

Disability Royal Commission

GPO Box 1422

Brisbane Qld, 4001

By email: DRCEnquiries@royalcommission.gov.au

14 December 2021

Dear Commissioners,

Amplifying the voices of autistic people through advocacy.

Amaze works to build community understanding of autism, influence policy change for autistic people and provide independent, credible information and resources to individuals, families, professionals, government and the wider community. We are closely connected with the autistic community through our national help line Autism Connect, our peer support networks and community capacity building initiatives

The purpose of this submission is to inform your inquiries into how rights recognized in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) may be better enshrined into all practical policies and practices to prevent violence, abuse, neglect and exploitation of people with disabilities.

In particular, this submission aims to highlight the need for user led, autism specific, nationally consistent advocacy services (systemic and individual).

Advocacy is a fundamental right enshrined in the UNCRPD.

Sustainable and independent advocacy supports for autistic people are essential for implementing and monitoring the UNCRPD. They are key to preventing violence, abuse, neglect and exploitation of people with disability and promoting a more inclusive society.

Advocacy services support people with disability to exercise their rights and freedoms by the provision of individual advocacy support; supporting people to advocate for themselves; and influencing long-term, systemic changes for a group of people.

There is considerable scope to improve support for disability advocacy

In 2019, the United Nations' Committee on the Rights of Persons with Disabilities expressed concern about the unsustainability and inadequacy of resources for continuous, individual and independent advocacy programmes in Australia.¹

As you are aware through submissions received and your recent public hearings, key challenges facing disability advocacy in Australia include a lack of funding growth to meet increased demand, inconsistency in implementation of Commonwealth and state disability advocacy funding, a lack of nationally consistent data for disability advocacy and funding uncertainties. The NDIS has also created extra demand for services. In 2017, data from the Disability Advocacy Resource Unit (DARU) found that the number of reports for disability services and the NDIS increased by 70% upon introduction of the NDIS.² The NDIS has passed significant burden to families to navigate the scheme and a market of supports and service systems. The Amaze community is frequently seeking support to navigate NDIS processes and outcomes, and we hear from many other advocacy organisations that the NDIS continues to dominate their workload.

Autism-specific advocacy services are needed

On 1 December 2021, the Department of Social Services invited applications via a closed non-competitive process to deliver individual advocacy services under the National Disability Advocacy Program (NDAP) from 2022 to 2025. To be eligible to receive a grant, an organisation must be one of the organisations listed in the Grant Opportunity Guidelines. We have reviewed the list of organisations and it does not contain a single autism organisation or advocacy group.

This closed non-competitive process and ongoing failure to invite autism organisations to tender for the NDAP program is unacceptable. It is also unacceptable that no autism organisations or advocacy groups have been funded to provide individual advocacy under the National Disability Insurance Scheme Appeals Program.

Autistic people require advocacy services that are user led and have a thorough understanding of the issues faced by autistic people. General disability advocacy groups tend to lack this detailed

¹ United Nations Committee on the Rights of Persons with Disabilities, 2019. *Concluding observations on the combined second and third periodic reports on Australia*. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICAqhKb7yhsnzSGolK0aUX8SsM2PfxU7sdcBNJQCwIRF9xTca9TaCwjm50InhspoVv2oxnsujKTREtaVWFXhEZM%2F00dVJz1UEyF5IeK6Ycmqrm8yzTHQCn>

² Disability Advocacy Resource Unit, 2017. *Disability Advocacy by the Numbers*, pp. 16. Available at: <http://www.daru.org.au/disability-advocacy-by-the-numbers-data-integrity-supplementary-report>

understanding. Autistic-led advocacy groups can build autism competency within general advocacy groups, as well as directly support autistic people and their families.

In 2020, the Australian Autism Alliance conducted the largest and most comprehensive consultation survey of autistic people and their carers to date, with almost 4000 responses received. This survey included questions about people's confidence and understanding in engaging in self-advocacy activities. The insights were illuminating.

- More than 22% of autistic adults reported that they did not know where to get help if they were experiencing violence, abuse or neglect.
- 45% did not know where to get help if they were experiencing discrimination or exclusive practices, such as a lack of opportunities to access education, accommodation, recreation and leisure.
- 39% did not know where to get help with the law, tenancy, Centrelink or with having enough money to meet their needs, or to speak up for themselves and self-advocate in general.

Qualitative responses included:

"I stumbled across an advocacy group who have been very helpful in preparing for my son's interview, and my daughter's second planning session. It would be great if it was more widely known that advocacy groups are available".

"Parents of autistics must become very strong advocates for their child's needs to be met at school, in community and in healthcare setting. It is a full time job with an enormous mental load for parents to carry. Concerned how parents with limited resources, lower levels of education or from culturally or linguistically diverse backgrounds cope with advocating for their child".

"When in need of an advocate they are expensive and not funded the wait times are incredibly long therefore the person with autism is left without any support from an advocate most times".

"When parents have so many barriers to advocacy for their children, how are the autistic children themselves able to advocate for their own needs and well-being?"

"Whenever we need advocacy for an issue eg something at school. We have to wait at least 6 weeks for disability advocacy and by that time the meeting or issue is resolved".

“When it’s a child, it’s important that the parent /carer is supported enough to have the confidence and knowledge to advocate on their behalf”.

“Would be good to be able to access a community autism friendly program (perhaps online) to learn how to advocate for himself and develop his self-esteem to be able to do so”.

“Would like to see a role created for an autism advocate to be the link between home and school - would reduce family stress, particularly if parents/s working”.

International studies have also revealed challenges for autistic people in accessing mainstream disability advocacy services. A 2003 UK survey by the National Autistic Society of 55 general, learning disability and mental health advocacy organisations found that 32% of those organisations would not provide services to people who revealed that they had an autism diagnosis. The remaining 62% indicated that they experienced significant difficulty working with autistic people and had little confidence in the ability to advocate effectively for this population.³ Much of the concern expressed was around their understanding of autism or concerns about advocating for people with communication difficulties. Although that study is now almost 20 years old, these findings align with recent commonly reported experiences of autistic people in Australia.

There needs to be scope for funded advocacy services that are designed to work with autistic people and their families, in parallel to generalist services for people with disability. Notwithstanding the recent moves away from funding diagnosis specific advocacy, the self-advocacy movement for autistic people is relatively new compared to those with physical and sensory disabilities such as vision and hearing impairment. So rather than seeing this as a step backward it is actually playing catch up in terms of the realisation of the rights of autistic people in comparison to other people with disability.

Systemic and structural advocacy plays an important role in aligning government policy and program design with the needs and expectations of autistic people. There is a clear role for a co-ordinated voice that brings together autistic organisations around the nation to identify systemic issues and inform the Commonwealth Government on policy and program development. This should be complemented by a properly funded peak body that represents autism organisations and works within the Disability Representative Organisation landscape.

³ National Autistic Society, 2003. *Autism: The Demand for Advocacy*. Available at: <https://www.scie-socialcareonline.org.uk/autism-the-demand-for-advocacy/r/a11G00000017ykcIAA>

RECOMMENDATIONS:

- Fund user-led, autism specific advocacy services (individual and systemic) through transparent and open tender processes.
- Support the capacity and capacity building activities of autism specific advocacy services to operate nationally, in parallel with generalist disability advocacy services.
- Develop a nationally consistent approach to advocacy, with clear and agreed roles for the Commonwealth Government and the States and Territories, built on an ongoing and consistent funding model.
- Ensure funding growth is applied to advocacy programs to maintain pace with the increased demands caused by the NDIS.

Amaze stands ready to assist

Please contact me by email at Nicole.rees@amaze.org.au if you have any questions or would like further information. We would also be pleased to attend any future public hearings on these matters.

Yours sincerely,



Nicole Rees

Deputy CEO | Executive Manager, Policy & Advocacy.