

family

A D V O C A C Y

**Submission to the Department of Social Services (DSS) on
the National Disability Advocacy Framework (NDAF)
2022-25**

Cecile Sullivan Elder
Executive Officer, Family Advocacy
cecile@family-advocacy.com

Leanne Varga
Systemic Advocacy and Campaigns Manager
leanne@family-advocacy.com

Family Advocacy
(02) 9869 0866
Suite 704, 88-90 George Street,
Hornsby, NSW 2077, Australia

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Acknowledgement:

Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

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Summary of recommendations

Recommendation 1

The National Disability Advocacy Framework (NDAF) must be aligned with the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) in all areas.

Recommendation 2

The “Definitions” section be expanded to include:

- **Family advocacy:** supports families to advocate with or on behalf of their family member with disability
- **Citizen advocacy:** an ordinary citizen is matched up and takes up the advocacy issue with and on behalf of a person with disability.

Recommendation 3

Refer to Rights and Interests (not just rights) throughout the National Disability Advocacy Framework.

Recommendation 4

That the Department of Social Services (DSS) set up a working party to undertake an in-depth analysis to ensure alignment with all of the legal and policy instruments that underpin the NDAF with the Safety Targeted Action Plan (TAP) to close the gap between policy and practice.

Recommendation 5

Under Presumption of Rights and Capacity,

Add:

“All people have the right to an inclusive education”

“All people have access to secure, stable and fairly paid work as compared to all Australians, with opportunities for advancement and progression.”

And alter:

“Children and young people with disability have the right to participate, in whatever capacity, in decisions that impact on their lives, *and that their views be given due weight in accordance with the age and maturity of the child.*”

“Adults with disability are presumed to have capacity to make and take part in decisions affecting all aspects of their life, *with whatever supports are needed to build this capacity.*”

Recommendation 6

Ensure Co-design is genuine.

Recommendation 7

Under Outcomes, alter:

Regardless of where they live, people with disability can access quality, independent and impartial advocacy support for their whole life.

Recommendation 8

Re-evaluate how the effectiveness of advocacy agencies are measured in consultation with the advocacy sector.

Recommendation 9

Under Responsibilities, Reform and Policy Directions:

Add: Enhance and improve high quality disability advocacy development.

And alter:

Building awareness across the disability sector and the community of the rights and interests of people with disability and the importance of disability advocacy.

The collection, use, and public reporting of evidence based data for administration and planning of disability advocacy and improvement of services systems.

About Family Advocacy

Family Advocacy is a community based, state-wide disability advocacy agency which promotes and defends the rights and interests of children and adults who have developmental disability¹ across NSW.

The work that Family Advocacy undertakes falls into three main areas:

- Statewide Advocacy-advice and advocacy information for individuals
- Advocacy development for family members, friends and allies of people with developmental disability
- Systemic Advocacy

We support families to advocate with and on behalf of people with disability from a wide range of socioeconomic backgrounds, First Nations people, culturally and linguistically diverse people, and people from metropolitan, rural and remote areas. Some of the areas we provide advocacy support include early childhood education, education, employment, housing, guardianship and NDIS.

The majority of our Management Committee members and staff are parents or family members of people with developmental disability. This intentional foundational structure enables the organisation to be well versed in the 'lived experience' of disability including the important issues and barriers that present themselves in the lives of their family members with disability.

Family Advocacy was founded to fulfill a need for advocacy development, so that family members could conduct the most potent and effective advocacy possible, with and on behalf of, people with developmental disability. We highlight that this type of advocacy is freely given by the family member but does require investment in the family member to build their advocacy capacity.

Since its inception over 30 years ago, Family Advocacy has been involved in multiple evaluations and reviews of both State and Federally funding advocacy programs. More recently, we provided a detailed [submission](#) for a NSW Review, which we recommend be read as it covers many of the important considerations required for the NDAF to provide a robust, independent and impartial, responsive, effective, sustainable, secure and equitable system of advocacy for people with a disability.

¹ Developmental disability is a disability that occurs in the developmental period of a person's life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability

1. Do you believe the new NDAF encompasses your vision of advocacy? If not, what changes are required?

Family Advocacy welcomes the opportunity to provide a submission to the DSS in response to the draft “NDAF” consultation. For the most part, we support the NDAF vision of advocacy. We applaud any attempt by the Government to have a process that has at its core the genuine desire to strengthen the provision of advocacy in Australia so that it provides strong, independent social advocacy, with and for, people with disability. We are pleased with and agree with the DSS, in that **the NDAF is aligned with the UNCRPD in all areas**. However, we do have some concerns and we ask that the DSS take heed of them and adopt our recommendations.

From our perspective, we submit that an absolutely essential piece of the NDAF is for the DSS to **recognise and support “family” as the agents of positive social change**, to build their capacity to advocate to have skills, knowledge and confidence in order to ensure they have high expectations and a strong inclusive vision for the person in their life with disability. Throughout the submission, we share examples we hear directly from parents of people with disability.

Definitions

One area of concern is the omission but essential need to **add the Family Advocacy model**. Whilst we acknowledge the definition of Individual Advocacy as a “one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer, to prevent or address instances of unfair treatment or abuse” has attempted to refer to a family member, there is so much more to the family advocacy model that we submit it requires its own stand-alone definition for the reasons outlined below.

Add Family Advocacy model

By way of explanation, **advocacy undertaken by families** is the most significant and plentiful form of advocacy that exists, as families are advocating for their family member, in some form or another, usually required from birth. Children cannot advocate for themselves and nor can many people with that may experience significant impairment. The majority of people with disability in NSW that have their issues taken up are represented by a parent or family member.

Informal advocacy undertaken by families of people with disability provides the greatest potential for advocacy to be done by people who will be around in the long term, that have the closest relationship to the person and usually hold the interests of the person at the heart of the advocacy efforts. In many cases family advocacy is undertaken when their family member with disability experiences limitations in

cognitive understanding, has limited decision making competencies and may not be able to express their own interests, needs or rights in a multitude of situations. It is usually the family that first identifies a significant issue in their family member's life that needs urgent attention.

In many cases, where advocacy is required and the family member with disability has identified a significant issue or barrier, the person may not be able to address the issue without significant support of the family unit. Therefore, providing advocacy advice and advocacy development to this group forms a critical component to protecting and safeguarding vulnerable citizens with disability.

Informal advocacy undertaken by families is both cost effective and provides an ongoing safeguard for the person with disability. Relying on professional (paid) advocacy to take up important issues as they arise in a person's life, will always be fraught as there will never be enough professional advocates to deal with the number of people needing advocacy. There is also the risk of the easy and quick issues being dealt with in a system where little professional advocacy is available, simply as a means to get through the numbers. This is problematic as we know that many advocacy issues facing people who are extremely vulnerable and marginalised, can take years to reach any real conclusion.

A contemporary example of the recognition of the legitimacy of family, friends and allies in the life of a person with disability, is the number of people now acting as 'nominee' for children and adults within National Disability Insurance Scheme (NDIS). Advocacy or advocacy related activities are undertaken on behalf of the person, when dealing with the NDIS. They are representing the interests of the child or adult with disability ('by whom' is the advocacy being conducted and 'for whom' is the advocacy being conducted), putting forward the case for necessary supports (the 'what' that is being advocated for), by attending meetings, writing letters, providing reports from others, making phone calls, informing themselves via research and talking to others (the 'how' advocacy is being done).

The families' experiences we hear highlight the importance of the DSS recognising that the family is the natural authority for their family member and they are best placed to be the decision supporter for a significant cohort of people with developmental disability.² Families ought to be recognised as having credibility and experience in understanding the impact of their family member's disability has on their everyday life, as well as the most optimal support arrangements, the ability to challenge stereotypes, and provide the proper decision making assistance which place the person with the disability in the "driver's seat". Indeed, the acknowledgement and respect of the role of family in the lives of people with

² <https://www.family-advocacy.com/assets/Uploads/Downloadables/453f2744d5/10753-The-Natural-Authority-of-Families-MKendrick-CT06.pdf>

disability is one of the general principles listed to guide the actions of the National Disability Insurance Agency.

In regards to a person with developmental disability, it is most important to have a family member involved and present in any meeting, using supported decision making, as in many cases, a tremendous amount of support will be needed in a delicate and respectful way.³

In the common scenario where the service sector dominates the life of a person with disability, it is important to arm the family member in order that they may be able to rebalance the power dynamic. Also, other informal effective decision support structures such as circles of support and microboards are more often than not, set up by the family.

Impact of family advocacy model on the person with disability's life and their family

Below is some of the input we received from families when we did a survey in 2020, when NSW disability advocacy services were in danger of losing funding from the state government. This is what families said when asked what would be the impact on their day to day life if we were not able to provide our advocacy services.

I use the advocacy skills I have learnt over the years from Family Advocacy almost every day of my life as I'm the main person in my son and sister's life who manages all their day to day supports.

We no longer live in NSW but for the past 24 years have had contact with Family Advocacy. They were an integral part of the successful advocacy for my son to enter mainstream education at the age of 5 in a NSW school. They were a guide and information source for developing the direction our family took in framing the inclusive life our son has enjoyed since we first met them when he was 3 years old. The success of their advocacy can be witnessed in the way his life has evolved. Without them our son would have led a less meaningful life, instead of the one, that the vision Family Advocacy inspired, is the case today.

³ We do acknowledge the view that in some cases, the family can be the cause of neglect, abuse, violence and exploitation and make decisions which are in their own interests rather than what is in the best interests for the person with disability.

As a parent it is often difficult to manage the day to day needs of your child - add to that needing to plan for the future, fight for funding and against discrimination and exclusion. Family Advocacy has been a "go to" for me for many years. It is important to be able to access information and guidance from an informed and objective disability service whose interests lie with people with disabilities.

Working with Family Advocacy has not only enabled us to achieve fairness it has also had a stabilising effect on our family. Family Advocacy know their stuff and when I ring them with an issue they are able to advise me straight away what our entitlements are and how to achieve them through positive interactions with the school. I have been saved hundreds of hours of research, I have a confidence that I know where I can get the right answer and I have the encouragement that I am not in this alone and that we are going to be able to find a positive resolution to the situation. I am glad for the uplift I receive as otherwise life can seem very daunting.

Family Advocacy gave us a voice when we had immense problems with my son's education in NSW. They supported us with information, contacts and public discussions. As a family fighting for equal education rights for our son we felt very much like Adam and Goliath trying time get the government to help or support us. Family advocacy really gave us a voice.

Family Advocacy is like our brains trust. We get to tap into the collective lived experience of people with disability and their families who have faced similar challenges to us.

These quotes from families illustrate it is almost guaranteed that issues requiring advocacy will continually emerge for their family members with disability. As families' competencies in advocating and understanding systems develop, we have noted a reduction in the contact with our organisation over time, hence minimising the reliance on formal advocacy supports. These same families may reconnect with our organisation when they come into contact with another system or barrier that they are unfamiliar with and the process starts again.

Family Advocacy has spent many years building the advocacy competencies of families and has many examples of how this advocacy leadership development has created safer and more optimum arrangements for many people with disability. This also extends to the impact that families have had in creating systems change across NSW and also across the country.

Accordingly, we recommend that the "Definitions" section be expanded to include:

Family advocacy: supports families to advocate with or on behalf of their family member with disability

Add Citizen Advocacy model

For whatever reason, where there is no family or they do not live locally, to avoid a person “slipping through the cracks”, the citizen advocacy model⁴ exists, particularly for people with developmental disability. We do not claim to be experts in this model but suggest the DSS explore it further. Citizen advocates and proteges (the person with disability) are recruited, matched and supported by the staff of the Citizen Advocacy office or program. Paid staff are required to recruit, match and support otherwise it would not happen. Without it, a vulnerable person who is living within the confines of a service system is completely exposed to the vagaries of that service system and its ever changing policies, agenda and identities. In its 2001 paper, *Advocacy for NSW A Critique of Government process and a way forward*, the Disability Safeguards Coalition stated:

Many people with disability, particularly people with developmental disability, have no support and cannot access services designed to support them on an individual basis. Many do not understand the purpose of individual advocacy and how they could personally benefit. They have no-one to argue for them and are too vulnerable to advocate for themselves.

Many advocates have been faithful companions for decades and saved the person with disability from terrible situations, often saved their lives and sometimes on repeated occasions. We believe Citizen advocacy ought to be listed as separate advocacy to ensure it receives adequate attention and funding.

Accordingly, we recommend the “Definitions” section be expanded to include:

- **Citizen advocacy:** an ordinary citizen is matched up and takes up the advocacy issue with and on behalf of a person with disability

⁴ <https://citizenadvocacytrust.com.au/what-is-citizen-advocacy/what-is-the-citizen-advocacy-model/>

2. Are the principles of the NDAF appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

Principles for Advocacy

Family Advocacy asserts that Disability Advocacy must sit within a framework that ensures:

- a shared understanding of the need for advocacy
- an absolute recognition of the heightened vulnerability of people with disability and that this will occur over their life span
- a commitment to the values and principles that underpin social advocacy
- a commitment to human rights and social justice platforms on which this framework rests.
- Accountable to people with disability, their families and other relevant stakeholders, including Government
- Clear about what does and does not constitute advocacy
- Protecting and promoting the human, legal and civil rights of people with disability
- Enabling people with disability to access appropriate supports and services that maximise independence, autonomy, productivity and inclusion.
- Disability Advocacy must be proactive in its approach⁵
- Disability Advocacy involves taking positive, ethical action on behalf of a person or group⁶
- Disability Advocacy operates from a clear values base of social justice⁷
- Finds a balance between rights, choice, the dignity of risk and what is in the best interests of the person with disability.

Advocacy services providers:

- Should be resourced to deliver responsive, timely, competent **advocacy related** supports and services
- Should be completely independent from disability service provision ie services that provide any form of accommodation, day programs, group activities, employment support, plan management, support coordination or other similar service function

⁵ Proceedings of the National Advocacy Workshop, Principles, Strategies & Effectiveness, June 1994, p. 1

⁶ Dyke, J., Towards Principled Evaluation of Advocacy – A Discussion Paper, March 2000, p. 12

⁷ Dyke, J., Towards Principled Evaluation of Advocacy – A Discussion Paper, March 2000, p. 14

- should be free to the user of the advocacy service.

With these general principles in mind, we recommend the following considerations and alterations:

Refer to Rights and Interests (not just rights)

All throughout the NDAF, there are references only to rights but we recommend “and interests” needs to be added to this. There is a fine balance between allowing a person with disability to have the dignity of risk and make their own choices versus having choice at the expense of what is in their best interests.

Therefore, we recommend the following alterations to NDAF which are in italics and underlined:

Introduction

Disability Advocacy supports people with disability by ensuring their rights and interests are maintained.....The Strategy recognises advocacy helps safeguard people’s rights and interestsThis Outcome Area aims to ensure ‘the rights and interests of people with disability are promoted, upheld and protected.....

Rationale

Advocacy provides people with disability support and capacity to make and participate in decisions that impact their lives to ensure their rights and interests are promoted and protected.....

The Framework is underpinned by a person-centred and rights based approach whereby policies and programs are designed to respond to individual needs and aspirations, and reflect the rights and interests of people with disability.

Access to Supports

The will, preferences and rights and interests of people with disability who may require decision-making supports, must direct the decisions that affect their lives.

Safeguards

The rights and interests of people with disability are promoted, upheld and protected, and people with disability feel safe and enjoy equality before the law.

Responsibilities, Reform and Policy Directions

Building awareness across the disability sector and the community of the rights and interests of people with disability and the importance of disability advocacy.

Implementation

Under this heading, it states that the NDAF will be supported by a disability advocacy work plan will align with the Strategy's Targeted Action Plans (TAP). We are wanting clarity around how the NDAF ties in with the TAP? This consultation is only consulting on the NDAF but it seems we need to discuss the TAP as to how it aligns. As we all know, the devil is always in the detail.

There are some concerns in the NSW list within the TAP. For example, the NDIS Quality and Safeguards Commission is not viewed in a positive light by the advocacy sector as being effective. The TAP does not state that segregated schools will be dismantled and merged into an inclusive education system in accordance with the UNCRPD. The 'behaviour support market' is certainly steeped in the medical model and requires a values thinking paradigm shift.

On this basis, **we recommend an in depth analysis is required, perhaps with a working group made up of stakeholders, to ensure that all of the legislative and policy instruments that underpin the NDAF**, the United Nations Convention on the Rights of Persons with Disabilities, Disability Discrimination Act 1992, Australia's Disability Strategy 2021-2031, Closing the Gap National Agreement, NDIS Quality and Safeguarding Framework, and the Information Linkages and Capacity Building program **are all aligning together with the TAP**. If the deeper thinking is placed around how all of these instruments intersect with the TAP in a practical sense so the end user, the person with disability, receives the intended benefit, and avoids any unintended consequences, then this will **help close the gap between policy and practice**.

Presumption of Rights and Capacity

We strongly recommend the following additions:

"All people have the right to an inclusive education"

(In accordance with General Comment No.4 of Article 24 UNCRPD, Article 28 and of the United Nations Convention on the Rights of the Child (CRC))

“All people have access to secure, stable and fairly paid work as compared to all Australians, with opportunities for advancement and progression.”

(in accordance with Article 27 of the UNCRPD)

We also suggest the following alterations:

“Children and young people with disability have the right to participate, in whatever capacity, in decisions that impact on their lives, and that their views be given due weight in accordance with the age and maturity of the child.”

(in accordance with Article 12 UNCRC)

and

“Adults with disability are presumed to have capacity to make and take part in decisions affecting all aspects of their life, with whatever supports are needed to build this capacity.”

Everyone has a right to participate in decisions that affect their own life. Informed choice requires the opportunity to make a choice and the capacity to do so. However, **people with developmental disability** need to be given not only the opportunity to make decisions but also **require the investment in their capacity** to do so. Good decisions are made when people receive good support with a clear understanding around the nuances involved for a person with a developmental disability. For the reasons outlined above about family being the expert and providing the most potent and effective advocacy, we would recommend that investment be made in the family to be able to build this decision making capacity in the person with a developmental disability.

Person-centred approach and genuine co-design

Putting the person with disability at the centre of the NDAF is a critical component. Central to this, is to not pay lip service to the “Nothing about us, without us” mantra. The term co-design has become a popular and misused phrase which often, refers to a person with disability being asked for an opinion on a proposed framework that has already been designed or written and can be very prescriptive with little room to suggest new ideas. We wish to ensure that the DSS apply co-design for policy and reform in the true sense to include not just design at the early stage but also where relevant co-implementation, co-monitoring, and co-review. In other words, providing “shared power” or a true partnership with people that have a lived experience of disability, which includes their family and when relevant, their representative organisations.

3. Are the outcomes of the NDAF clear and achievable? Should different ones be included? If so, what should be included?

Under Outcomes, we recommend the following alteration which is underlined and in italics:

Outcomes

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

Advocacy needs to be independent and impartial

Over many years, one of the strongest messages from the advocacy movement in NSW and other states is about the need to minimise and even eliminate a wide variety of conflicts of interest in order for advocacy to be as effective as possible. The most vigorous and emphatic advocacy has undoubtedly been that which is located in agencies which are autonomous from, and separate to, service providers and organisations which serve the interests of other parties (such as support services - support coordinators, Local Area Coordinators), .

Direct service providers, by their very nature, meet the needs of many stakeholders and there are many compelling reasons why advocacy from within a human service is compromised, conflicted and weak:

- Workers inside an organisation are expected to put the organisation's interest first
- Workers put themselves at personal risk if they oppose the organisation that employs them
- Advocacy is often misinterpreted as disrespectful of authority
- Advocacy may separate a human service worker from the support of colleagues
- There are usually few allies within the organisation
- It is very hard to get above the culture of an organisation
- Organisations usually have a cost benefit attached to direct service provision so the interests of the person are often, and sometimes unconsciously trumped in relation to potential gain
- Relational conflicts can and will be experienced with peer organisations that also offer direct service provision which can dilute the potency of the advocacy
- An organisation may be placed in a position of advocated against its own interests

Essentially, anyone can be an advocate, provided they have the skills needed and that they do not have a conflict of interest. Conflicts of interest occur when an advocate has something at stake (an

interest) that is different from, and in competition with, the interests or wishes of the cause or person that they are advocating for.

Conflict of interest is a most crucial point. Bearing in mind that the word advocacy is currently being attributed to a large number of activities and agencies, advocacy efforts are in danger of being confused or weakened.⁸

In summarising this point it is important to identify that often, when reform of this kind occurs, it is usually undertaken by considering other relevant movements around the country. Often, however, such movements may not provide the best example of this. A recent example pertaining to 'conflict of interest' has occurred in several of areas relevant to the NDIS roll out. Decisions have been made within the NDIA concerning the management of 'conflicts' which have knowingly increased conflicts in a variety of key roles and partner organisations. This has clearly been done to accommodate the roll out rate and ensure positions required are in place to accommodate this. There have been compromises made to the impartial nature of these roles. Undoubtedly, these compromises are often made in a variety of agencies and government structures. However, we firmly believe that these types of compromises do not belong in the advocacy sector and that sustainability of agencies and the unmet needs experienced by people with disability should be addressed elsewhere. Advocacy agencies are uniquely placed and require 'an arm's length approach' to ensure that the clarity of the work remains clear.

Family Advocacy are hearing more examples whereby therapists are attending more meetings with families as support. This can be of benefit if there is a current or ongoing issue with a child – speech, occupational therapy, or a behavioural therapist to support with goal settings or strategies – but not on an ongoing basis – with valuable NDIS funding being used up to prepare and attend these meetings and many families reporting that the therapist is attending to just be the support person in the meeting – again replacing the parent as the expert and now the therapist as the expert in the room. Therapists also have their own agendas to continue receiving NDIS funding to stay in business. They are not mediators, advocates or negotiators – they have no place in meetings with schools if not related to therapy goals/strategies.

Important to be clear of what advocacy is and is not

Further to the above discussion, for advocacy to be truly impartial, and as reminder for us all, it is useful to identify things that are worthwhile endeavours AND what *does not* constitute advocacy action.

⁸ Advocacy for NSW A critique of Government process and a way forward. The Disability Safeguards Coalition, May 2001.

For example:

Advocacy funds should not be used for:

- Direct human service provision (*as not on the side of the vulnerable person or group, significantly flawed in terms of meeting fundamental needs, accountable to others, and have loyalties to different parties*)
- Government advisory bodies (*accountable to the Minister or Department, not to people with disability*)
- Counselling (*relies on the client to act to resolve a matter, whereby advocacy relies on the party being advocated against to act*)
- Mediation and conciliation (*cannot be on the side of the most vulnerable person and, in fact, in mediation and conciliation, independent advocacy could be needed by the less powerful person - taking sides has no place in mediation. It is therefore not advocacy*)
- Complaints handling (*often located in a human service framework only and often resulting in mediation and conciliation [refer above], mostly short term in nature*)
- Case management (*not on the side of the vulnerable person or group but more an agent of the human service industry*)
- Guardianship (*substitute legal decision-making where people are unable to make decisions themselves due to the nature of their disability; decisions taken are not necessarily concerned with fundamental needs and often people require strong advocacy when others are considering seeking guardianship*)
- Support groups (*not on the side of the vulnerable person or group, not accountable to them, nor particularly vigorous*)
- Research (*in and of itself*)
- Friendship, buddy services

A very recent example of where it becomes problematic when not having this clarity of what advocacy is and is not, is the [Ask Izzy website](#). There are quite a number of problems with regards to how this website is set up for Disability Advocacy, and we are very concerned that the most vulnerable cannot get access to the advocacy they need. Accordingly, this needs to be addressed urgently, in consultation with the advocacy sector.

There are many statutory and voluntary agencies, therefore, that are important in the lives of people with disability and their families but that cannot perform advocacy. In fact, advocacy on behalf of people

with disability should expect at times, to be at odds with the views of such bodies and agencies, as well as those of members of the broader community.

Agencies that cannot be advocates:

- **Government Advisory bodies**, such as the Disability Council of NSW (a government advisory body, members appointed by the Minister and not accountable to and with no mandate from people with disability)
- **The NSW Ombudsman** (Statutory body, functions are enshrined in law and without any legally enshrined advocacy function and not accountable to and with no mandate from people with disability)
- **Office of the Public Guardian** (Statutory body, functions are enshrined in law and without any legally enshrined advocacy function and not accountable to and with no mandate from people with disability)
- **Disability Service Providers** (have conflicts of interest, cannot be impartial, and are not accountable to and with no mandate from people with disability)
- Organisations that promote the **interests of parents or carers** rather than the interests of the person with disability, as opposed to organisations that support families to advocate for their family member with disability (such as Family Advocacy).

While these agencies have important and legitimate functions, by contrast advocacy is principally directed to protect, promote and defend the rights, needs and interests of individuals or groups of individuals, wherever it is required. This may include being in contradiction to the views of members of the community, generic services, specialist non-government and government service providers, other government agencies and even peak bodies and Government Advisory Councils.

Outcomes Measurement

As an advocacy organisation who will no doubt, be held accountable to these outcome measures, there are a few important points to raise at the outset:

- Accountability relates to who a group is answerable to (for example, for an advocacy agency it would be people with disability, members, other significant stakeholders, funding bodies).
- Evaluation determines whether the work done by the agency is appropriate, effective and of quality.

These two principles are distinct from each other and should be differentiated between. For too long the focus has been heavily slanted towards quantity to the exclusion of the importance of quality.

We submit that the current outcomes measures do not work well through the DEX system, and needs an overhaul with intensive consultation from the advocacy sector. For a number of years, the Commonwealth Government has relied on a monitoring system dependent on output and outcome measures. This has proved very problematic as it has been clear to all involved that this is not an effective way to monitor and evaluate advocacy.

Cross and Zeni identify a number of issues with this type of system:

- *Advocacy does not necessarily result in clear outcomes*
- *It can take many years of advocacy effort before a result is evident*
- *An outcome focus risks orienting groups towards responding to cases where there will be an easily achieved and assessable outcome*
- *Outcomes determine the number of people, but not the amount of work, nor do they indicate the quality or nature of the outcome*
- *Advocacy action that is unsuccessful today, may well result in a positive outcome next year*
- *Often there is no clear causal link in advocacy where one can claim that X activity produced Y outcome.*⁹

The Government's approach of enumerating outputs and outcomes in easy-to-read tables does not provide a method of demonstrating effectiveness of advocacy efforts. The key issue is that outputs, outcomes and performance indicators taken in isolation from qualitative approaches cannot provide meaningful accountability. In addition, one of the potential key indicators - process - has not been identified and little or no work has gone into identifying how this could be measured.

Outputs, outcomes and performance indicators alone are relatively meaningless, as advocacy is seldom directly and solely responsible for outcomes - it can only influence them. Governments making decisions solely based on output and outcome measures has the potential to alter the nature of funded advocacy. This is, in part, because in order to get the necessary 'numbers' advocacy may be funded by addressing the 'quick and easy' issues rather than the more complex advocacy around the longer term and more 'difficult' issues.

⁹ Cross, J., & Zeni, L., *Safeguarding Advocacy for People with Disabilities in Australia*, 1993, p. 75.

Any outcome measuring framework should take into consideration the issues raised previously in this submission. Further to this, in our recent experience with adapting our reporting mechanisms to DSS we were required to undertake quite extensive recalibrations of our existing database to accommodate this. This was not taken into consideration by DSS and agencies had to 'foot this unexpected bill'. The impact of this created a significant blow out in the budget as well as extensive internal work to accommodate the new reporting process. Our case in point is that any changes that may occur to current collection of data should take into consideration the impacts that this may create internally for agencies including the potential added costs associated with these changes.

When considering the quality of services, a significant gap currently experienced within this domain is the ineffective evaluation of advocacy services. A current expectation from funders both State and Federal is that agencies undertake a third party evaluation that align with the National Disability Standards. These 'audits' also considers quality management systems within each agency and can cost as much as \$10,000 annually.

Our experience of this process is very poor in relation to not gaining meaningful insights into needed service improvements when considering bigger questions such as 'Is the organisation's work addressing the 'real needs' of people with disability and how can the work be strengthened to ensure this?'. Countless attempts by funders to ensure an effective audit process is in place have failed. Family Advocacy has looked internationally to gain these insights, as the current system does not provide the guidance for continuous improvement. An example of looking internationally recently involved connecting with 'experts' in the field of service provision (including advocacy) for people with disability to scope costs to undertake an evaluation. We decided not to proceed with this evaluation as it was too costly, however, it would have been vitally informative to the work of our organisation for a number of years to come. **It is evident that this component of measuring the effectiveness of advocacy agencies needs to be completely re-evaluated** and the possibility of seeking international guidance on how to undertake these forms of evaluations would serve the current review well.

It is important to mention that evaluations of some advocacy models are being undertaken well, particularly when considering the 'Citizen Advocacy'(CA) model. An extensive evaluation tool, 'The CAPE Manual', has been developed and is still currently being utilised within some existing CA programs both nationally and internationally. The CAPE was developed a number of years ago but remains current and is a sound tool that takes an extensive look at the many elements involved in delivering this model.

Due to its depth, it provides important insights needed to build the operational and delivery aspects of the agencies. This evaluation tool is undertaken in a 'peer review fashion' relying on a small group of people and can be relatively cost effective as much of the work is undertaken free of charge and on a cost reimbursement basis. It can be accomplished in this way as participating in the evaluation enables professional development to occur on behalf of the evaluators as there is a mix of experienced and novice evaluators on the team. Due to the nature of peer reviews there are multiple safeguards in place to attempt to minimise 'ill feelings', 'unprofessional responses' and concerns surrounding confidentiality. This is currently an optional evaluation for CA programs.

There is potential for a similar model of evaluation to be undertaken within the other models of advocacy and this would require some important consideration but would be possible. It would be very important to develop a sound evaluation tool that gave agencies depth in learning as well as safeguards and considerations concerning the use of a peer review mechanism. It could also act as a means for professional development across the sector.

Accordingly, we recommend the DSS:

Re-evaluate how the effectiveness of advocacy agencies are measured in consultation with the advocacy sector.

4. Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?

Under responsibilities, reform and policy, we recommend to Add:

Enhance and improve high quality disability advocacy development.

Within Individual advocacy there must be recognition of advocacy conducted by families and the importance of an advocacy development framework to support this.

"Advocacy development is those actions and processes that enlist the energy and commitment of individuals and groups in our community so that they choose to take a considered action called advocacy on behalf of and alongside people with disability" ¹⁰

¹⁰ Queensland Advocacy Development Project, *A Working Framework for Advocacy Development in Queensland*. March, 1996, p. 14.

Family Advocacy strongly encourages the formal recognition of Advocacy Development. However, for Advocacy Development to be undertaken effectively, there needs to be a clear and shared understanding of what Advocacy Development is and whose interests are to be taken up by those undergoing "advocacy development" training.

Family Advocacy contends that it is people with disability whose interests should be paramount here, and that any advocacy development must be focused on outcomes that improve the lives of people with disability. Otherwise, there will be great confusion in terms of whose interests receive primacy within any resulting advocacy action.

"Advocacy development is very much a journey during which the person or group becomes firmly grounded in advocacy principles, an understanding of the real life issues and vulnerability of people with disabilities and their families, and the vision of valued, inclusive lives for people with disabilities in their community." ¹¹

Some principles which could be used to guide Advocacy Development could include but not be limited to:

"Advocacy development:

- *is guided by a heightened sense of the vulnerabilities and needs of people with disability*
- *seeks out, supports and develops people who are (potential) advocates and who stand with/for people with disability*
- *encourages (potential) advocates to stand with people with disability who are vulnerable, against all that stops or denies people a life free from destruction, segregation and isolation*
- *encourages (potential) advocates to strive for the inclusion of people with disability in all spheres of life and society*
- *encourages and strives for better understanding within the advocacy community of advocacy principles, including the need for advocate and program independence, concern with fundamental needs, loyalty, minimised conflict of interest and vigour."* ¹²

Advocacy development will be required by people with disability, families and carers, citizen or volunteer advocates and for paid advocates themselves. A funding enhancement to cover the cost of

¹¹ Advocacy Plan Working Group, *The Development and Funding of Advocacy in Queensland*, August, 1994, p. 10.

¹² Queensland Advocacy Development Project, *A Working Framework for Advocacy Development in Queensland*. March, 1996, p. 18.

advocacy development activities is fundamental, otherwise current agencies will have to reduce the amount of formal, paid advocacy undertaken to free up funding for this development.

Advocacy development is a specialised area of advocacy, which requires a high level of expertise in processes that:

- draw people in
- teach the theory and principles of social advocacy
- identify and support advocacy leadership
- harness people's energy and passions
- develop a commitment to and shared vision about advocacy
- identify conflicts of interest
- critically examine the lives of people with disability.

Accordingly, we recommend the following responsibility be added to the NDAF:

- **Enhance and improve high quality disability advocacy development.**

And alter:

Building awareness across the disability sector and the community of the rights and interests of people with disability and the importance of disability advocacy.

As previously stated, the word “and interests” needs to be added after “rights”. Also, this will be strengthened by teaching about the history of devaluation of people with disability, the impact of the unconscious biases of society (such as seeing them as a burden or an object of pity) that leads to devaluation and consequently, to a heightened vulnerability to violence, abuse, neglect and exploitation.

The collection, use, and public reporting of evidence based data for administration and planning of disability advocacy and improvement of services systems.

Data must be transparent and so made accessible to the public.

5. Does the NDAF identify what is needed in the current and future disability environment? If not, what changes are required?

Mental health individual advocacy - There has been a dramatic change with a significant rise in the disability advocacy sector providing advocacy support to people with psychosocial disability. This has been a significant shift away from those whom advocacy supports have been provided historically. Consultation with the disability advocacy sector needs to occur going forward to ensure this marginalised group receives the support needed and that the sector is designed to ensure positive outcomes for people with disability.

Conclusion

We hope the DSS takes heed of our above concerns and adopts our recommendations. Importantly, we do not believe this consultation is exhausted with the reading of this submission. We would like to continue this discourse with the DSS and our family members. We invite the DSS to provide our family members with the opportunity to meet with you as it is a vital part of this particular consultation process.