**Submission for the review of The National Disability Advocacy Framework.**

Thank you for the discussion paper Review of the National Disability Advocacy Framework June 2015 and the opportunity to comment.

Background.

My perspective comes from more than 50 years lived with a mixed bag of societal and familial attitudes that have shaped and continue to shape who I am. For the past 18 years I have been fortunate in having the role as mother. Together with my partner in business and life, we are raising four gorgeous children, the youngest who is 11 and happened to be born with an intellectual disability. One of my personality traits has always been to question and have passion for what I believe is right and true. Speaking my mind, so to speak, has not always been welcomed by others. Over the past 11 years I have found my niche with channelling this mindset into an additional role, becoming an effective Family Advocate in order to achieve what I and my partner believe is giving our daughter Rhiannon the greatest opportunities to be who she wants to be. Living a good life with many valued roles, just as we desire for all our children.

When Rhiannon was born her disability was diagnosed almost immediately. There were naturally a host of thoughts that washed over us, based around values and stereotypes that came from my partner and my own limited experiences of people who had disabilities, having grown up in the sixties and seventies. I had also had medical experience having finished school and trained as a Registered Nurse. Over my 15 year career in this system I occasionally nursed people who were unwell and also had disabilities. I also had a brief experience doing some Agency work where I was sent to one particular institution for the care of people who were significantly disabled. It was here that I found the culture and environment extremely confronting and disturbing. Now as an Advocate when I hear the term most vulnerable this memory of the waste of human lives resonates.

Overriding any particular thoughts at this time were the predominance of emotions. As Rhiannon required surgery and post-operative care in a Neonatal Intensive Care Unit for the first week of her life, our first initial time of bonding had to incorporate the navigation of a medical system. It was here that I felt the full brunt of people’s low expectations for my daughter’s life. Unlike the joyous time of my other children’s births, I was being told by a so called medical expert, when Rhiannon was just 24 hours old, that I might expect a considerable list of possible medical conditions including Alzheimer’s disease and leukaemia because they were attributed to be statistically higher with Down Syndrome. Having a different view myself, I still remember thinking to myself at the time.. ‘and she might not.’ It was of great relief to return home to our small rural community where we had strong supportive networks and close friendships. Here I could reconnect with my natural authority as parent.

Advocacy Experience.

I first attended a workshop run by Family Advocacy called ‘One of the Kids,’ when Rhiannon was three years old. I was seeking information about Inclusive Education. I found this extremely helpful and felt empowered to ensure that my daughter would be able to attend school together with her other siblings. Two years later in preparing for Rhiannon’s transition to school, my partner and I were sponsored and attended an intensive weekend workshop hosted by Family Advocacy’s called ‘Travelling through the Education Maze.’ This weekend was so inspiring and gave us such clarity of vision that we subsequently became members of the Institute of Family Advocacy. Since then I have attended many events, conferences and leadership weekends that has shaped my journey, skills and identity as a Family Advocate.

Rhiannon is now a primary school student in a regular mainstream classroom. She is very active and engaged with many interests and hobbies and is extensively connected to her community, surrounded by lots of natural and informal supports. This has not just happened on its own. As social inclusion is not always a given, she has benefited from some purposeful thought, planning and intent. When she was 6 years old we embarked on establishing a Circle of Support to help us plan for her to achieve the same opportunities in life that we envisaged for our other children. We as parents, siblings, extended family, friends and allies have a specific vision for her and how we want things to look. This includes a plan of action that constantly evolves to help guide us forwards. Rhiannon is now having input into this process and articulating her own dreams and aspirations. It includes the most ordinary things that other 11 year olds want, like having friendships.

At the same time, since 2010, we have been fortunate in managing the individualisation of some support funding for Rhiannon. In July 2012 we piloted a Direct Funding arrangement which continues today along with other people around the state of NSW, while awaiting the roll out of the National Disability Insurance Scheme (NDIS). We find that having control and directly managing these funds aligned to the goals of Rhiannon’s Plan has brought normality back to our family life. We no longer have to deal with regularly incorporating the service system into the mix of our busy lives, something we found to be challenging and energy depleting. It means that I can relax into my role as mother without having to constantly rationalise to others what it is that we want to help Rhiannon achieve.

I am always conscious of the different hats I wear. My role to Rhiannon is always first and foremost mother, with four children, this feels the most comfortable of hats. However, as needs often arise, I and the rest of her family members must be able to speak up for her best interests confidently and purposefully. It is the guidance and insight we have gained from our connection with Family Advocacy that has made us most effective in wearing the hat of Family Advocates. This is different to Carer or Parent Advocacy which is not a hat I readily identify with wearing. I am aware that Carer Advocacy is different to Family Advocacy. The first is about the carer and has potential to take an approach that focuses on burden. When I advocate personally for Rhiannon’s rights as a Family Advocate, I must always reflect and be clear that I have her best interest at the forefront. It is essential that I speak to her attributes rather than looking for deficit to highlight and be conscious of minimising conflict of interest. I must keep in mind Rhiannon’s own desires and viewpoint, supporting her as she grows to develop skills to become an effective self-advocate who we can then walk beside as needed.

The National Disability Advocacy Framework (The Framework).

The Discussion Paper outlines the following excerpts:

1. The NDIS is a major reform which is bringing significant change to the delivery of services and support to people with disability. In April 2015, the Council of Australian Governments’ Disability Reform Council agreed that NDIS would fund:

* decision supports
* safeguard supports
* capacity-building for participants, including support to approach and interact with disability supports and access mainstream services.

1. The Disability Reform Council agreed that systemic advocacy and legal review and representation will be funded outside the NDIS. This is in line with the 2011 Productivity Commission Inquiry Report into Disability Care and Support, which recommended advocacy be funded and provided outside the NDIS.

In addition there is one fundamental Outcome in The Framework that stands out to me as imperative. That being point (e) also quoted in the Discussion Paper as:

1. People with disability receive independent advocacy support that is free from conflict of interest.

The proposal in the discussion paper does not make it clear where Individual Advocacy and in particular Family Advocacy will sit. My interpretation of Excerpt 1 is an inference that it will exist under the umbrella as decision supports, safeguard supports and capacity-building. This is alarming for several reasons.

* + To be clear from the outset support is not the same thing as Advocacy.
  + Firstly the NDIS is merely a new system of reform. It will not change the fundamental vulnerability that will always exist particularly for people with developmental and intellectual disability. Alongside Individual Advocacy, Family Advocacy is the best way to safeguard these people. It will be more important than ever to maintain the status quo and stability of existing advocacy systems. Just as it stands now, trusted advice can then be sought readily. Much better than being thrown into an even greater maze that must be navigated through during this time of change.
  + In contradiction to Excerpt 2, it will no longer be separate or independent as the Productivity Commission recommended. Systemic Advocacy and legal review will not be the only forms of advocacy needed.
  + There is a greater risk of conflict of interest occurring if advocacy is incorporated within the new system. This is explicit in The Framework as noted in Excerpt 3. It would be detrimental to people if the service industry developed an advocacy market. It could become unclear whose best interests were being served.
  + The supports outlined in Excerpt 1 will need to come at a cost and ultimately will be paid for out of individual’s funding budgets. A need for advocacy is not something people might normally expect to budget for, if ever. Perhaps believing that the NDIS will be some sort of panacea, which of course it is not. When things suddenly go pear shaped and advocacy is needed, what will have to move sideways out of a person’s Plan in order to fund this additional cost?

It also seems irrational to separate Individual and Family Advocacy from Systemic Advocacy. So often a systemic issue becomes apparent because many people are having the same issues and subsequently seek advocacy advice. This then gives impetus to identifying a drive for change and has been the force to bring about the introduction of many positive policies. There are numerous examples of this I have witnessed over the years including the implementation of

* the “Every Student, Every School” Learning and Support framework implemented by the NSW Department of Education and Communities in March 2012 <https://www.det.nsw.edu.au/media/downloads/about-us/how-we-operate/national-partnerships-program/every-student-every-school/learning-and-support.pdf> and the
* Supported Living Fund which is a form of individualised accommodation support funding for adults with disability aged 18 to 64 years implemented by the NSW Family and Community Services Aging, disability and homecare in 2011. <https://www.adhc.nsw.gov.au/individuals/support/somewhere_to_live/individualised_accommodation_support/supported_living_fund>

Lead by Family Advocacy, I together with many other Family Advocates were supportive and active, while campaigning for these changes to come about. This comes from a strong desire to create social change for the better of everyone not just our sons and daughters.

Having read The Framework, it seems to me to be very good in the present form, given that it is only 3 years since it was endorsed in 2012. With the onset of the NDIS there could be a need for some strategic rewording but otherwise it seems to serve the purpose that it is intended. That being to protect the rights and overcome the barriers of people who live with disability.

However within The Framework there is not a clear emphasis on Family Advocacy. The institute of Family Advocacy in NSW is a unique organisation and I am not aware any other organisations like it in Australia. In this time of change it seems more important than ever to include within The Framework’s Principal, Outcomes and Outputs reference to family advocacy such as

* Disability Advocacy must strengthen the capacity of the families of people with disability, actively encouraging their support.
* Informal and natural supports, including Family Advocates are encouraged around people living with disability and the capacity of families are strengthened.

Conclusion.

Family advocates hold the greatest interest for their family member. It is a powerful means to safeguard individuals and an asset not to be lost. It is freely given and driven by love and devotion to another. It also creates a greater conscience of social justice. It cannot be replaced by a new system of reform. In Rhiannon’s life this far, the benefits that have come to her through what we have gained from our association with Family Advocacy and then as Family Advocates is undeniable. I cannot imagine how it would have been or could be otherwise. Please ensure when reviewing this framework that consideration is given to the continued funding of Family Advocacy.