



Response to National Disability Advocacy Framework Review

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Summary of Recommendations

1. That the Framework continues to include both individual and systemic advocacy.
2. That family advocacy continues to be included in the Framework.
3. That the Framework continues in order that people with disabilities and their families can access trusted, inclusion-focused sources of advice, support and information, particularly in changing times.
4. That the Principles also state that:

Disability advocacy strengthens the capacity of the families of people with disability to speak out for the rights, interests, needs and inclusion of people with disability by actively supporting and encouraging family advocacy.
5. That the outcomes in the Framework be maintained, as they provide appropriate measures and accountability for advocacy by and for people with disability.
6. That an additional outcome focused on natural supports for people with disability be included, such as:

People with disability are supported to have a network of natural and informal supports, including family advocates. Families are supported to advocate for their family member with disability where needed.
7. That outcome E, which reflects the importance of protection from conflict of interest, be maintained.
8. That the following output be added to the Framework:

Disability advocacy which builds the capacity of family leaders who can advocate both systemically and for the interests, rights, needs and full inclusion of their children and siblings with disability.

Introduction

The Institute for Family Advocacy & Leadership Development Inc. (henceforth, Family Advocacy) is a state and federally funded disability advocacy organisation in New South Wales (NSW), founded by families of people with disability. Our goal is to advance and protect the rights of people with developmental disability to achieve meaningful lives and enjoy the same opportunities and living conditions as the majority of Australians. The organisation has a high presence and profile across the State:

- building the capacity of families to undertake an advocacy and leadership role;
- auspicing a successful ongoing capacity building project, called Resourcing Families;
- making representations to Government regarding inclusive legislation, policy, funding, monitoring and practice, that meets the needs of people with disability;
- and providing advocacy related information, support and advice to families about inclusive education, community, employment, housing, negotiating services, support provision, funding package management and meaningful lives to name but a few. This function supports families to be the strongest advocates they can be for their family member with disability.

The focus of our submission is on the impact of the National Disability Advocacy Framework (henceforth, the Framework) on people with disability and their families' capacity to advocate on their behalf.

Family Advocacy performs a combination of family and systemic advocacy. "Family advocacy is an independent, community-based model that usually involves family members acting on behalf of a son or daughter or sibling" (Weafer, 2003, p.39), and "systems advocacy lobbies for reform and change of social systems and structures that discriminate against, abuse and neglect people with disabilities" (Seymour and Peter, 2004, p.12). Family advocacy is a cornerstone in the lives of many people with disability and those that love them, ensuring that they can have a good life with the things most of us would expect in Australia, including:

- natural support, such as friends, networks and a place in the community;
- purposeful everyday occupations such as their local school or open employment;
- having their rights promoted, protected and upheld, with access to both informal and formal safeguards.

Case study

A mum may call Family Advocacy because she is facing difficulty at her son or daughter's school when asking the classroom teacher to make reasonable adjustments to the curriculum for her child with disability. Adjustments are needed so that her child can continue to be included in the regular class at the local school. Family Advocacy staff would work through her options; provide her with information about her child's rights; support her to be assertive in asking for her child to be included, and to look for a mutually workable solution in dialogue with the school.

Family Advocacy's vision of advocacy in the NDIS environment

Family advocacy for people with disability

The current Framework encompasses family advocacy with good reason. Family advocacy is a model of advocacy that harnesses the most important and constant relationships in the lives of many people with disability. It empowers family members to be advocates for inclusion, promotes and protects the rights, interests and needs of the person with disability, and promotes lives full of potential, enabling people to gain the best natural safeguards possible, that is, meaningful and freely given relationships. While family advocacy is categorised as individual advocacy, the ripple effects of this approach are both wide and deep.

Families have been undertaking advocacy for their family members with disability since long before funded advocacy under a national framework was in existence. Family advocacy happens because of the authority of the family in our society, and the love and care that families have for their children. Indeed many family advocates undertake this role instinctively and without formal support. However, funded family advocacy development with an overarching framework means that families can undertake this role with more effectiveness and a much deeper understanding of the issues, pitfalls, and possibilities. This has three particularly important outcomes outlined below.

Firstly, Family Advocacy is effective because it recognises the conflict of interest that can sometimes be present between, for example, parents and their children, and demonstrates ways to recognise, minimise and protect against this conflict. One of the ways Family Advocacy does this is by being a mission driven, rather than membership driven, organisation. While we do have members, and encourage their maximum involvement in all that we do, we are driven by our vision of families being agents of positive social change so that the inherent value of people with a developmental disability is recognised in our society.

Secondly, Family Advocacy is one of the most cost effective means of ensuring access to advocacy. Although it will never be efficient for every person with disability to have a paid, individual advocate, most people have families. By reaching out to those families, and focusing their skills and parenting toward being an effective advocate for their family member with disability, family advocacy is a major way in which people with disability can have access to effective advocacy.

Finally, the effects of family advocacy are not only wide, as outlined in the paragraph above, but deep. Rather than a simple rights based model, we focus on the roles and belonging of people with disability, making sure that they have a valued place in the ordinary lives of their family and community. Rather than simply insisting that a child has the right to be in the regular class at school, we work with families to help others value their family member with disability. For instance, although Grace, who has attended the regular class at her local school, has faced some difficulties over the years, her parents have a vision of an included life for her in which her peers genuinely know her. Recently Grace was voted class captain, a 'face of the class' role. This evidence of deep belonging is part of what Family Advocacy can do.


Over the years we have supported families whose advocacy has opened up wonderful possibilities, and we share some case studies below.

Case Study: Mac

Mac Wilson-Burns was once described as the 'most disabled child ever to be mainstreamed'. Mac is now in Grade 4, working at grade level using a combination of partner assisted foot switches, typing in Morse code, using auditory and visual scanning and his 'old faithful' yes/no foot switches. His friends regularly invent 'Mac-ifications' to include him in activities like handball, class activities and sport.

making the world more ALLsome

HANDBALLbuggy



You might remember me mentioning that the "Handball Machine" was the catalyst for those "[Macifications](#)" (mods to Mac's wheelchair) his classmates worked on last year?

The kids (Mac included) just decided one day Mac needed a way to play handball. Their idea was to have something mounted at the front of Mac's jogger to allow him to "play" without getting hurt.

For days, I would turn up at school with them telling me what they had tried, asking me to bring in more items to test, giving me the results on their experimentation.

Lots of behind the scenes family advocacy has led to this place of inclusion. His mother Gina is actively involved with Family Advocacy as Mac (age 10) pursues an inclusive education in a regular setting, with his friends, despite his multiple, severe disabilities. Learn more at <https://inkyed.wordpress.com/>.

Image from Inky Ed.

Case Study: Alex and Dan

Alex is Dan's Dad. The following is an excerpt from an interview with Alex. Alex and his family have been associated with Family Advocacy for over 20 years.

Our vision is to achieve a good, valued life for Daniel using natural supports and intentionally creating an enduring community of support around him. It's a useful touchstone.

We knew Dan's interests better than anyone else. It was important that he did something that was genuinely worthwhile and valued. In particular he is very strong and likes and will seek out heavy work, he likes delivering things and he just loves newspapers. He also has a wish to own an airline which we are still working on.

I began looking around for a Dan friendly house and eventually found one and he moved in. I didn't really know how I was going to afford to have someone stay with him overnight. Not long after he moved in there was no one to stay with him one night except me. Dan didn't want me to stay because I lived in that other house over there and I should go home. He got quite cranky so eventually I did a deal whereby if he got into bed and stayed there I would go home. He did and I did. He has been there ever since, although I did do a few drive-byes in the night. In the end the money wasn't an issue.

As can be seen from the above examples, family advocacy is distinct from carer advocacy in that it prioritises the person with disability. Family Advocacy support paragraph 7 of the Framework, which states:

The target group of the framework are people with disability. The framework is underpinned by a person centred approach whereby policies and programs are designed to respond to individual needs and aspirations. Consideration of the role of families and carers will be taken into account. However, the needs and aspirations of the person with a disability are paramount.

While carer advocacy, as conducted by Carers Australia and similar organisations, may prioritise the needs of carers, family advocacy is advocacy that solely prioritises the value, inclusion and good life of the person with disability. It is built on the principle of inclusion of people with disability in the regular lives of families, communities, schools, workplaces, indeed, in every aspect of our society, with the view that good communities are made up of a diverse range of people. It is an internationally recognised model of disability advocacy. This is why it has been included in the disability advocacy framework from the beginning.

Family Advocacy includes siblings, grandparents, family friends and allies. While naturally the majority of family advocates are parents, we also have many sibling advocates. For example, in an upcoming workshop on future planning for families of people with disability regarding wills, trusts and legalities, we are particularly encouraging siblings to attend and have two sibling panellists (see Figure 1 below).

Future Planning event

Saturday 8 August – 9.30am to 3.00pm, West Ryde


Presented by Family Advocacy and Ashurst Law Firm


Hear from Ashurst on the legalities of wills, trusts and more!
This day is exclusively for families. Siblings and other adult family members are encouraged to attend.

[Click here to read the flier](#)
[Click here to register for this event](#)

Meet Our Guest Speakers!

Everyone has a unique experience in planning for the future of their family member and we know that hearing different perspectives is useful. We hope that our three guest speakers and their experiences will assist you in your own planning as you move forward!

 **Wendy Stroeve** is the parent of Alex, a 25 year old with high support needs. Alex's life to date has been shaped by a strong family vision of a life lived in connection with others and that offers a wealth of rewarding experiences. His family believes what they do now to share this vision with significant people in his life will be critical in planning a future for him that continues to offer him good quality of life.

 **Matthew Dimmock** is a passionate advocate for his sister and his two children who have a disability. He is guided by a firm belief in the potential of all people to live valued, contributing and connected lives embedded in their local community. He is also passionate about the transformative power of inclusive education on the future lives of all children, and is excited about the possibilities presented by the expanding self-directed funding space in NSW.


 **Catherine Hogan** has a sister and a son with intellectual disability, both of whom live in their own homes. Catherine and her extended family and friends crafted her sister's living arrangements and are responsible for coordinating the day to day supports, both paid and unpaid, that have enabled her to live in her own home for the past five years. Up until 2012, Catherine had spent 17yrs working at Family Advocacy and has guided hundreds of families in their negotiation with the many 'systems' they encounter and continues to do so. Catherine now has her own consulting business in Sydney.

Figure 1: Future Planning Event

The link between family and systemic advocacy

In addition, family advocacy enables families to come together to make systemic change. This happens both when numerous families contact Family Advocacy about an issue that has systemic roots, such as school enrolment refusal, and when Family Advocacy leaders and staff become aware of issues at the systemic level, such as a review of the Disability Discrimination Act Education Standards and alert families that they may wish to contribute to positive change in that area.

This link between advocacy capacity development with individual families and systemic advocacy can be seen in campaigns such as 'Kids Belong Together' in the 1990s. When thousands of parents of children with disability were being refused enrolment in the regular class of the local neighbourhood school, families and advocacy agencies campaigned to change education policy and education infrastructure so that students with disability could expect a quality education together with their peers.

Later, Family Advocacy ran a campaign about individualising accommodation funding so that people with disability could have homes of their own. This campaign resulted in the Supported Living Fund in NSW. This is a type of package that can be used for costs of supports in an individual living arrangement. It is very flexible in that it is portable and can be administered by a service provider of the recipient's choosing. This was the first non-crisis driven accommodation package in NSW.

The key feature of the Framework, that it includes both systemic and individual advocacy types, perfectly encompasses Family Advocacy's vision of advocacy and enables family advocates to have maximum impact. Family Advocacy makes some suggestions for further improving the Framework in the following sections for this submission.

Recommendation 1

That the Framework continues to include both individual and systemic advocacy.

Recommendation 2

That family advocacy continues to be included in the Framework.

The principles of the Framework: guiding the delivery of advocacy for people with disability in a changing environment

Many people with disability and their families rely on advocacy organisations as trusted sources of advice, support and information, particularly in changing times. They may use a trusted advocacy organisation as a filter in an information saturated environment. People with disability will experience massive changes in the systems that affect their lives over the next few years.

Ensuring continuity in the Framework will mean advocacy organisations are able to enact Principle B, which states “[d]isability advocacy promotes the interests and wellbeing of people with disability and promotes their full and valued inclusion as contributing and participating members of the community”.

Family Advocacy commends the principles of full inclusion at B, positive systemic change at C, and diversity at G. We also see possibilities for improvement of the framework and note that there is no reference to families in the principles. We therefore suggest that as well as principle F that

Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy;

a new principle could state that

Disability advocacy strengthens the capacity of the families of people with disability to speak out for the rights, interests, needs and inclusion of people with disability by actively supporting and encouraging family advocacy.

This would further embed the notion that family members have a role and a responsibility in making sure their family members with disability are included and live valued lives, and that advocacy skills and capacity development are required to make that happen.

Recommendation 3

That the Framework continues in order that people with disabilities and their families can access trusted, inclusion-focused sources of advice, support and information, particularly in changing times.

Recommendation 4

That the Principles also state that:

disability advocacy strengthens the capacity of the families of people with disability to speak out for the rights, interests, needs and inclusion of people with disability by actively supporting and encouraging family advocacy.

The outcomes of the Framework

Family Advocacy believes the outcomes of the Framework reflect the needs of people with disability, and have widespread relevance in the advocacy sector. Below we discuss the outcomes as they have applied to systemic advocacy for inclusive education in NSW over the past decade. This systemic advocacy has been informed by family advocacy. As discussed earlier in this submission, in the 1990s the 'Kids Belong Together' campaign challenged the exclusion of kids with disabilities from local schools. More recently, family advocates have pushed for, and achieved with government, progress for inclusive education, and we demonstrate how this corresponds to the outcomes of the Framework with a few examples below.

Outcome A states that advocacy should contribute so that:

people with disability are accorded the rights and freedoms described in the United Nations Convention on the Rights of People with Disabilities and other relevant United Nations Rights Treaties;

The principle of inclusive education was adopted at the Salamanca World Conference (UNESCO 1994) where inclusive education was viewed as a human rights issue and as a means of bringing about personal development and building relationships among individuals, groups and nations. This was stated clearly in Article 2:

Regular schools with an inclusive orientation are the most effective means of combating discrimination, creating welcoming communities, building an inclusive society and achieving education for all.

Family Advocacy has advocated for the presence of specialist teachers in regular local schools since 2007 when we began a campaign called 'Help When it's Needed', so that teachers, student learning support officers and students with disability pursuing a mainstream education, would have help on site. In 2012, as a part of a National Partnership, the NSW Department of Education and Communities implemented this policy with a suite of other measures called Every Student Every School.

Outcome B and C of the Framework also state that advocacy should contribute so that:

people with disability achieve economic participation and social inclusion;

and

people with disability enjoy choice, wellbeing and are supported to pursue their life goals;

A key part of economic and social inclusion is learned at the school level where expectations are set. Studies show those students with disability included in mixed rather than congregate environments have better educational and vocational outcomes. A key part of this is moving away from the stigma of diagnosis to a focus on needs of a person, diverse learning styles, and appropriate adjustments of lessons. Accordingly, Family Advocacy has long advocated that planning for individual students should be based on their education and support needs rather than disability label and IQ testing. Through advocacy and working with government we were very pleased to also see the introduction of a functional assessment tool as part of Every Student Every School. The Personalised Learning and Support Signposting Tool means that students no longer have to be labelled with a diagnosis to receive support. This removes a barrier to inclusion in education and sets children up positively for the future.

Family Advocacy considers that the outcomes would be improved by the inclusion of an outcome focused on natural supports for people with disability such as:

People with disability are supported to have a network of natural and informal supports, including family advocates. Families are supported to advocate for their family member with disability where needed.

This outcome would encourage the development of natural networks for people with disability. It would also reflect the importance of advocacy skills and capacity development by people likely to have long-term relationships with people with disability.

Additionally, Family Advocacy wishes to emphasise the importance of outcome E, which states:

people with disability receive independent advocacy support that is free from conflict of interest;

This outcome is fundamental to the effectiveness of advocacy, which may involve supporting people to make decisions regarding their resources. If an organisation also provides services or non-advocacy or capacity building supports to people with disability, there is a fundamental conflict of interest. Therefore we strongly encourage the maintenance of outcome E.

Recommendation 5

That the outcomes in the Framework be maintained, as they provide appropriate measures and accountability for advocacy by and for people with disability.

Recommendation 6

That an additional outcome focused on natural supports for people with disability be included, such as:

People with disability are supported to have a network of natural and informal supports, including family advocates. Families are supported to advocate for their family member with disability where needed.

Recommendation 7

That outcome E, which reflects the importance of protection from conflict of interest, be maintained.

The outputs of the Framework

Family Advocacy supports the outputs of the Framework. They emphasise tailoring of individual advocacy, collaboration and coordination, and positive contributions to policy and practice. We argue that, as shown in the many positive contributions to individual lives and government policy outlined above, the current Framework outputs remain relevant.

However, Family Advocacy does identify a gap in terms of an outcome that reflects the results of families advocating for their family members with disability. We suggest the following output be added:

Disability advocacy which builds the capacity of family leaders who can advocate both systemically and for the interests, rights, needs and full inclusion of their children and siblings with disability.

This is particularly important as family leaders play a crucial role in contributing to individual inclusion and thus also to systemic progress for people with disability.

Recommendation 8

That the following output be added to the Framework:

Disability advocacy which builds the capacity of family leaders who can advocate both systemically and for the interests, rights, needs and full inclusion of their children and siblings with disability.

Conclusion: Needs of people with disability and their families in the current and future disability environment

Family Advocacy considers that the Framework has been a positive force in the sector. It was developed in collaboration with advocacy organisations, and thus has widespread legitimacy. Family Advocacy's view is that keeping the broad structure of the Framework, and the general principles, outcomes and outputs, with some necessary adjustments for the NDIS environment, will provide continuity for people with disability who rely on advocacy organisations.

For people with disability, the NDIS is only one piece of the puzzle, as entrenched direct and indirect discrimination remains. Advocates want to ensure that when people with disability face barriers within the NDIS and within broader society, they have an independent, effective and experienced voice behind them. We believe this is a cost effective and common sense way to address the vulnerabilities of people with disability. While there are few studies on advocacy itself, one study on legal representation showed that representatives were less adversarial and got better outcomes than other resolution mechanisms, including self-representation (Hunter 2003). Demonstrating the positive outcomes shown in this submission, the National Disability Insurance Agency Regional Director of the Hunter trial site Lee Duncombe stated at a recent conference that "we contact advocacy organisations often and I can't think of a case where that hasn't been positive."

Selected References

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