Submission to Ageing and Disability Commission
NSW Disability Advocacy Review – Issues Paper

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18 October 2019

Preamble

Family Advocacy is a community based, state-wide disability advocacy agency which promotes and defends the interests, rights and needs of children and adults who have developmental disability[1] in NSW.

The majority of 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 fulfil a need for advocacy development in NSW, so that family members of people with developmental disability could conduct the most potent and effective advocacy possible.

Family Advocacy has been conducting advocacy advice, support and development as well as systems advocacy in NSW for over 28 years and has been involved in multiple evaluations and reviews of both State and Federally funding advocacy programs in this time. 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

Family Advocacy welcomes a process that has at its core the genuine desire to strengthen the provision of advocacy in NSW so that it provides strong, independent social advocacy for and to people with disability. It applauds any attempt by Government to ensure that organisations that are funded to provide advocacy to those most in need, actually do what they are funded to do.

Family Advocacy is keen to be part of a review which leads to the development of a funded advocacy program that is:

- Principled
- Coherent
- accountable to people with disability, their families and other relevant stakeholders, including Government
- clear about what does and does not constitute advocacy; and
- guided by a long-standing social advocacy framework eg. for whom, by whom, for what, against what and how done?

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, sometimes from birth. Children cannot advocate for themselves and nor can many people with cognitive impairment. The majority of people with disability in NSW that have their issues taken up are represented by a parent or family member.

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[1] Developmental disability includes any disability that arises within the developmental period and includes intellectual disability, cerebral palsy, Down Syndrome, spina bifida, autism and multiple disability.

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 identify 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 NSW 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' or the person responsible, 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 ongoing need for a strong advocacy sector in NSW is undisputed. As stated in the NSW Disability Advocacy Review Issues Paper, "Under the *NSW Disability Inclusion Act 2014*, NSW Government agencies continue to have a role to create a more inclusive community in which mainstream services and community facilities are accessible to people with disability to help them achieve their full potential. This includes **ensuring that the voices of people with disability are heard** when the Government makes decisions about supports and services that affect them – either as people with disability specifically, or as part of the broader NSW community." [2]

Additionally, the Productivity Commission's Report into the National Disability Agreement identifies confusion within Government at both State and Federal levels, as to whose responsibility it is to fund Advocacy. It states that "The exact supports to be provided through the National Disability Advocacy Program, ILC grants and NDIS plans at full scheme are yet to be fully clarified or established (although the Department of Social Services, through the Disability Reform Council's Senior Officers Working Group, is currently reviewing advocacy projects, policies and priorities (Commonwealth of Australia 2018a, p. 11)). As a result, much of the current State and Territory Government funding of disability advocacy appears to be

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[2] NSW Government Ageing and Disability Commission NSW Disability Advocacy Review, Issues Paper, September 2019, pg 4

operating on a ‘wait and see’ basis.”[3] Clearly this is not good enough and furthermore, this notion of ‘wait and see’ relies heavily on the notion that these systems, when fully established, will resolve the inherent discrimination that occurs for this group of people.

Given that Australia is a signatory of the United Nations Convention on the Rights of Persons with Disability (UNCRPD), people with disability in NSW require a clearer, more consistent commitment to the ongoing provision of strong, vigorous, independent advocacy support now and in the long-term. This should always form a foundational component of the NSW Government’s commitment to people with disability.

It is important to note that although we see this review as an opportunity to strengthen the NSW advocacy sector, it is being conducted at a time when there is no guarantee of funding for NSW advocacy services post June 2020. Before any steps are taken to reshape the current system, it is critical that the NSW government commit to an extension of the current funding agreements to enable the recommendations from your review to be considered and where applicable, adopted.

SOME PRINCIPLES THAT COULD BE APPLIED WHEN CONSIDERING A REVIEW OF DISABILITY ADVOCACY IN NSW

In conducting this Review, key principles should be developed that should underpin the Review recommendations, and the future shape of any disability advocacy services program. Some suggested principles that could be applicable are as follows:

Advocacy is an important element in:

- *Protecting and promoting the rights of people with disability.*
- *Enabling people with disability to determine what is in their own best interest.*
- *Enabling people with disability to access appropriate supports and services.*
- *Informing systemic responses to the needs and aspirations of people with disability.*
- *Enabling people with disability to take part in public debate and government decisions making that affects them.*

We agree with these principles and would also add:

- That the UNCRPD becomes a key operational focus and provide guiding principles within advocacy organisations.

Are these the right principles to apply?

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.

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[3] Productivity Commission Study Report, Review of the National Disability Agreement, January 2019, Box 3.12, pg 91

Therefore, two of the above-mentioned principles could be stronger:

- 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.

Are there any others?

Yes – the following:

- Disability Advocacy must be proactive in its approach[4]
- Disability Advocacy involves taking positive, ethical action on behalf of a person or group[5]
- Disability Advocacy operates from a clear values base of social justice.[6]

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.

PATTERNS OF NEED FOR PEOPLE WITH DISABILITY IN NSW

Are there changing patterns of need that should inform the future provision of advocacy services; for example, emerging disability related conditions, changing circumstances giving rise to new or different needs?

The landscape, including the many systems that sit within it, are constantly changing for people with disability, requiring ongoing monitoring, assessment and responses by the disability advocacy sector. A slight change in governmental policy for example can affect this group tremendously, leading to further disadvantage.

The introduction of the NDIS is still in its infancy. The NDIS provides support for around 10% of people with disability in NSW, with a restriction on people over 65 years of age who are not eligible for the scheme. The other 90% of people with disability which includes children, young people and older people continue to rely on mainstream and specialist service most often delivered by the NSW Government and associated agencies. Reports, such as the Productivity Commission's Inquiry into the National Disability Agreement released in 2019, identify significant 'interface' issues between the supports delivered through the NDIS and mainstream services such as health, housing, education.

In relation to the NDIS, there are many barriers that will continue to need to be addressed as people with disability learn about the scheme, seek to access it as well as create and implement their NDIS plans. Information, advocacy and representation for people with disability in NSW will be required over the long term. Interactions with disability service

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

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

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

providers also form a large component of this work, as many people with disability experience a heightened level of vulnerability due to the current changing service system and a newly emerging service system. Again this work of monitoring, assessment and response is critical to safeguarding and protecting the rights and interests of people with disability going forward and over the long term.

More broadly, the policy and service delivery areas for which NSW Government and its associated agencies are responsible continue to undergo review, reforms and improvement. Under the NSW Disability Inclusion Act 2014, the NSW Disability Inclusion Plan and government agency and local government Disability Inclusion Action Plans, review and implementation of plans must include consultation with people with disability and their representative organisations. This also involves the development of information and advocacy supports to navigate change.

A snapshot of policy reform areas that impact on people with disability includes, but is not limited to: health, mental health, early childhood education, school education, TAFE, transport, social housing (including the devolution the large institutions), planning and the built environment, sporting, recreation and cultural activities, access to justice, access to voting, violence prevention, child protection, out-of-home care, juvenile justice and the adult justice system, trustee and guardianship. Consideration of any one of these areas involves legislative, policy and practice frameworks that impact on people with disability and the need for better and improved approaches to realising the rights of people with disability.

Finally, we are beginning to work with people with disability who are engaging with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The Disability Royal Commission will go for three years and will investigate what has led to the widespread and systemic violence against people with disability including in the state of NSW. The roll-out of findings and recommendations from the Royal Commission will create the need for ongoing change and improvement on the way that NSW Government programs are delivered and will have considerable impact on advocacy organisations and their resources.

WHAT AREAS OF FOCUS, MECHANISMS AND KINDS OF ACTIVITIES COME UNDER THE BROAD HEADING OF 'ADVOCACY'?

Is it important to distinguish between different advocacy focus areas (e.g. information and referral, individual advocacy, group/systemic/representative advocacy) and different advocacy mechanisms (e.g. self-advocacy, campaigns, skills training, resource development)?

Because the needs of individuals are complex, there are many different 'forms' of advocacy required. No one kind of advocacy will provide 'the answer' nor will a 'one-stop' shop approach work towards reducing or removing the multitude of barriers experienced by people with disability.

Therefore, it is important to differentiate between the different forms and functions or mechanisms of advocacy.

Forms of Advocacy:

- **Individual Advocacy -** of which there are subsets:

  - self advocacy: people with disability advocating for themselves
  - family advocacy: parents or relatives advocating on a person's behalf with the support of advocacy advice, advocacy development strategies, information and referral
  - citizen advocacy: an ordinary citizen taking up the advocacy issue on behalf of a person with disability
  - paid, formal advocacy: advocacy conducted by paid advocates

- **Systemic Advocacy** - of which group or representative advocacy are subsets.
- **Legal Advocacy**

Each different form of advocacy uses different **advocacy mechanisms or strategies:**

Individual advocacy uses a combination of advocacy development (developing the person's advocacy skills), provides advocacy related advice and information provision, so that the person is knowledgeable about the issue at hand and referral when necessary.

It is important to note here that Family Advocacy would be very concerned if at the end of this review there was a move to increase 'professionalised advocacy', or advocacy that is conducted only by paid advocates, and to reduce funding from agencies committed to supporting unpaid, informal advocacy eg. Citizen Advocacy and advocacy agencies that provide advocacy advice and development for families. **We strongly recommend that is it necessary to increase and continue both forms of advocacy.**

When formal advocacy that focuses on *doing for*, is only utilised it also creates an environment whereby the remedy and reliance are only on support to do for others, instead of providing support to equip others to do for themselves. Further to this and when considering families, 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.

It has long been recognised within the advocacy arena that 'paid' advocacy has the potential to drive out unpaid or voluntary advocacy. This comes about for a number of reasons starting with the strongly held assumption within our culture that professional solutions are best. Instead of 'doing for', empowering people who are willing and well positioned tremendously bolsters the advocacy efforts and most importantly adds a vital layer of protection for people with disability.

The 'quick fix' mentality which is also rampant in our culture, can also mean that the easy, 'solvable' issues get attention by paid staff so that 'outcomes' can be produced whereas the more difficult, long-term issues that can have life-changing outcomes for a person, may be relegated to the 'too hard basket' and not be given the attention they rightly deserve.

Again, an advocacy sector that supports both formal and informal advocacy models is essential in ensuring that the vital layers of protection are in place across NSW and for the long term.

Systemic advocacy uses a combination of strategies such as: lobbying, running campaigns, holding public meetings, responding to Inquiries, State and Federal Submissions, meeting with and writing to those in positions of power to take up issues pertaining to law, policy and procedures, resource allocation and other decisions made by Government and other agencies, attendance at roundtable discussions, reference groups, consultations and a wide variety of stakeholder meetings.

Previously in NSW, there was a push to limit systemic advocacy to issues that “emerge from individual advocacy”. This is a very narrow and constraining view of the function of systems advocacy and places systems advocacy in a position of ***reactive*** advocacy only and does not allow for ***proactive*** advocacy.

It is common for agencies carrying out systemic advocacy to be aware of emerging issues that have the potential to impact profoundly on people with disability in the future, and which people with disability themselves may not be aware of. To be hobbled by a system that limits advocacy action only to those issues raised by individuals, completely undermines the function, intent and efficacy of systems advocacy and will significantly narrow the breadth of issues that could be taken up and importantly limits the progression.

One example of this was the extensive work undertaken by NSW advocacy organisations in relation to progressing the closure of large institutions in NSW. This issue was not necessarily identified through individual advocacy responses received across the state but was seen as a critical step that Government needed to take from a social justice perspective and a human rights framework. This is also an example of systems advocacy work that can be undertaken that may be at odds with some groups and in this case, some families.

Australia, like many countries often tends to think in isolation to what is occurring around the world and in many cases is behind many jurisdictions concerning the progression of the rights and living conditions of people with disability. It is the job of systemic advocacy organisations to keep track of this and to gather learnings from these countries concerning these progressions, make contacts with relevant agencies abroad and to then translate that to ‘our environment’ for possible development.

Systems advocacy should also operate as an “early warning system” so that actions are taken preventatively. This monitoring role requires an extensive network of contacts and information sources. Advocates focused on individual issues are unlikely to have the time, expertise or networks to facilitate this. Once a problem has arisen and is already impacting on people, it can be much harder to undo than if it had been prevented in the first place. Proactive systems advocacy is an essential element of any advocacy system; it must not be stymied by a narrow approach and should be guided through a human rights framework such as the Convention on the Rights of Persons with Disability (CRPD).

Also having a ‘systems view’ to identify and attempt to alleviate the multitude of issues experienced by people with disability is key to the systemic work undertaken. It is not uncommon for many mainstream and service systems to have within them many points of tension that significantly impact on the rights and interests of person with disability. It is a requirement of the systemic advocate therefore to pinpoint the ‘most appropriate’ point that will work towards alleviating the tensions more broadly, instead of attempting to address all the tensions that exist. As the latter approach would not lead to the necessary adjustments and most potent systems reform needed. This work can therefore occur over the longer term and in some case many years.

Interplay between individual advocacy and systemic advocacy

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.

Individual advocacy provides many people with the much needed support to prevent abuse, discrimination or negligent treatment and/or enable them to lead meaningful lives as contributing members of the community. Individual advocacy provides an avenue for people to access their rights. It can provide people with support and means to redress injustice on an individual basis, and is often personally empowering for the person who is seeking redress.

However, individual advocacy cannot change the structures and systems which determine the way that laws are written, government policy is determined and implemented, and the way that services are provided to groups of people.

Individual advocacy is most effective when located within a framework that recognises the need to continually critically evaluate our structures and systems and improve the way they serve the needs of individuals. Systemic advocacy serves to ensure that such a framework is in place.

Systems advocacy by its very nature is in conflict with government as advocates highlight the ways in which current arrangements lead to abuse, discrimination, negligent treatment, inhibit the achievement of rights or place barriers in the path of full inclusion of people with disability.[7]

For example, with knowledge that particular policies and practices of the Department of Education and Training prevent children and young people being fully included in the regular class of their local neighbourhood school, it would be ineffective to simply support the parent in negotiations at the level of the local school. It is far more sensible to seek to change the practice at the state level thereby obviating the need for advocacy support for many other local parents.[8]

Should any of the above focus area categories or definitions be added to or changed?

Yes; as we have discussed, 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

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[7] Advocacy for NSW A critique of Government process and a way forward. The Disability Safeguards Coalition, May 2001. Pg 26

[8] Advocacy for NSW A critique of Government process and a way forward. The Disability Safeguards Coalition, May 2001. Pg 17

"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".[9]

Family Advocacy strongly encourages the formal recognition of Advocacy Development and points to the inclusion of Advocacy Development into the NSW Disability Advocacy and Information System funded through the Department of Aging, Disability and Home Care (ADHC). 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."[10]

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."* [11]

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 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.

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

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

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

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.

The term 'Supported Advocacy' is not a familiar term used in the advocacy sector in Australia and is not required. There is much individual advocacy conducted that is not supported in any way.

How important do you think it is that a NSW disability advocacy framework aligns with disability advocacy frameworks in other States/ Territories and nationally?

At this point in time and in consideration of the development stages of other states and territories, we do not think it is important to align with other jurisdictions. NSW has an opportunity to be a leader in the advocacy space and the current review should be more about learning from the strengths as well as the shortfalls occurring nationally. This information, coupled with consideration of international advocacy practices, should be used to strengthen the current system within NSW.

For example, currently there is no jurisdiction that aligns with the principles and objectives within the UNCRPD. Therefore, standards and directions that the advocacy efforts can take are subjective in relation to the individual organisations perception of what is needed. This is particularly prevalent in the systems advocacy work undertaken, therefore creating a missed opportunity for the continual progression of the rights and interests of people with disability. The UNCRPD clearly outlines the obligations, and the directions required, to ensure that people with disability realise their rights and interests as full citizens. Aligning the advocacy efforts with the UNCRPD would enable a more consistent and potent approach across NSW and avoid misaligned work to be undertaken - which currently stagnates and at times pushes backwards - the realisation of full citizenship. By utilising the UNCRPD it would also assist Government in consistently working towards their obligations as a signatory to the Convention.

WHAT ACTIVITIES ARE INVOLVED IN CARRYING OUT DIFFERENT CATEGORIES OF ADVOCACY?

What other activities occur as part of effective advocacy within each advocacy mechanism?

The National Disability Advocacy Program (NDAP) currently provides the greatest depth in Australia in relation to identifying the variety of models that are required to make up a multi-layered approach to advocacy.

Approaches to disability advocacy can be categorised into six broad models being:

- **Citizen advocacy:** matches people with disability with volunteers.

- **Family advocacy:** helps parents and family members advocate on behalf of the person with disability for a particular issue.
- **Individual advocacy:** upholds the rights of individual people with disability by working on discrimination, abuse and neglect.
- **Legal advocacy:** upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.
- **Self advocacy:** supports people with disability to advocate for themselves, or as a group.
- **Systemic advocacy:** seeks to remove barriers and address discrimination to ensure the rights of people with disability.

We would strongly support that all models identified within NDAP are required within NSW; however even within these models, there is a lack of direction on behalf of the Department of Social Services (DSS). Particularly in relation to how the work is undertaken, what is required, and to whom it is to be delivered. Again leaving it up to the individual discretion of each agency to undertake their version of the work. More work needs to be done with agencies who deliver each model to understand the important elements required in delivering advocacy services to people with disability. For example, in considering the key elements in delivering the model of Family Advocacy there are many crucial components that make this a potent model of advocacy. As discussed earlier the **advocacy leadership development** forms a key component of this. Both from the potency of advocacy undertaken by families and systems advocacy taken up collectively by families in defending and promoting the rights and interests of people with disability more broadly.

Another key component is that a ‘Family Advocacy’ model of advocacy should have a strong governance structure with governance positions held by well-informed families. The competencies of families are built through an effective advocacy leadership development focus that builds and supports development, leading to experienced and well informed families taking up governance positions within organisation. This approach ensures that the governance and the work of the organisation is safeguarded. It is also critically important to the model that families and the organisation are aware that the work undertaken by the organisation is focused on the interests of the person with disability and not the interests of the family. Another key component to delivering this model is to ensure that conflicts both ‘perceived’ and ‘actual’ are identified and counteracted and that to retain independence is seen as foundational. Without these, and other key components of the model, we would lose both the intention of the work, and the strength of the impact.

This shortfall in understanding the key components of each model could be overcome by developing ‘Practice Standards’ or ‘Guidelines’ that clearly articulate what should be required of each model. The success of this would be weighted on the ability for the development phase to consider many examples both nationally and, particularly, internationally in designing these guiding documents.

Another important component of this is ensuring that the advocacy sector has access to relevant training and development to ensure that models were delivered in their most potent form. For agencies to maintain their ‘model coherency’ requires knowledge and intentional thinking, planning followed by the implementation of structures that safeguard their work.

Is this a useful approach to analysing advocacy?

Family Advocacy does not support the suggested matrix of categories and activities featured on page 10 of the Issues Paper as many advocacy issues that come to the attention of advocacy agencies will never fall neatly into one or the other category. The lives of many people with disability are complex, and the supports they require must be flexible and nimble enough to change, adapt and respond as needed.

In the process of analysing advocacy, it is useful to identify things that are worthwhile endeavours AND what ***do not*** constitute advocacy action.

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

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 interest of the person with disability, as opposed to organisations that support families to advocate for their family member with disability.

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.

WHAT OUTCOMES DO WE HOPE TO ACHIEVE WITH THESE SERVICES?

How could NSW best measure the outcomes of advocacy organisations?

While reviewing numerous reports, papers and books that have been written on the subject of advocacy, it is apparent that there is already a plethora of material from which to draw a sound monitoring and accountability framework.

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.

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.*[12]

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 not 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.

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.

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

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.

How frequently should outcomes be reported?

Annual reporting is sufficient for collecting relevant data. More often will increase the administrative demand on agencies and an annual reporting process enables ‘lengthier’ work to be captured in one reporting cycle instead of over multiple cycles over the course of the year.

WHAT FACTORS SHOULD INFORM THE DEVELOPMENT OF A NEW SYSTEM FOR THE PROVISION OF FUNDED ADVOCACY SERVICES IN NSW?

What are the advantages or disadvantages of integrating funded advocacy with service support provision?

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 other organisations which serve the interests of other parties.

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.[13]

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 type 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 address elsewhere. Advocacy agencies are uniquely placed and require 'an arm's length approach' to ensure that the clarity of the work remains clear.

Should funded advocacy be directed towards broader or more specific cohorts?

The most vulnerable people in society are not able to 'ask for' or 'access' advocacy themselves. They will need to be sought out in order to be assisted. This will require people with expertise in particular disability types, as approaches and supports are unique to groups of people depending on their disability type.

Family Advocacy strongly recommends for organisations to be funded that have specialised expertise with particular disability types. The fact that most disability types have agencies, associations and peak bodies that are specific only to them has not occurred by accident. They have sprung up because of the recognition that specialised expertise and experience around the particular disability type is essential. Attempting to be 'all things to all people' is a flawed strategy, which will weaken the sector and not enhance the delivery of advocacy services across the state.

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[13] Advocacy for NSW A critique of Government process and a way forward. The Disability Safeguards Coalition, May 2001. Pg 14

"...different forms of disability should not be combined in the one advocacy organization. Indeed each agency should respond to a group that consists of a clearly identifiable group of people with similar needs and whose difficulties are able to be 'known' by the agency, In fact, within disability groups there are such diverse needs that it is feasible for advocacy groups to specialize in particular groups or issues. The combining of disability groups is only likely to be successful where the issues are the same for all involved. This however, will be rare".[14]

What level of independence from the disability support system should advocacy organisations have in order to be eligible to be funded?

In order to be effective and coherent, there must be a clear division between agencies that undertake advocacy and service providers that provide direct service to people with disability, in order to minimize conflicts of interest.

Much has been written on the subject of conflict of interest, in relation to advocacy. Generally, it is also linked to the notion of 'independent' advocacy.

"Independent advocacy is a major safeguard and often the only safeguard for people with disability who are vulnerable. Independent advocacy promotes, protects and defends the welfare and rights of people with disability to ensure:

- *their human rights and citizenship*
- *their equality of opportunity to pursue options and choices similar to that of all citizens*
- *their access to goods, services and facilities essential to ordinary life in the community*
- *their participation in decisions and in social and political life*
- *the fair and equitable distribution of power and resources".*[15]

The very word 'independent' begs the question - independent of what? Within the context of this review, there are a number of points along the process where these two related issues take on significant meaning.

Independence is a cornerstone of advocacy. In order to ensure that independence is not undermined, a number of elements must be considered:

- the sources of funding for advocacy programs
- the recipients of advocacy funding
- the management of advocacy organisations
- the way in which advocacy agencies recruit staff and/or advocates.

What are the advantages and disadvantages of alternative funding arrangements?

Government funding brings with it major sources of conflict of interest. These include the fact that government funding for advocacy often comes from the same source as is responsible

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[14] Cross, J., & Zeni, L., *Safeguarding Advocacy for People with Disabilities in Australia*, 1993, p. 43.

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

for the services which may be the target of advocacy. In addition, governments now buy advocacy just as they buy direct human services.

Kendrick, in his comments on the American advocacy scene notes that *"(The) advocacy world has long noted that all money comes with strings attached to it, and that 'he who pays the piper plays the tune'. Advocates are well aware that their 'structural' independence is highly dependent on advocacy groups or individuals not placing themselves into worrisome conflicts of interest. One key source of such conflict may often be in the very funds that sustain the work. The crucial test is whether these funds bring with them any kind of inhibition about the kind of advocacy that could be attempted".*[16]

If it does its job well, at some time advocacy is likely to be a "thorn in the side" of Government thereby creating tensions between the advocacy agency and its funder. In addition, the integrity of the advocacy being undertaken is likely to be compromised through - consciously or unconsciously - adopting a weakened stance around issues.

Private funding which, on the surface, looks attractive because it is free of government influence, does not come without strings attached. Most corporate and philanthropic sources of funding have their own priorities and politics. Gaining funding from the private sector also brings with it a number of added predicaments. The enormous energy and resources required to attract private funding can bring the advocacy effort to a standstill. Funding from this source is almost exclusively short-term or one-off and more importantly, optional. Moreover, dependence on this source of funding would make an advocacy agency vulnerable to the inherent vagaries of 'philanthropic giving'. Viability would be under constant threat and has significant implications for staffing and continuity of service.

None of this is intended to be an argument against the provision of government and private sector funds. Governments have a duty to allocate recurrent resources to advocacy for people with disability and should be prepared to do this in a way which promotes the independence of advocacy while, at the same time, ensuring that the funding is spent in accountable ways.

One option that could be considered:

The establishment of an Advocacy Funding and Development Office. This Office could be responsible to the relevant Minister and be guided by a Board or Committee of individuals chosen on the grounds of expertise and experience in advocacy, including government representation.

Its roles would include:

- allocation of recurrent funding
- allocating resources to new advocacy initiatives
- funding, facilitating and encouraging advocacy development
- developing advocacy-specific codes of practice and ensuring that agencies receiving funding, report against such a code of practice
- carrying out, or sponsoring, evaluations and reviews of funded advocacy.

In Family Advocacy's view, this model would be simple, accountable and inexpensive and would have less conflicts of interest compared with any other option.

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[16] Kendrick, Michael J. (2001), *Some Observations on the American Advocacy Scene*, Gray, Barry and Jackson, Robin (Editors)

WHAT RESOURCES ARE REQUIRED FOR EFFECTIVE AND EFFICIENT SYSTEM PROVISION OF FUNDED ADVOCACY SERVICES IN NSW?

What are the most significant resource deficiencies in the current disability advocacy service system?

Many agencies would face the same financial constraints as Family Advocacy. Over the past 20 years, the non-discretionary costs associated with providing advocacy services have risen considerably, with little commensurate increase to funding beyond CPI, which is inadequate. The result of this is that each year a greater percentage of funds are absorbed by non-discretionary costs and less is available for the actual advocacy work of the organization.

The costs that have risen considerably, and not been covered by an increase to funding are:

- Workers' compensation
- Salaries, plus superannuation and on-cost
- Insurances
- The cost of maintaining and upgrading technology
- Rent
- Rural and regional out-reach

Running parallel to this increased costs of providing a service, are the ever increasing demands on agencies by both Government and stakeholders, to do more and reach more people, within an environment of slowly decreasing financial capacity.

Family Advocacy has experienced a large increase in demand for the advocacy related advice and support function over the past few years. This demand is growing every year and has major implications for the other functions of the organisation as the issues being faced by people with disability are increasingly complex, are long-term in nature and can cross a number of government portfolios.

Not enough funding and very little opportunity for professional development for advocates.

What is the role of peak bodies in delivering any of the needed resources to the rest of the sector?

There is currently no strong focus across the country that focuses on building the capacity of advocacy agencies. The capacity that is required is two-fold, with the first being the focus on skill building and training and the second organisational capacity building. There are interstate examples of 'peak' support models and international examples to learn from. However, we would recommend that these and other models be considered and NSW then work towards an enhanced model to address the needs in NSW. It should be seen as a priority of the review that a peak arrangement is provided in NSW. Any peak arrangements should carefully consider the 'set up' arrangements and interplay between the 'peak' and the agencies as the design would strongly dictate the fluidness between the two and the responsiveness of the approach with a strong collaborative approach needed in this. The peak should be flexibility in its design so it can undertake the identified work as well as be responsive in its work.

I had recently had the opportunity to attend an exchange to an international advocacy peak in Washington DC, the National Disability Rights Network (NDRN). The formation of NDRN arose out of an identified need that support was crucial across the federal legal advocacy sector which comprised 57 agencies. The approach taken by NDRN is quite comprehensive and it has adopted a ‘learning-continuous improvement approach’ to its work and its ability to be adaptive to what was is required across the country.

One element of their work involves providing what they called ‘Training and Advocacy Support Centre’ (TASC). The TASC component of the work primarily served as a mechanism to be responsive to agencies’ needs from funding issues, organisational structures, the ‘actual work’ undertaken, developing and the sharing of common resources, and to ensure that linking between the agencies was occurring. An example of linking involved agencies’ staff being connected through training, networks and other events and the chairpersons or committee representatives were also brought together at least annually.

Quality assurance and compliance considerations also formed a component of TASC work and ‘peer reviews’ were supported across the agencies with defined standards and evaluations. Training and development was also undertaken and it was either in response to what the agencies said they needed or gaps in training where identified more broadly due to common issues arising across the agencies. This program seemed to constantly add more elements to their work as they identified needs across the country. The training and implementation is not mandatory and questions were asked within TASC such as, ‘Who we are as a system and what agency may need to be a part of that system’. One example of this was the development of ‘standards’ for the agencies as it was identified as a strategy to strengthen practice and to ensure model coherency. The development of the standards was done with extensive collaboration with the 57 agencies and it was a considered a document that was owned by ‘the agencies’ and not NDRN.

In relation to oversight and the power structure between the agencies and NDRN is was a membership organisation only. Individual agencies could join at their discretion and I believe all 57 had joined. NDRN was primarily funded by government to provide this support and all 57 agencies had oversight by the funders.

In concluding this point, we would recommend that any considerations of ‘potential peak arrangements’ should have investigated outside of current arrangements in Australia as it seems that more advanced models are currently operating internationally.

For the interest of this review, we have attached two documents that would be relevant to consider. The first is the recently developed ‘Standards’ and second is the ‘TASC guide’ which outlines some of services provided. If in undertaking this review you wish to be connected with NDRN I would be happy to make this connection as only a component of their work was covered in this submission.

What is the role of representative bodies in delivering any of the needed resources to the rest of the sector?

Family Advocacy takes the position that the ‘representative function’ forms a component of the work undertaken in the ‘systems advocacy’ role. This would involve making representation to all levels of government and to decision makers more broadly and it is seen as representing the interests of people with disability. This work is primarily done with, and through the support of people with disability and families. We do not see the ‘representation’ component of this work as sitting outside of this.

In the current landscape and with the focus on people with disability having the opportunity to participate in this work it is essential that families are also considered as part of this equation. Many organisations that purport to be ‘representative’ are often enabled to due this through their extensive involvement with families. As discussed previously, families are often the ones speaking up with or on behalf of their family member with disability and often the ones directly involved with the advocacy work undertaken. We have previously addressed in this submission why this is essential for many people and the safeguards that this creates particularly for the many people with disability that experience extreme complexities and vulnerabilities.

Are there capacity-building resources that advocacy services require to support their sustainability?

We recognise the absolute need for any advocacy organisation to be provided with ongoing access to capacity building. This stems to both organisational capacity building and capacity building for staff, committee and even members. However, it is important within this that each organisation also has flexibility to decide what is most relevant to them. To this point it should also be organisational choice to pursue training outside of generic training and possibly there could be a pool of funds that requires submitting a request to access this. Capacity building could also be built into each organisation’s budget and discretion could be then used as to what may be required.

It is important to add that methods of obtaining better practice are never achieved just through one mechanism so to allow for flexibility in these considerations would possibly lead to stronger practices.

WHAT ARE THE SOURCES OF FUNDING?

In what ways can the roles and responsibilities of the Australian, State and Territory Governments be better apportioned or clarified?

Advocacy must never become a ‘fee for service’ support. All people with disability in Australia, regardless of whether they receive funding support or not, must be able to access advocacy if and when they need it, and across their lifespan. The instability that this approach would create would have significant ramifications for people with disability and for the stability of the advocacy sector more broadly.

CONCLUSION

To conclude, we would once again like to emphasise that although we see this review as an opportunity to strengthen the NSW advocacy sector, it is being conducted at a time when there is no guarantee of funding for NSW advocacy services post June 2020. Before any steps are taken to reshape the current arrangements, it is critical that the NSW government commit to an extension of the current funding agreements to June 2022. This will enable the recommendations from your review to be considered and where applicable, adopted. This process should not be rushed and should be well thought through to ensure we are left with a stronger and more responsive advocacy sector for people with disability.