



## STATEMENT FROM THE AUTISM FAMILY SUPPORT ASSOCIATION ON THE NEED FOR REFORM OF VICTORIAN DISABILITY ADVOCACY SERVICES – MARCH 2023

AFSA is the collective voice for people with severe and profound autism and their parents, carers and families. We provide fellowship, peer support and information.

AFSA believes that advocacy support for people with disabilities, especially people with severe and profound autism needs urgent reform. There is a significant lack of individual advocacy support for families of those with severe and profound autism and their families, especially in times of critical need.

AFSA has many member families whose loved ones 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 families and carers extreme stress on a number of levels. The cumulative (negative) effect on family functioning and resilience is well recorded, both anecdotally and in research.

AFSA has identified a number of issues and concerns that need to be addressed to improve the availability, timeliness and quality of individual advocacy support on behalf of people with severe and profound autism.

### **ACCOUNTABILITY**

What actual accountability is there from those organisations currently receiving funding for the delivery of individual advocacy services?

Measurement and evaluation of performance must include quality, as well as quantity; that is, outcomes achieved and direct “customer feedback” by way of survey of those who have used services.

Funding and service agreements must include clear “deliverables” for organisations that are being funded by government.

### **TRANSPARENCY**

Organisations that hold themselves out to offer advocacy must be far more open about the expertise they have to offer, the range of services they can provide and the timelines of these services.

There should be an “intake” system that allows a potential user to know what to expect and when. There should be greater standardisation of questions at the start of a process of seeking support from an advocacy service to see if it is the “right fit”.

The DFFH website needs to identify which organisations offer “individual” advocacy and which offer “systemic” advocacy and those which may offer both. Any costs or charges that may apply should also be made clear.

## BETTER USE OF TECHNOLOGY

Proposals need to be developed, pilots trialled, and innovation encouraged to better use technology and appropriately co-ordinate “offerings” from different organisations. Numbering systems or wait lists should be considered and centralised triage should be explored to identify and direct requests to the “right area” and prioritise cases.

A central call centre auspiced or operated by DFFH should be established. Data can also be captured at this central spot in regard to issues, users' profiles, to whom allocated, wait times and time of completion. Users need to be able to provide feedback on services provided to the central data collection area to drive improvement and service enhancements. Sometimes the issue requires more than advocates and there needs to be an avenue to escalate the issue to secure legal representation in a seamless fashion.

Subject to proper privacy protection, standard details of a request for assistance might be captured once so that a customer does not need to keep repeating their story as they get “shifted” or “shafted” from one organisation to another.

## AVAILABILITY AND RANGE

In our 2022 AFSA Annual Survey member families reported the need for individual support in the following areas

- **NDIS**
- **Education**
- **Justice**
- **Health and Wellbeing**

There seem to be limited options for timely and effective support in many of these areas.

## RESOURCING AND CAPABILITY

There appears to be a capacity issue in that many organisations funded to do advocacy work (and other organisations not funded but perceived to be able to offer some assistance) do not appear to have sufficient resources to meet the demand they experience. Anecdotally AFSA hears that some families receive excellent support and assistance when they can get the right person with the right expertise and the knowledge and determination to pursue an issue.

The “right” capability may mean the availability within the one service of a multi-disciplinary team covering legal, social work and community development areas of expertise.

## REGULATION AND REGISTRATION

It seems unclear exactly what laws or regulation govern “advocacy” services. Who is able, legally, to hold themselves out as “advocates”?

AFSA would not want unnecessary “red tape” or regulations to get in the way of more services being provided but there must be an appropriate degree of oversight and supervision.

Privacy and safeguarding of a person or family's often sensitive or personal information is another area that seems unclear. What responsibilities and "codes of conduct" do advocacy organisations need to comply with around privacy and protection of information?

### **SYSTEMIC ADVOCACY**

What measures are used by funding bodies to determine how successfully or effectively an organisation is carrying out its role? Who determines whether value for money has been delivered?

### **TRAINING FOR ADVOCACY**

What training is available or "mandated" for current or future advocates in both the publicly funded and the "private" sector? Can the Victorian Government, through DFFH, encourage development of training packages and courses?

### **CONSULTING AND LISTENING TO USERS**

Government needs to consult and listen to users and people with disabilities and their families and carers.

AFSA believes that urgent reform is required to ensure more skilled and accessible advocacy services are available for the support of people with profound and severe autism and their families.

### **WHO IS AFSA**

The Autism Family Support Association is the collective voice for autistic people with complex and high support needs and their parents, carers and families. We provide fellowship, peer support and information. AFSA actively raises our community's concerns with state and federal government policy makers to achieve better services and outcomes for autistic people and their families. Via our website, social media and meetings AFSA provides links to contemporary evidence-based information and resources, networks and support services. AFSA is managed by a voluntary committee. We represent lived experience and speak on behalf of our autistic family members and their loved ones. We partner with like organisations to share our experiences and information.



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