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Tasmania’s Disability Strategy 2025 – 2027 (‘Draft Strategy’)

Advocacy Tasmania’s Submission on the Draft Strategy

This submission was authorised by the Chief Executive Officer of Advocacy Tasmania, Leanne Groombridge on 30 January 2025. For comments or enquiries, please email ceo@yoursaytas.org

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Introduction

Advocacy Tasmania is an independent, not-for-profit, client-directed organisation that works for older people, people with disability or mental health issues and people using alcohol and drugs. We are in our clients' corner, fighting for their rights and dignity across Tasmania, where people experience the highest rates of disability anywhere in Australia.[1]

We work with thousands of people with disability every year who still experience widespread and systemic barriers to enjoying life on an equitable basis with others. Our clients are routinely denied quality healthcare, housing, the basic services they need to live and autonomy, dignity and agency in their own lives. Our clients' experiences have directly informed both our responses and recommendations below.

We hope our clients' lived experiences will help to strengthen the Draft Strategy. While we understand the draft is an interim strategy pending legislative implementation, too many of the issues our clients experience day in, and day out and they cannot keep waiting for real and transformational change. The people we are failing as a community need the world to change, and they need the Government to consistently step up, lead and really meet the challenges they face.

Specific, Actionable Change

In reviewing the Draft Strategy, there appears to be a significant disconnect between the aspirational goals contained within the background, context and principles, and the specific Actions and Indicators through each section of the plan.

The high-level frameworks this plan exists within and relates to, all recognise intimately the harms people with disability continue to be subjected to in all domains of life in Tasmania. They recognise the basic rights, dignity and agency of people, and paint a picture of a world with less rampant ableism, discrimination, and routine systemic abuse of people with disability.

We find these aspirations often missing when it comes to the specific, actionable plans, outcomes, and measurable changes to be achieved throughout the Draft Strategy. There is a

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[1] Disability, Ageing and Carers, Australia: Summary of Findings (2018) *Australia Bureau of Statistics* <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018>.

lot of language along the lines of ‘improved understanding’, ‘increased access to justice’ or ‘reviews completed’, often in areas where there has already been significant, ongoing reviews for decades.

We would appreciate a greater level of attention and specificity regarding what exactly will change for people with disability over the next three years, and how the Government will know it has been successful in achieving these changes.

Recommendation 1: Increase Specificity and Accountability

Review the Actions and Indicators throughout the plan, to ensure they are all specific about what exactly will be achieved, how specifically it will impact the lives of people with disability for the better, and when and how the Government will know those changes have been achieved.

ADS Outcome Area 3: Safety, Rights and Justice

Autonomy and Agency

We appreciate that there are several references in the Draft Strategy to implement Supported Decision-Making Principles regarding changes to the Guardianship and Administration Act (‘Act’). However, we are deeply concerned there are no references to the urgent work that needs to happen next to actually create change in this area.

Currently, the amended Act contains no effective, funded mechanisms to provide real, supported decision-making support to people with disability. It is a good idea, but without the necessary mechanisms and funding to realise it in practice.

Our experience has been that legislative changes tend to be symbolic without a comprehensive and funded system that shifts the status quo for those suffering under these systems. A funded supported decision-making system, which has been at the heart of guardianship reforms for decades, would take good ideas and transform them into something that people can enjoy within their own lives. It would give real dignity, choice and control back to people with disability who would otherwise be left suffering and asking when anything will actually change for them.

Tasmania needs a funded supported decision-making scheme, and people cannot wait another three years for work to begin on developing one.

Recommendation 2: Supported Decision Making

Include a specific item within ADS Outcome Area 3 to develop and implement a funded Supported Decision Making Scheme across Tasmania by 2026.

We continue to have serious concerns about giving the Office of the Public Guardian ('OPG') additional powers to resolve disputes with guardians, administrators and advanced care directives. As a legal decision-maker of last resort, the OPG has an inherent conflict of interest in its involvement in matters. It is not independent and has a significant organisational history of work that removes basic decision-making autonomy and agency from people with disability.

We are also concerned that these dispute-resolution pathways continue to lack effective remedies for people who are harmed by the decisions of others. Without enforceability, change continues to be slow and ineffective for our clients – who have often experienced life-changing harm at the hands of others.

Given the upcoming changes with the independent Disability Commissioner, we believe these powers should be transferred to an independent body. Additionally, the Disability Commissioner should have expanded powers to support people with disability and address the injustices they face.

Recommendation 3: Dispute Resolution & Remedies

Modify ADS Outcome Area 3 to grant the independent Disability Commissioner external dispute resolution powers, enabling them to review statutory body and private actions and provide timely, accessible, and effective remedies for people with disability.

Too many of our clients continue to experience systemic discrimination throughout Tasmania’s justice system. They are treated as unreliable witnesses of their own lived experiences, infantilised, ignored and disbelieved.

We acknowledge the review of the Witness Intermediary Scheme and that recommendations will be considered throughout the Draft Strategy. However, more needs to be done here, as people are being actively denied justice on a routine basis.

We support the plan including a specific item to reconsider and implement the communication intermediaries’ recommendations of the Tasmanian Law Reform Institute (‘TLRI’). The TLRI’s original recommendations were never to solely implement a Witness Intermediaries Scheme, and a much broader and funded approach is necessary to start to address the systemic and structural barriers people with disability experience throughout Tasmania’s legal System.

Recommendation 4: Justice Intermediaries

Modify ADS Outcome Area 3 to specifically include consideration and implementation of a full Intermediaries/Communication Assistant scheme for people with disability who need them in any interactions with the Tasmanian justice system.

ADS Outcome Area 4: Personal and Community Support

Improving Access to Support in Remote Areas

We welcome the creation of more foundational supports for people with disability. An ecosystem of disability supports that better meets the needs of people with disability in and outside of the NDIA needs to be a major priority over the next three years.

Through our advocacy work, we know major systemic issues continue to exist, especially in remote areas. There are major barriers to accessing services, thin markets, and a huge cohort of people denied the benefits of the NDIS. There is an urgent need to increase support services in remote areas to eliminate the access barriers currently faced by people living in these locations.

Florence's Story

Florence is a 58-year-old woman diagnosed with Primary Progressive Multiple Sclerosis (PPMS) that causes global muscle weakness, muscle spasms, heat sensitivity, fatigue and neurological pain and sensitivity. She is unable to walk and uses a power wheelchair to mobilise.

Florence resides in the remote area of Zeehan in Tasmania where there are limited NDIS and disability service providers. Due to the shortage of these service providers, there have been periods where Florence's care has been neglected due to the inability of service providers to get a support worker to her location. The care neglect and continuous stress of finding a support provider to provide support for Florence resulted in a deterioration of her condition and the need for Florence's husband to resign from his full-time job to become her support person.

Florence's husband has worked with her as her formal and informal support for 16 years. He has learned the ins and outs of caring for her and has previously worked as a support worker. In the last 5 years, he has been working with Florence; there have not been any incidents of falls, harm, neglect, abuse, or hospitalisation because of the support provided.

However, due to recent changes in the NDIS legislation, the exceptional circumstances granted by the NDIA for Florence's husband to be her paid formal support have been revoked. Florence's husband will now have to return to work resulting in Florence's limited access to support. As was previously the case, there will be days when Florence will have to sit in her excreta or go without food because her husband will be at work and there will be no service providers to provide support in her location.

The closest service provider to her location is overwhelmed with limited disability workers to cope with the high number of demands. Although the NDIA did provide a list of services that Florence may access in closer remote areas to her location, it still does not address the issue of appropriate services and access to such services. For example, to access support in other remote areas, Florence will be required to travel long distances or make significant life changes to align with NDIA operations.

Unfortunately, Florence's situation is one of far too many where recent changes in the NDIA legislation now act as a barrier to support, rather than a solution.

The NDIS National Workforce Plan 2021-2025 reflects that around 500,000 NDIS participants will require support from almost 353,000 workers.[2] However, the availability of the 350,000 workers and their interest in working in remote areas of Tasmania without generous incentives remains a massive issue. Further, the difficulty of finding a suitable worker would be an ongoing challenge for Florence, as their impairment is unique and requires a specialised disability worker.

Unlike Florence, who had already gained access to support through the NDIS but now faces systemic policy barriers, Steven's inability to gain access to the NDIS highlights the major obstacles faced by people with disability and the impact of the decreased numbers of specialised and allied health professionals statewide in Tasmania.

Steven's Story

Despite a childhood and adult history of symptoms of autism, Steven did not receive a formal diagnosis of autism until the age of 30 in August 2023. There were missed opportunities for early diagnosis of ADHD in Steven's childhood due to being homeschooled. The effects of the delayed diagnosis were a childhood filled with extensive traumatic experiences compounded with ADHD comorbidities of depression, anxiety and complex PTSD.

Even though Steven now has the required diagnosis to get the support required to improve his quality of life, help is still far away for Steven in obtaining psychological interventions and strategies due to limited psychologists and clinicians in Tasmania. While Steven was diagnosed through a telehealth consultation with an interstate psychiatrist, he needed face-to-face support.

Patients in Steven's situation are routinely placed on waitlists which can span up to six months or longer, and a lack of clinicians means that people with similar experiences in Tasmania, particularly those in the rural areas of Tasmania, either relocate interstate for support or continue to live with poor quality of life despite ADHD diagnoses.

Even with substantial advocacy support, Steven had huge barriers to accessing medical care. For example, one provider in Hobart on their website advises as follows *"We currently have*

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[2] NDIS National Workforce Plan: 2021-2025 <https://www.dss.gov.au/national-disability-insurance-scheme-review-and-reforms/resource/ndis-national-workforce-plan-2021-2025>.

no capacity in this area, however, if you fill in our enquiry form, you'll be added to our waiting list." Similarly, another provider on their website advises that they can only provide 291 assessments for ADHD. Many clinics are at full capacity or not accepting new clients.

Recommendation 5: Rural and Remote Focus & Increased Specialist Access

Modify ADS Outcome Area 4 to specifically include a focus on foundational supports in rural and remote areas, and significantly increasing access to medical specialists throughout Tasmania.

The NDIS provides eligible people with permanent and significant disability with access to reasonable and necessary disability supports.

The NDIA was created to administer the NDIS using an insurance model of providing individualised funding for eligible people with significant and permanent disability to improve their access to support. However, as noted in various Administrative and Review Tribunal (ART) cases, the definition of permanency has not been adequately addressed yet. What we see through our work is people with significant disability being denied access to support they often desperately need.

To determine the permanency of a disability, part of the NDIS rules provides that all reasonable treatments must have been adequately explored. However, barriers to treatment such as finances, religious beliefs or client choices imply that some people cannot gain access to the NDIS. An example is the experiences of Flora who was diagnosed with Fibromyalgia, back pain, obesity, Liver Cirrhosis and depression.

Flora's Story

Flora had undergone numerous treatments for her conditions and at one point refused further treatments for chronic pain because the medication side effects were resulting in other mental health issues such as depression. Having stopped treatment, Flora was unable to gain access to the NDIS and had her case reviewed at the ART. Unfortunately, Flora withdrew her case at the ART due to re-traumatisation. All her medical documents were summoned and reviewed by the NDIA and it became apparent that Flora required NDIS support. However, the NDIS rules highlight that all treatment options must be explored.

Having not explored the medication treatment options to the satisfaction of her specialist, Flora was deemed unable to gain access to the NDIS, retrospectively affecting her access to support. Flora advised that different medications have been trialled to treat her chronic pain, but the most effective medication had a significant side effect of causing depression. Flora did not want to take medication for depression, as she had no prior mental health condition before starting the medication prescribed for her chronic pain.

While there are benefits to the NDIS being managed under an insurance scheme, unless the human rights model of choice and control are underpinned in its policy management, the word “inclusive” often merely serves as a window dressing when it comes to determining who, among people with disabilities, gains access to support and under what criteria.

Recommendation 6: Human Rights and Medicalisation

Modify ADS Outcome Area 4 to include a governmental advocacy focus over the next three years to improve the human rights model of the NDIA and reduce the harms of forced over medicalisation of people with disability.

People with disability are supported to access assistive technology.

Assistive technology is often central to people with disability being able to live their lives on a more equitable basis. Assistive technology designed for people with disability promotes independence, reduces ableism, administers care, and provides access to supports such as telehealth; a vital service for people living in some remote areas of Tasmania. Yet, just because technology is assistive does not mean it is accessible for people who need to rely on it. For example, many online forums that should serve as a means for information dissemination and reduction in social isolation are inaccessible. Inclusive ideas become exclusive in practice.

In reviewing the Draft Strategy, the focus must shift from assistive technology to accessible technology to promote access to support and inclusion. Having assistive technology is not enough, having an accessible technology should be the minimum requirement for all disability service providers.

Recommendation 7: Accessible Technology

Modify ADS Outcome Area 4 to shift the focus from assistive to accessible technology.

Conclusion

There is a long way to go for the rights, dignity and agency of people with disability throughout Tasmania. We hope the Draft Strategy can be strengthened to ensure it is specific and actionable and leads to Tasmania being a better place for people with disability to live. Transformational change cannot wait for three years.

A funded, supported decision-making scheme would go a long way to achieving this goal and reducing the well-established harms that guardianship and administration have caused to people with disability over recent decades. We hope the Draft Strategy will include much more support for people in their interactions with the justice system, reduced conflicts of interest with the OPG and greater powers for the Disability Commissioner to provide effective and timely remedies for people with disability through the state.

We hope for a state where people do not have to continue to have the experiences of Florence, Steven and Flora. Without meaningful change, these experiences will continue to be common. Services in regional areas, access to appropriate and necessary healthcare and professionals, and accessible technologies can all be massively improved.

We hope the Draft Strategy can be strengthened in each of these areas, and the Tasmanian Government will take a key leadership role in ensuring national plans and actions go beyond incremental change and create the transformational change people with disability have been calling for, for decades.