

## National Disability Advocacy Framework 2022-25 Submission

18th of June, 2022

Thank you for the opportunity to comment on the aforementioned framework. Communication Rights Australia has provided advocacy support to people with disabilities who communicate using little or no speech for over three decades. As such, we have seen many changes to advocacy services during this time, none more detrimental to people with disabilities than in recent years. We hope that this consultation process will shed light on some of these issues, and contribute to positive change. Furthermore, we welcome the opportunity to talk further about the issues below and would love to be a part of change which affords people with disabilities the right to more equitable and accessible advocacy services in future.

### 1. Principles.

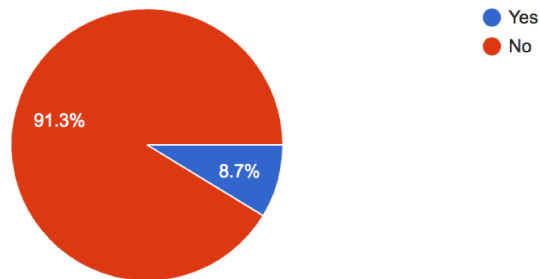
*1.1 Presumption of rights and capacity: Children and young people with disability have the right to participate, in whatever capacity, in decisions that impact on their lives.*

Many of the children and young people that we interact with describe not being able to participate in decisions which affect their lives, due to not being taught a functional communication method, and therefore relying on appropriate advocacy support, which is not available. Specifically, there is a lack of advocacy to support children and young people with disabilities who communicate using little or no speech. Prior to 2019, Communication Rights Australia was one of the only advocacy organisations operating within Australia which provided this service. However due to changes in the way advocacy support was funded, we were no longer able to provide this service. Consequently, we are currently forced to turn people away every week, who require specialist advocacy support which meets their unique communication needs. A recent survey we undertook with people with disabilities who communicate using little or no speech and their families, demonstrates the gap currently not being addressed by advocacy services across Australia (see below).

6. Did the advocacy service you accessed meet your or your family members communication needs?



23 responses



Survey comments:

*"There were no advocacy organisations to help us in our unique situation"*

*"[Advocacy services were] Either not available at the time we needed it or the advocates we had just did not have the skills to advocate- which just ended being a waste of time"*

*1.2 Access to Supports: Facilitating effective and appropriate communication for people with disability is an essential component of disability advocacy.*

Whilst we fully support this principle, we would like to point out that it will only prove successful if more specialist advocacy is funded and monitored for adequacy. Far too many of the people we speak to with a disability have been unable to access advocacy because services provided failed to meet their communication needs. The current National Disability Advocacy program funds a set amount of advocacy services on a reoccurring basis every three years. Yet, it is not clear how these services are monitored to ensure that the needs of people with disabilities who communicate using little or no speech are being met. The following quotes demonstrate the views of people with high communication support needs and their family members, in relation to the adequacy of the advocacy services they have received.

*"This is a very, very, specialised area. It's CCN/CSN - Complex Communication Needs/Complex Support Needs, that requires individual experts with particular training in AAC and knowledge, which none of the advocacy organisation had across Victoria".*

*"Would definitely appreciate any kind of advocacy but one that could understand and advocate for my son as he is non-verbal but is often dismissed as "just" another child with autism or the non-verbal aspect/needs are overlooked".*

*1.3 Safeguards: Individuals are supported to identify and understand when they have been subject to violence, abuse, neglect and exploitation and to understand what actions they can take in response to what they have experienced.*

At present, Australian advocacy services predominantly operate on a system of self reliance, whereby people with disabilities seek them out as and when they need them. In the past,

advocacy services have been able to engage with communities and do more proactive work aimed at raising awareness about issues such as recognising violence, abuse, neglect and exploitation. However, at present, restrictions in funding and the fact that there appears to be no specific advocacy service working with people with high communication needs, makes proactive awareness raising and engagement work impossible. If this principle is to be realised in action, consideration should be given to investing in more funding for specialised advocacy services to provide education and awareness raising services. Furthermore, currently due to increased demand for advocacy services which cannot be met, greater advocacy support is needed to carry out this work. Currently there are long wait lists for assistance from most if not all advocacy agencies, limiting their work only to urgent and immediate issues.

*“There were waiting lists everywhere, as long as 6 to 12 months or longer. The advocates weren't specialised in AAC, or have a basic understanding of our Childs right to communicate using their AAC”*

*“None [advocacy services] available/ long wait lists/ none well versed in AAC use”*

*“Advocacy agencies have no capacity”*

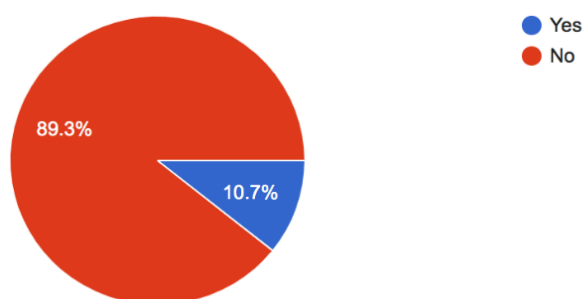
## 2. Outcomes

2.1 Regardless of where they live, people with disability can access quality and independent advocacy support.

As per point 1.3, currently there is a real need for more advocacy services, particularly those which specialise in supporting people with high communication support needs. There are long wait lists and many people who took part in the survey conducted by Communication Rights Australia this year described frustration with the lack of specialist advocacy support available to them.

4. If you answered yes to question 3, were you able to access advocacy support easily?

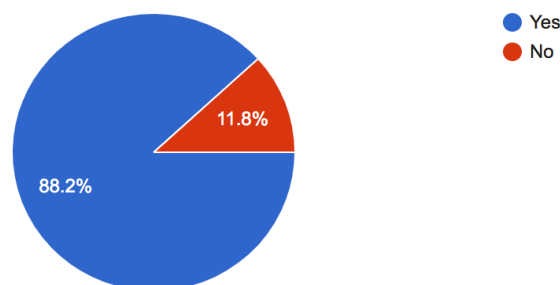
28 responses



In order for this outcome to be realised, investment needs to be made towards increasing the amount of advocacy services available, particularly to people with high communication support needs, as survey responses below illustrate.

8. Would it be helpful for you or your family member to access advocacy which specialised in supporting people who communicate with little or no speech (e.g., via augmentative and alternative communication)?

34 responses



2.2 People with disability have a range of ways to express their views and wishes about supports and services, play an active role in working out how things will improve, and can access a complaints mechanism and independent support and advice when providing feedback or making a complaint in relation to the supports and services they purchase or engage.

As per the previous points, people with disabilities who communicate using little or no speech have limited opportunity to access advocacy services which meet their needs. More specialist advocacy services with expertise in supporting people with disabilities with high communication support needs need to be funded if this outcome is to be realised.

## Summary

In summary, Communication Rights Australia welcomes the opportunity to discuss the issues raised in this submission, particularly in relation to the lack of specialist advocacy services which are available to support people with disabilities with high communication support needs. Communication Rights has been advocating for funding to resume individual advocacy services for over three years, but due to the manner in which the current National Disability Advocacy Program is funded, has had no platform within which to be heard on this issue. Funding for individual advocacy appears to be granted to the same organisations on a three yearly cycle, with little information available about their adequacy in relation to supporting people with high communication support needs. The data Communication Rights has received via survey and anecdotally via email, suggests that advocacy services are in limited supply for people with disabilities in Australia, and even more so for people with high communication support needs. Consequently, whilst we as an organisation fully support the principles and outcomes of the National Disability Advocacy Framework, we would like attention to be paid to how it is realised. In particular, we would like more attention to be placed on monitoring advocacy services to determine how adequately they are meeting the

needs of people with high communication support needs. Furthermore, we would like to see more funding allocated to the provision of advocacy services, in particular, specialist advocacy services with specific expertise in supporting people who communicate using little or no speech.

We thank you for the opportunity to comment on the National Disability Advocacy Framework, and hope to be a part of future conversations about how it is realised.

Sincerely

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