Submission No. 7 to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Commission):

The important role of family and the Family Advocacy model

"Part of the joy of living in your own place"
Al Graham hosting his first Christmas brunch with family in his own home

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Table of contents

Summary of recommendations 3

Introduction 4

The crucial role of family advocacy 6

Research of the Family Advocacy model 8

Build the capability of family in Supported Decision Making 10

Summary of Recommendations

Recommendation 1: *That the Royal Commission formally recognise and acknowledge that the family holds unique knowledge and experience, especially as they advocate with and at times on behalf of the person with disability in their family, particularly when a person is young.*

Recommendation 2: *That the Royal Commission recommend to support the Family Advocacy Model of advocacy and support the growth of this model across Australia amongst the other vital advocacy supports provided to people with disability.*

Recommendation 3: *Build the capability of families to provide support for advocacy related decision making of their family member with disability.*

Introduction

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

Family Advocacy has a vision of a future where authentic inclusive thinking is the norm, where people with a disability have the opportunity to flourish, to be part of the community and to experience the everyday alongside other community members. It also includes the right to live safely and with dignity, free from violence, abuse, neglect or exploitation

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.

This experience extends to the extensive advocacy that has had to be undertaken by families in order to safeguard against typical opportunities and rights of passage that are in threat or not afforded to their loved ones with disability. These families hold a firm knowledge shaped by experience that ongoing advocacy is required if their family members are to experience the many good things that life has to offer.

In this regard, Family Advocacy was founded to fulfil a need for advocacy support and development across 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 leadership development as well as systems advocacy in NSW for over 31 years and has been involved in multiple evaluations and reviews of both State and Federally funding advocacy programs over this time. As the infographic illustrates, the work that Family Advocacy undertakes falls into three main pillars:

- Statewide Advocacy advice and support to individuals
- Advocacy leadership development for family members of a person with disability - Advocacy is often undertaken by families and can be required over the lifetime of their family member. Strengthening the advocacy capacity of families is essential to this.
- Systemic Advocacy - informing government regarding legislation, policy, funding, monitoring, and practice in areas that impact on the needs and interests of people with disability.

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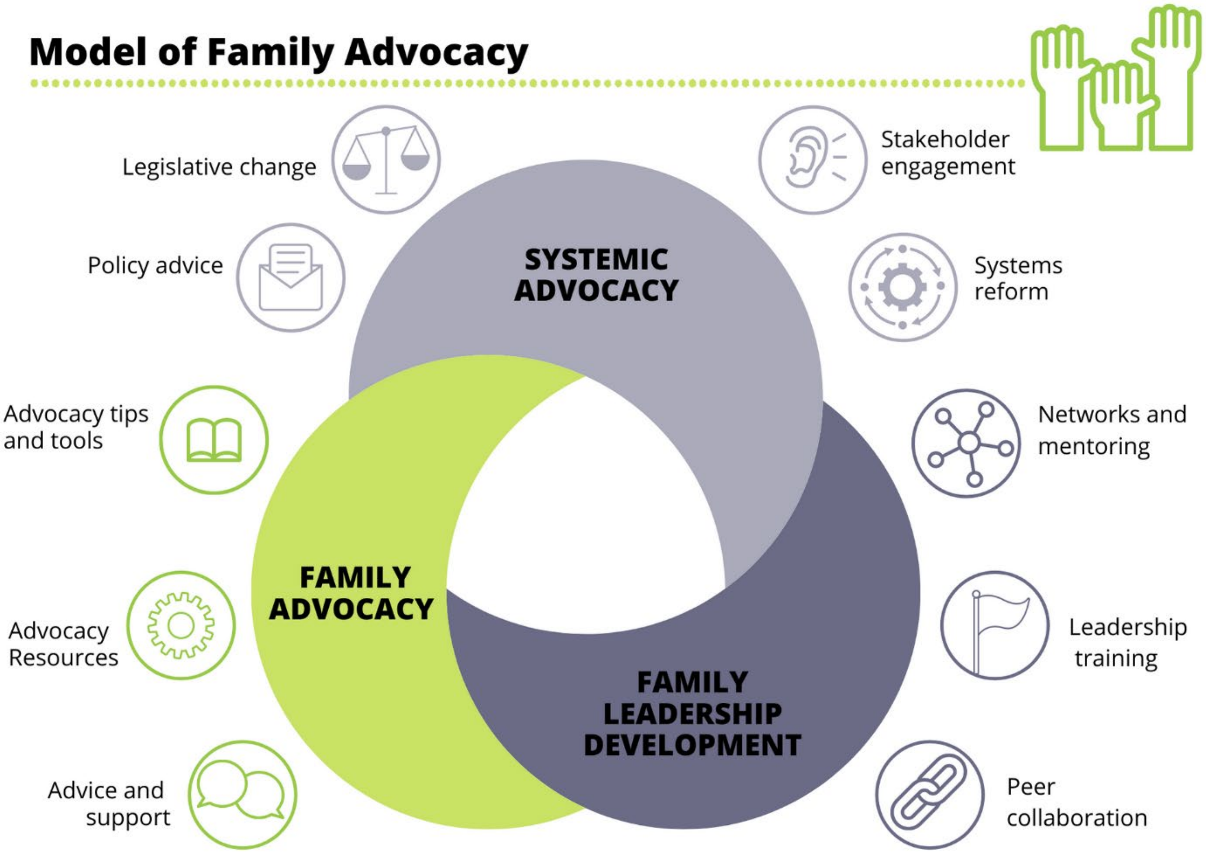
[1] Developmental disability includes any disability that arises within the developmental period and includes intellectual disability, cerebral palsy, Down Syndrome, spina bifida, autism and multiple disability.

The infographic below illustrates the Model of Family Advocacy, and is discussed in much more detail in UNSW, Social Policy Research Centre's (SPRC) report, [Family Advocacy Model Research](), on Page 8.



We discuss below the crucial role of family advocacy over the life span of a person with developmental disability, the Family Advocacy Model of advocacy, and why we strongly recommend the Royal Commission supports the Family Advocacy Model of advocacy amongst the other vital advocacy supports provided to people with a disability.

The crucial role of family advocacy

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 without trusted support.

> *“We are her voice when she has no voice.”*
>
> - Parents of a child with a disability

As a general rule, parents and family members of people with disability:

- know their family member most fully and for the longest period of time,
- are the constant in people’s lives,
- are the setter of expectations,
- are the repository of knowledge,
- tend to care the most, and provide the most care,
- have a greater responsibility over their family member’s wellbeing,
- have a stake in their life outcomes,
- hold a degree of independence which allows them to call into question the credibility of other parties, demonstrate deep care,
- take greater responsibility over their family member’s wellbeing,
- are often best positioned to see the big picture, to see how everything in its entirety, builds into a person’s life, and as therefore,
- can often see the incongruences of different interventions in early childhood, in education and employment.

For this reason, informal advocacy undertaken by families of people with disability provides the greatest potential for advocacy to be done potently with high expectations and support for a life of inclusion and the natural byproduct of safeguarding the person from violence, abuse, neglect, exploitation. 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. Its also usually the families that ‘push back’ in the first instance when systems designed to support this group, fail their purpose. Family advocacy also acts as a quality measure against poorly delivered services or lack of access to more community focused services whereby, if not invested in, leaves many people with disability at the mercy of poor services and support.

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 leadership 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. If advocacy is undertaken, it is rarely a once off and so the development of advocacy skills is essential. 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). 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). Indeed, the acknowledgement and respect of the role of family in the lives of people with disability is one of the general principles listed to guide the actions of the NDIA.

Family, in whatever shape or form it may have, has a critical and vital role in the care and support of any individual. Family, especially in the formative years, are the constant in people’s lives, the setter of expectations, and the repository of knowledge[2]. For many people with disability, this reality can be life-long.

On the front cover, we shared with you a photo of Al Graham. After finishing his Inclusive Education journey, Al communicated to his family his desire to live independently. His mum, Penny, advocated at many points alongside Al to enable this to happen, from advocating around ensuring her son has access

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[2] “The Natural Authority of Families” by Michael Kendrick.

to the right information and level of supports, and navigating the barriers of the NDIS. Recently, all their efforts paid off, and Al moved into his own home where he lives independently with supports in place. He was delighted to host brunch at his place for Christmas. Unfortunately, too often, when people with disability face similar barriers, the end result is living in a group home that is not of your choosing and with people who are not of your choosing. If the family had not stepped up to advocate, this might not have been the case for him.

Utilising this knowledge of and their relationship with the person enables options to be explored that are sustainable in the long term. Successful inclusion stories shared throughout this submission, highlight how key it is for a parent to hold a clear Vision for their child, thinking ordinary and typical, being included in mainstream society, high expectations in the long term, and good collaboration. Accordingly, it is essential the Commission recommends the investment in the advocacy leadership development of families and we refer to the Family Advocacy Model of advocacy upon which we are founded, discussed below on Page 8.

Recommendation 1: *That the Disability Royal Commission formally recognise and acknowledge that each family member holds unique knowledge and experience, especially as they advocate with and at times on behalf of the person with disability in their family, particularly when a person is young.*

Research Undertaken of the Family Advocacy Model

Family Advocacy would like to submit a report we commissioned with the Social Policy Research Centre (SPRC) at UNSW, Sydney, Family Advocacy Model Research, dated October 2022, to the Commission, to undertake independent research to explore the impact of the Family advocacy model at the person, family and community/systems levels, and to identify mechanisms of social change within the model.

This research highlights the “approach means the family can focus on the vision and local action needed to realise equal rights and entitlements of the person, in ways that can inform action for the rights other people and families in similar situations.

Family Advocacy engage a wide range of demographic and diverse families from across the state. Assisting families with similar advocacy goals to connect with each other and organise themselves, means that action and social change are decentralised and families with lived experience are involved in every part of the model – governance, delivery (peer to peer education, learning), leadership development and advocacy for systems and policy change.”

It is important to note that where this model of advocacy differs from some other forms of advocacy is in the advocacy undertaken. For many advocacy organisations, for example, the formal advocate ‘takes on’ an issue and works to remediate it. Taking the person impacted out of the equation whilst the matter is being resolved. This model of ‘doing for’ is an important part of the Australian disability advocacy landscape. Our model, however, works to invest in people with disability and their families so they are well equipped with the knowledge, skills and confidence to take on the issue at hand. Our advocates are there to support at every point in the journey to advise and support, however, we do not undertake the advocacy required.

The very nature of this approach naturally builds the confidence and resilience to take on the required advocacy around the person in their life. It also acts to alleviate pressure points that may build into a more critical issue. As people become more familiar with their child’s rights, and their confidence in interacting with mainstream systems increase, often issues are alleviated much earlier on, thereby mitigating critical issues/barriers.

Viewing the advocacy sector holistically, we submit and urge the Commission to read Family Advocacy’s submission to the Ageing and Disability Commissioner for the NSW Disability Advocacy Review, dated 18 October, 2019. Although there have several changes made by the Ageing and Disability Commissioner in the NSW advocacy landscape, the content and considerations remain relevant in relation to what the advocacy sector needs to look like at both State and Federal levels. In particular, the ongoing commitment to support the multilayered levels of advocacy.

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.

Accordingly, in order to navigate a better and more robust advocacy sector, the family advocacy model needs to sit within in and amongst a suite of advocacy options.

Recommendation 2: *That the Royal Commission recommend to support the Family Advocacy Model of advocacy and support the growth of this model across Australia amongst the other vital advocacy supports provided to people with disability.*

Build the capability of family in Supported Decision Making

On 12 December, 2022 the UN Special Rapporteur, Gerard Quinn, gave evidence the Commission on the rights of persons with disabilities. He said:

“We are how we are because of the range and depth of social capital in our lives. We all take cues from each other in our decision making - especially those close to us. Our personhood in this important sense is shared. That is what makes the concept of 'supported' decision-making so interesting. It is not primarily about State-led or State-directed support services - it is primarily about embedding people in layers of naturally occurring social capital to develop their competence and confidence in decision-making. To put it bluntly, it is about social inclusion.”

He also made reference to the recently published UNCRPD Guidelines on deinstituionalisation, including in emergencies., 10 October, 2022. Interestingly, the Guidelines allow for family involvement and support but only on the express consent of the individual with a disability. Even though Article 23 (respect for home and family) makes no express allowance for it, the Guidelines call for family support to enable families to help them meet their support-related responsibilities. See the excerpt below:

VI.Inclusive community support services, systems and networks

A. Support systems and networks

69. Support systems and networks include the relationships that an individual develops with family members, friends, neighbours or other trusted persons who provide the support that a person requires for decision-making or daily activities, in order that the person can exercise the right to live independently and to be included in the community. Support systems are important in enabling persons with disabilities to participate and be fully included in the community. Support systems are key for some persons with disabilities, in particular for persons with intellectual disabilities and persons requiring

> intensive support, in navigating and determining the support services that they may require.
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> 70. States parties should invest in peer support, self-advocacy, circles of support and other support networks – including organizations of persons with disabilities, particularly those of survivors of institutionalization – and centres for independent living. States parties should encourage the creation of such support networks, provide financial support and fund access to and the design of training in human rights, advocacy and crisis support.
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> 71. States parties should recognize the existence of informal support and ensure that communities and families are trained and supported in providing support that is respectful of the choices, will and preferences of persons with disabilities. Persons with disabilities should have access to a wide range of support options, whether or not they wish to be supported by their families or communities.
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> 72. Support persons, circles of support and support networks may be chosen by persons with disabilities only, and not by third parties such as judicial or medical authorities, members or service providers. Supporters should respect the will and preferences of persons with disabilities. Support persons should never be appointed against the will of persons with disabilities.
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> 73. Peer support should be self-directed, independent of institutions and medical professionals, and autonomously organized by persons with disabilities. It is especially important for survivors of institutionalization, and in the interests of consciousness-raising, supported decision-making, crisis support and crisis respite, independent living, empowerment, income generation, political participation and participation in social activities.
>
> 74. Where persons with disabilities decide to receive support from their families, adequate support services should be provided for family caregivers, so that they can in turn support their relative to live independently in the community. Support arrangements can include a multiplicity of supporters acceptable to the person using the support, or to the parents or guardians of children with disabilities, ensuring continuity and quality of support. States parties should recognize informal support, such as circles of support and family and peer support, and should fund community-based support, such as counselling services. Such services should not entail the placement of children or adults with disabilities in institutions, even for short periods of time.

We reiterate this latest Guideline in the UNCRPD, particularly in relation to the recognition of the existence of informal supports such as family members and recommend families are trained and supported to provide support that is respectful of the choices, will, and preferences of the person with disability.

Specifically, in relation to Supported Decision Making, Family Advocacy provided a detailed and comprehensive submission to the NDIA in September 2021. Given all of the recommendations remain current, we resubmit our submission on Supported you to make your own decisions[3] (SDM) to the Commission for adoption of the recommendations.

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[3] https://www.family-advocacy.com/assets/Submissions/30f4268a9a/Submission-NDIA-Supported-decision-making-Sept-2021.pdf

We provide an excerpt of the conclusion as it summarises the recommendations and our concerns around the potential pitfalls when supported decision making is not done well:

“*Whilst SDM is an important right for people with disability to exercise, significant safeguarding is necessary through natural relationships, usually through the family unit. Good decisions are made when people receive good support with a clear understanding around the nuances involved for a person with developmental disability.*

People with disability need to be given not only the opportunity to make decisions but also the investment in their capacity to do so. The NDIA should support the capacity building of the person with disability and their decision supporter to understand the pitfalls around the illusion of choice, of placing too much weight on consequence as a learning strategy, and with the dignity of risk.”

Informed choice assumes you have had the opportunity to practice choice making over time. This starts with families and young children. Did we have the chance as a youngster to make small choices and then with practice expand the choices you were allowed to make? With time, you are making greater and more complex choices. You cannot assume people can make major choices after years of making no choices at all. People need practice, coaching and opportunity.[4] And so do the families that support them to do so.

Accordingly, it is vital that the Royal Commission focuses on building the capability of families so they are well equipped to teach their children in an age appropriate manner about how to make informed choices, particular advocacy related decisions, and that they be supported to be aware of any potential pitfalls or conflicts of interest.

Recommendation 3: *Build the capability of families to provide support for advocacy related decision making of their family member with disability.*

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[4] Jeffrey I. Strully, *Authentic Choice: Myths, Excuses and a Deepening Understanding of Choice*, Belonging Matters – Thinking about…Decision Making, Issue 16, August 2013