Disability Advocacy Victoria Inc.
Peak body for independent disability advocacy in Victoria

The Importance of Disability Advocacy

A Disability Community Perspective

March 2025

A Community Perspective - Alison's Story

My name is Alison Brown De Moreno. I'm a multiply disabled, neurodivergent, ambulatory wheelchair user. I also serve as Co-Chair of the Disability Resources Centre, a cross-disability advocacy and campaigning organisation based in Melbourne. Professionally, I've worked in the healthcare industry, with experience in medical indemnity, private health insurance, compliance with AHPRA, and currently as a Client Executive in Health and Wellbeing for a global insurance broker.

I want to explain why disability advocacy is crucial for people with disabilities, especially now as the future of independent disability advocacy funding is so uncertain.

At present the disability advocacy sector is chronically underfunded and subject to short term funding contracts. This has resulted in a high level of workforce turnover due to job insecurity, and demand for services greatly exceeding supply, with most organisations reporting long waiting lists. Without adequate and urgent resourcing, this situation is predicted to worsen. It is estimated that the demand for advocacy services will grow at approximately 5 per cent per annum on average.[1]

In my further education, I faced significant discriminatory barriers that—if left unresolved—would have led to my exclusion from my enrolled academic program. Despite my privileged position due to my education and professional background, I still needed the expert assistance of disability advocates to resolve my issue. I doubt it would have been resolved without their help.

To be clear, my issue should have been straightforward. I knew exactly what changes I needed to continue my studies. However, when I first brought this to the university's attention, they were unresponsive to my concerns and unwilling to accommodate my needs.

It took considerable time and effort before I even learned about seeking help from disability advocates. Once I connected with Disability Resources Centre, I got on the right path, and my issue was resolved relatively quickly, allowing me to continue my studies.

Such a simple and quick resolution to a disability advocacy problem is rare.

If I needed advocacy support to avoid exclusion from an academic program—where all parties were willing to make changes once I brought the problem to their attention—what chance does a disabled person with less privilege have?

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[1] Deloitte 2022, Demand Study of the National Aged Care Advocacy Program (NACAP)

- I'm talking about the cultural safety of First Nations Australians with disability living in our cities and in rural and remote Australia.
- I'm talking about children with autism in the education system subject to restrictive practices.
- I'm talking about people with communication support needs.
- I'm talking about people with complex cognitive impairments who are a risk of harm to others who live in closed environments with no access to advocates

My Advocacy Story

As a student with a disability at Victoria University, I encountered significant systemic barriers that highlighted the crucial need for disability advocacy in education. My experience serves as a stark example of the challenges faced by students with disabilities and the importance of strong advocacy support.

When the COVID-19 pandemic hit, like many others with disabilities, I adapted to online learning and thrived under Victoria University's block model. This unique approach allows students to take one unit intensively for four weeks. I had struggled for years under the traditional online model, as my health—like that of many disabled people—is unpredictable. At VU, if I became ill and needed to withdraw, I could try again in the next block instead of waiting for the next semester. Combined with working from home, my health improved significantly, and I excelled academically.

As the COVID situation improved and the university announced a return to in-person classes, I initially felt prepared to attend, even purchasing a more practical wheelchair to facilitate this transition. However, the emergence of the Omicron variant drastically changed the landscape, with case numbers skyrocketing from single digits to hundreds daily. Given my disability and heightened health risks, I could not safely return to in-person learning.

On January 4, 2022, I approached the university and requested reasonable accommodation to continue my studies online. To my dismay, this request was denied. This denial marked the beginning of a challenging journey that would require significant advocacy efforts to resolve.

My first step was to file a complaint with the school itself and then to speak out on social media. In March 2022, I sought help from the Disability Resource Centre (DRC), which assigned a dedicated advocate to guide me through the process of challenging the university's decision. With their assistance, I took my case to the human rights commission, escalating the issue to ensure my voice was heard.

After a struggle involving legal channels and public advocacy, which took about five months to resolve, I secured the right to continue my education through online access to my law classes in June 2022. Some classes still required in-person attendance, but the university was willing to move those to a new building with better ventilation. I considered this a win, but I didn't rest on my laurels. I joined the student government as the accessibility officer, made a submission to the Disability Royal Commission into Violence Abuse and Neglect of People with Disability, joined the DRC in an official capacity, and in April 2023, The Age ran an article about my journey. Within days of the article's release, I was invited to meet with the head of the law department, and we developed a way for students to attend all classes online. This victory was not just personal; it set a precedent for other students with disabilities facing similar challenges.

My experience underscores the vital role of disability advocacy in education. Without the support and guidance of the DRC advocate, navigating this complex system and fighting for my rights would have been overwhelmingly difficult. The advocacy support empowered me to stand up against systemic barriers and push for positive change.

This journey has reinforced my commitment to disability advocacy. It has shown me that while individual efforts are important, systemic change often requires collective action and support. If I hadn't had access to disability advocacy, I likely would have given up, deciding that higher education wasn't for me. Alternatively, I might have ended up with an even higher HECS debt than I already have, as I would have had to repeatedly withdraw after the census date. Neither the university nor previous schools had informed me that I could apply for HECS to consider my disability status.

My story is a testament to the power of advocacy in overcoming systemic barriers. It highlights the ongoing need for strong disability advocacy services to ensure that all students, regardless of their disabilities, have equal access to education. By sharing this experience, I hope to inspire others to seek support when faced with similar challenges and to contribute to creating a more inclusive educational environment for all. It's crucial to remember that employers and educational institutions often work in their own best interests, and without advocates, many people with disabilities wouldn't know their options or the paths they could take to assert their rights.

Summary

Disability advocacy is unique and specialised and without it people with disability would frequently fail to access the same rights and choices as the rest of the community.

Disability advocacy organisations are trusted by people with disability to use an independent rights-based framework, free of conflicts of interest, led by the person with disability when resolving barriers to mainstream service systems.

The disability community is becoming ever more complex, and barriers to mainstream services systems are entrenched and frequently overwhelming, with significant detrimental impacts on health and wellbeing. It is often beyond the capacity and expertise of people with disability to address these issues without expert and trusted independent disability advocacy.

Despite my privilege, as a person with disability, I anticipate needing disability advocacy long into the future.

My call to action:

I ask the Victorian Government to act on the following recommendations:

1. The Victorian Government should undertake an independent review into disability advocacy in Victoria modelled on the approach taken by the New South Wales Government in 2020.
2. End short term funding - provide financial certainty for disability advocacy organisations and implement the recommendations outlined in the Disability Royal Commission.
3. Recognise disability advocacy as an essential service in relevant legislation and policies.
4. Commit to regular reviews and consultations with the disability advocacy sector to ensure ongoing effectiveness and responsiveness of mainstream service systems.
5. Implement the Disability Royal Commission's recommendations regarding First Nations Australians with disabilities' access to advocacy—fund culturally safe advocacy for First Nations Australians with disability.

Resolving Systemic Barriers: The Role of Disability Advocacy

People with disability work alongside professional, independent disability advocates to ensure that we access the same rights and choices as every other member of the community. People with disability approach advocacy organisations with a huge range of issues across discrimination, education, employment, domestic violence, housing and economic survival.

Here are three other case studies, each showing the length of time the issue took to resolve and the cost of resolution

The Right to an Adequate Standard of Living and Social Protection: Accessing the Disability Support Pension to Prevent Homelessness

Taylor is a young woman living with autism and ADHD who has been finding it hard to gain stable employment due to her disability.

Taylor contacted the Disability Resources Centre seeking advocacy assistance with navigating access to the Disability Support Pension which she needed as her main source of income. Taylor felt she was unable to sustain employment due her undiagnosed Autism and ADHD and the mutual obligations of the Newstart allowances that were placing a great deal of strain on her mental and physical health. Taylor lacked both informal and formal supports. Taylor was also having a lot of trouble finding a flexible employer who would accommodate her disability.

Due to her lack of income, Taylor was facing homelessness, and she was often unable to pay the cost of groceries and other day to day expenses such as medications, accessing public transport and paying her utility bills. Taylor could not apply for the Disability Support Pension as she did not have an independent clinical diagnosis.

The Disability Resources Centre advocate supported Taylor to engage with an external service provider, Community Collective Victoria, who offer independent clinical assessments for low income earners. Taylor received a diagnosis of Autism Spectrum Disorder Level 2 and ADHD.

Upon receiving these diagnoses, the advocate supported Taylor to acquire the evidence needed to complete and submit her Disability Support Pension application.

Taylor was approved for the Disability Support Pension, and she is now in safe and secure housing and no longer at risk of homelessness. Taylor is also able to look for employment free from extreme stress and uncertainty.

- **Duration of Advocacy: March 2023 - November 2024**
- **Total advocacy hours: 48 hours**
- **Total Cost of Advocacy: $2,977**

The Right to Education: Accessing Reasonable Adjustments to Study at University

Tom is a mature aged student studying at Australian Catholic University, with mental health and learning difficulties. Tom has previously completed several tertiary education courses and is committed to continuing his tertiary education.

Upon starting his current degree at Australian Catholic University, Tom sought support from the University to ensure his academic success. Unfortunately, Tom's application for reasonable adjustments were described by ACU as "unnecessary" and his capability to complete the course was questioned on multiple occasions by several University staff members including the national head of ACU's Disability Liaison Team.

However, Tom was determined to continue his study and participation as a student at the University. Over the next five years Tom continued to study and fight for the reasonable adjustments he felt he needed to continue his tertiary education completing units where he could, and dropping out of those he could not complete

Tom continued to fight the University through multiple complaints whilst facing structural and personal resistance from the University denying his accessibility needs that would enable his right to study. During COVID Tom was excluded from online learning and left without access to online classes. Following COVID, ACU notified Tom that his seven years to finalise his degree was almost finished. At this point he contacted the Disability Resources Centre to seek advocacy support.

The advocate arranged a series of meetings with the heads of ACU's Sports and Exercise Science Department, the Disability Liaison Unit and Tom to discuss the requested reasonable adjustments he needed to finish his degree.

While some reasonable adjustments were accepted by the University and Disability Liaison Unit the University made no effort to ensure that individual lecturers implemented these requests. Other necessary reasonable adjustments were deemed "impossible" to implement by ACU. Further it was noted that there was no opportunity to extend the 7 year time frame as this external policy was developed by the independent peak registration body for sports and exercise science ESSA.

The advocate contacted ESSA regarding the 7 year timeframe to finalise a degree and was informed verbally and in writing that this timeframe was designated by the university, not by ESSA. Despite this information being provided to the University, resistance to an extension of the timeframe for the completion of the study from the University continued.

During this time, Tom, a dedicated and passionate student was enrolled and undertaking units without all reasonable adjustments being implemented. Tom was encouraged to drop a particular unit of study taught by the head of the department as the lecturer "did not have enough time to implement [Tom's] adjustments".

After a consultation with a discrimination lawyer at Disability Discrimination Legal Service, the advocate worked with Tom to submit a complaint to the Victorian Equal Opportunity and Human Rights Commission.

As a result of this complaint ACU apologised to Tom for the misinformation given by staff regarding the 7 year timeline and for the barriers Tom has experienced in accessing necessary reasonable adjustments. The University has agreed to extend the 7 year timeframe, allowing for Tom to complete his degree on a unit per semester basis as recommended by his Medical and Allied health team. ACU has further agreed to all reasonable adjustments, including those previously deemed "impossible".

- **Duration of Advocacy: March 2023 - November 2024**
- **Total advocacy hours: 76 hours**
- **Total Cost of Advocacy: $4,638**

The Right to Access Justice: Accessing the NDIS Justice Planning Pathway[1] for Better Disability and Justice Support Outcomes

Michael is an Indigenous man with a psychosocial disability who has been recurrently detained in a mainstream prison over the past ten years. Michael is now living with his family in the community and is under a strict justice order requiring regular reporting to police and random Alcohol and Other Drugs (AOD) testing. Michael was made eligible for NDIS twelve months ago receiving a good initial general NDIS plan. Unfortunately, the NDIS Plan did not respond to his ongoing disability and justice support needs and he was not approved for access to the justice planning pathway.

The disability advocate worked with the NDIS to determine what information was needed by the NDIS to have him approved for access to the justice planning pathway. Access to the justice planning pathway was important because Michael would then be provided with a justice planner who has expertise in working with participants involved in the criminal justice system.

The NDIS advised the disability advocate that documentation related to his criminal justice history and his periods of incarceration was required for access to the justice planning pathway. Unfortunately, the state justice agency refused to provide this information to the guardian or the NDIS requiring Michael's guardian to submit a Freedom of Information application.

The disability advocate worked with the Justice Liaison Officer (JLO) to overcome this barrier to justice information relevant to the NDIS. The JLO negotiated with the justice agency to gain access to a limited version of Michael's history of incarceration. The JLO then worked internally to ensure that the limited justice information would be enough for Michael to be approved for eligibility to the justice planning pathway.

Michael was granted eligibility to the Justice Planning Pathway in September 2024

- **Duration of Advocacy: October 2023 to September 2024**
- **Total advocacy hours: 90 hours**
- **Total Cost of Advocacy: $5,493**

Disability Advocacy Victoria

Disability Advocacy Victoria (DAV), formerly known as Victorian Disability Advocacy Network, was established in 2003, and is the peak body for independent disability advocacy organisations. Despite being unfunded Disability Advocacy Victoria represents 16 disability advocacy organisations.

DAV promotes and defends the human rights and valued status of people with disability through systemic advocacy and by supporting and promoting effective independent, community-based advocacy organisations.

DAV will strengthen and promote independent, rights-based advocacy in Victoria and promote the rights, needs and choices of people with disability.

The State of Disability Advocacy in Victoria: Time to Review

The Victorian Disability Advocacy Sector

In 2023/2024 there were 23 disability advocacy organisations funded via the Victorian Disability Advocacy Program.

The Victorian Disability Advocacy Program is a Victorian Government investment to ensure inclusion and participation of Victorians with a disability in the life of the community by funding disability advocacy and self-advocacy organisations

A number of these Victorian disability advocacy organisations also receive funding from the Commonwealth Government through the National Disability Advocacy Program and a small number receive funding from other sources.

A number of Victorian disability advocacy agencies receive funding through the National Disability Advocacy Program.

Providing Disability Advocacy in Victoria

The Victorian Government states it is committed to ensuring fairness and safety for Victorians with disability, and disability advocacy is a priority commitment in the Victorian State Disability Plan, stating:

> ***“We will work to ensure all Victorians can have equal rights and challenge discrimination through access to a thriving disability advocacy sector led by and for people with disability.”***

Disability advocacy works to ensure that the human and legal rights of people with disabilities are promoted and protected so they can fully participate in the community. The work of disability advocacy organisations is varied and includes:

- *individual advocacy* - where an advocate works directly with a person with a disability to provide information, advice, or support to take action to uphold their rights.
- *systemic advocacy* - which addresses discrimination affecting a number of people with disabilities, by advocating for change to legislation, policies and practices.
- *self-advocacy* - where people with a disability speak up and represent themselves, and organisations support people to do this.

In June 2024 DAV conducted a survey of all Victorian disability advocacy organisations. The outcome of that work provides critical insights into the current state of disability advocacy in Victoria, highlighting significant challenges faced by the sector. This analysis examines the key findings related to service demand, capacity, funding impacts, and consequences for people with disabilities.

Doing More with Less

The DAV survey indicated a substantial increase in client demand for advocacy services. As stated in the document, *"The majority of advocacy organisations are experiencing increased client demand whilst at the same time experiencing a decline in the numbers of advocates funded to do the work"* (DAV Survey, Summary of Findings). This surge in demand underscores the growing need for disability advocacy services in Victoria.

The capacity of advocacy services to meet the rising demand is severely compromised. The survey reveals that 47% of disability advocacy organisations have reduced their full-time equivalent (FTE) staff numbers since July 2023, including disability advocates (DAV Survey, Impact on workforce sustainability). Moreover, 80% of organisations anticipate further reductions in FTE staff in 2024/2025 if no increase in funding is provided (DAV Survey, Impact on workforce sustainability). This reduction in workforce capacity significantly impairs the sector's ability to provide adequate advocacy services.

The survey highlights severe financial constraints affecting service delivery. Key findings include: 35% of disability advocacy organisations operated a deficit budget for the last three years, 58% of organisations expect to run a deficit budget in 2023/2024, and 44% of organisations are at risk of insolvency if they run a deficit in 2024/2025 (DAV Survey, Financial Sustainability). These financial challenges have led to difficult decisions, with 50% of organisations having to choose between cutting advocates or scaling back other services (DAV Survey, Thematic Comments). The funding shortfall has also resulted in the reduction of systemic advocacy, information and advice services, wrap-around supports, and engagement with government (DAV Survey, Summary of Findings).

The survey findings indicate severe consequences for people with disabilities due to inadequate advocacy support. These include reduced access to timely advocacy during a period of significant structural reform across the sector, long waiting lists for access to advocacy due to insufficient advocates to meet client demand, and the risk of collapse of the disability advocacy sector, creating a significant barrier to the disability community accessing services (DAV Survey, Summary of Findings and Thematic Comments).

Conclusion

The sustainability of the Victorian disability advocacy sector is at a critical point with a number of disability advocacy organisations operating a deficit budget, putting at risk the solvency of some of these organisations. Many of these organisations have faced a significant increase in people with disability needing advocacy, but they have fewer advocates to meet this need.

Disability Advocacy Victoria
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