten's history, understanding and knowledge of the sector and of people with disability will bring about significant improvements with the NDIA's systems and processes soon, and that this will result in a functional scheme for all who need it and who are particularly vulnerable without access to timely, quality services, supports and equipment and modifications. We live in hope that an overhaul of the scheme will have a significant impact on the freeing up of the function of a Support Coordinator to focus their time and use their expertise to assist participants of the scheme to effectively implement their plans and have equal opportunity to live their lives to the full.

We have faced yet another year of change, challenges and transformations. I am very grateful to have a skilled Team Leader in Ainsley Scott and a team of Support Coordinators who, embrace the changes, find workable solutions, and continue to provide a gold class service to NDIS participants and families who tell us that they highly value our service.

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