



**Autism Family Support Association Inc (AFSA)**

**Submission**

**National Disability Advocacy Framework 2022-  
2025**

**June 2022**

## OUR BACKGROUND

The Autism Family Support Association (AFSA) is a voluntary organisation whose purpose is to assist and support individuals with an autism spectrum disorder (ASD) in Victoria by providing emotional and practical support for parents, carers and families. It is estimated that there may be around 55,000 people in Victoria with ASD.

AFSA has many members whose loved one(s) with ASD present with complex support needs due to their challenging behaviours. These behaviours are intense, often physical and can be attributable to little or no effective communication, high levels of anxiety, poor social awareness, extreme sensory sensitivities and the need for routine and predictability.

Autistic 'meltdowns' can occur at any time, often without warning, and cause parents, carers and families extreme stress on a number of levels. The cumulative effect on family functioning and resilience is well recorded, both anecdotally and in research. Critically, the outcomes for individuals with autism is severely compromised.

## OUR VISION OF DISABILITY ADVOCACY

Our vision for disability advocacy services for our loved ones with autism embraces a human rights driven person-centred approach that acknowledges the roles and responsibilities of parents, carers and families.

As the collective voice for autistic people with complex and high support needs and their parents, carers and families AFSA actively engages in systemic advocacy. AFSA regularly raises our community's concerns with state and federal government policy makers to achieve better services and outcomes for autistic people and their families.

We also provide fellowship, peer support and information. In this role we regularly witness poor outcomes in the provision of individual and self-advocacy services. Our vision is for disability advocacy services that are specifically tailored to meet the needs of individuals with autism and their parents, carers and families.

## OUR CONCERNS RE DISABILITY ADVOCACY IN VICTORIA

In 2018 AFSA prepared a response to the Victorian Disability Advocacy Futures Plan 2018-2020. Our concerns presented then remain the same now we are in 2022 and particularly exacerbated by our collective COVID experiences. In summary, our families and their loved ones with autism desperately need accessible and effective advocacy support that promotes, protects and ensures their full and equal enjoyment of all human rights, and enables community participation and inclusion to the best of their ability.

We do not believe the current disability advocacy support service model in Victoria is adequate to ensure equity of access, quality of service and effective outcomes.

**Concern #1** – Limited **availability** of disability advocacy support services and the range of issues they can address, including education, NDIS, Justice and Health and Wellbeing (including the impact of COVID).

**Concern #2** – Limited **capacity** of funded advocacy support agencies to meet the demand for individual and self-advocacy.

**Concern #3** – Significant issues with the **capabilities** of advocacy support workers to provide effective advocacy when dealing with issues experienced by autistic individuals and their parents, carers and families. The complexity of autism often requires a multi-disciplinary approach to ensure adequate outcomes.

**Concern #4** – The lines of what a ‘disability advocacy support service’ comprises are often blurred. Advocacy agencies need to be more **transparent** when promoting their services, especially the level of individual advocacy services they provide (time limited, single issue, ongoing) and eligibility to receive these services. Too many individuals with autism and complex needs are deemed ‘ineligible’ or ‘too hard’ for advocacy support, especially at the school level.

**Concern #5** – **Accountability** via regulation and registration of disability advocacy support services to ensure quality and effectiveness of advocacy supports delivered. Funded advocacy support agencies should be required to provide qualitative and quantitative outcome metrics.

## OUR THOUGHTS ON THE DRAFT NATIONAL DISABILITY ADVOCACY FRAMEWORK

We agree with the outcome statement ‘to ensure that the rights of people with disability are promoted, upheld and protected and that people with disability feel safe and enjoy equity before the law’ as the core principal underpinning the NDAF and the provision of disability advocacy supports.

We agree that disability advocacy supports must be person centred but are concerned that the rights and responsibilities of the parents, carers and families of individuals with autism and especially those with complex needs are not adequately recognised within the framework.

The list of outcomes contained in the framework is laudable but the experience of those ‘at the front line’ is very different. Too often advocacy services are required when services and supports are denied or reduced using questionable algorithms, policy directions, delaying tactics or legal actions. This totally unacceptable situation should be addressed in the framework with a stronger outcomes statement relating to the need for realistic and equitable decision-making methodologies be used to determine who gets what services and funding levels.

The Disability Royal Commission still in progress has revealed many harrowing instances of violence, abuse, neglect and exploitation. We believe it is important that the NDAF makes specific reference to the eventual findings of the Royal Commission and that they will inform the ongoing principles of the NDAF.

We agree with the policy directions outlined and especially the joint role of state, territory and federal government in ensuring provision of an effective network of disability advocacy. In our view the most critical reform articulated in the draft NDAF is:

- *Improving coordination and communication between disability advocacy organisations, disability services, the National Disability Insurance Agency, mainstream services, community-based services and governments to develop the overall capacity of the disability sector, including promoting linkages between individual and systemic advocacy.*

Please note - AFSA is aware of many real-life experiences where currently funded advocacy support services have been unavailable, inadequate or discriminatory. It is beyond the scope of this submission to detail these.

**Submitted by the Autism Family Support Association Inc.**  
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