Response to the National Disability Advocacy Program Review

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Summary of Recommendations

1. That NDAP continue to recognise and support the specific models of advocacy, particularly family advocacy, and consider the benefits to people with disability of expanding our model of family advocacy as a model nationwide.
2. That the NDAP continue to facilitate and support a national networking and coordination body or bodies for the advocacy sector, and reconsider the recent funding cuts to peak bodies.
3. That funding be commensurate to support the access levels that are expected by government, and needed by the population.
4. That funding for innovative methods of access be provided, on the proviso that this does not reduce expectation of face to face interaction.
5. That further research on the impact of advocacy is conducted with those who access our services, and other advocacy services. This research should be funded by government, and undertaken with suitable academic researchers from the Australian university sector.
6. That a tender for the NDAP should have a select tender process that disallows traditional service providers from applying, as service providers performing advocacy would present a significant conflict of interest. We would suggest capacity development, which does not involve direct service provision or individual plan funded line items for families, does not fall into this category. We also suggest that the tender should only be open to the advocacy sector at this stage.
7. That any organisation funded to perform advocacy should have clear guidelines about how it will present the people it represents, and clear guidelines around genuine inclusion.
8. That NDAP should continue to provide funding for support and representation for people with disability in all areas of the justice system, and increase this funding in line with the statistics that show their massive over-representation in the criminal justice system.

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 25 years ago 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:

- building the abilities of families to undertake an advocacy and leadership role;
- 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;
- and auspicing a successful ongoing capacity building project, called Resourcing Families.

The focus of our submission is on the impact of the National Disability Advocacy Program (NDAP) 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, in particular for those who have intellectual, or severe or complex physical disabilities, 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.

Our organisation's planning is shaped around these goals and the ongoing sustainability of family advocacy, both as a model and as an organisation.

For the past 25 years, Family Advocacy has made it our priority to share stories, resources and support for families to advocate for their children, and also to make the inclusive journey easier for families by making change systemically. Below is a case study from Elizabeth, whose son Michael now lives a good life.

Case study: Elizabeth and Michael

My son Michael is now 49 years old so my history with Family Advocacy goes back quite a long time.

I had been complaining to services for a long period about their attitudes, service delivery, lack of interest, lack of age appropriate services etc. Back then I did not have any support.

After my very first Family Advocacy workshop I came home with such joy because I KNEW THEN that I was not asking/expecting too much, I was on the right track.

I attended as many workshops as possible knowing that I would feel refreshed and inspired to continue my advocacy. I travelled to Sydney and Family Advocacy came to Coffs Harbour.

For families like mine, in country NSW, Family Advocacy offers superb support, guidance and education.

I am now supporting one of my son's workers to attend as many workshops as possible.

Families may also contact us via telephone or in person for seemingly smaller or more specific issues, such as trouble at school. We are a trusted source of information and advice. We encourage parents to have a guiding vision of the good life described above, as this vision, while seemingly obvious, is not always automatic for people with disability and their families. Conflicting messages and expectations from doctors, therapists, early intervention specialists and special educators communicating low expectations and segregated pathways abound. We aim for children to have the most regular lives and best relationships possible.

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.

1. Models of advocacy

Family and systemic advocacy for people with disability

The current models of advocacy include family advocacy with good reason. Family advocacy is a model that harnesses the most important and constant of relationships in the life of a person with disability – their family. It empowers family members to be advocates for their family member, promotes and protects the rights, interests and needs of the person with disability, and encourages lives full of potential. It enables 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 members undertake this role instinctively and without formal support. However, funded family advocacy support means that families can undertake this role more effectively with a deeper understanding of the issues, pitfalls, and possibilities. This has two particularly important rationales, outlined below.

Firstly, the institutional knowledge built up by families and staff of Family Advocacy is extremely 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.

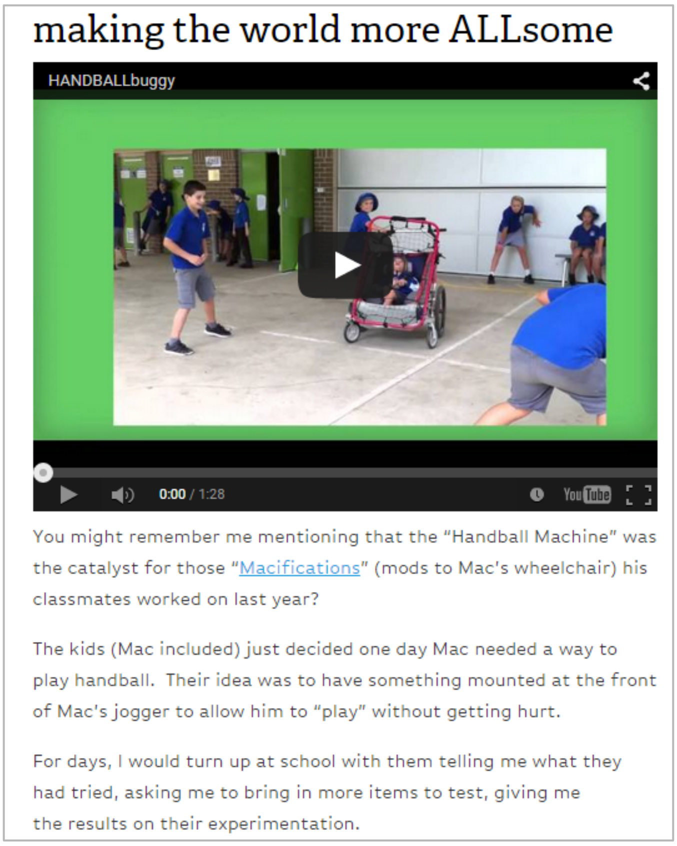
Family Advocacy is adaptable, and indeed, has already adapted to the NDIS environment. Our successful Capacity Building project, Resourcing Families, is funded for $450 000 per annum until 2018. This project was founded in 2010 when we became aware that although families wished to follow a more individualised path, they lacked some of the skills and information needed to individualise their funding. However, our experience is that capacity building has not in any way reduced the need for advocacy. If anything, as families choose to pursue an inclusive pathway, their need for advocacy increases, as this is still a far less common route than capture by direct, congregate services.

Secondly, the family advocacy model 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.

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

Case Study: Gina and Mac

Mac Wilson-Burns *was once described as the 'most disabled child ever to be mainstreamed'. Mac is now in Grade 7, 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 have invented 'Mac-ifications' to include him in activities like handball, class activities and sport.*



making the world more ALLsome

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.

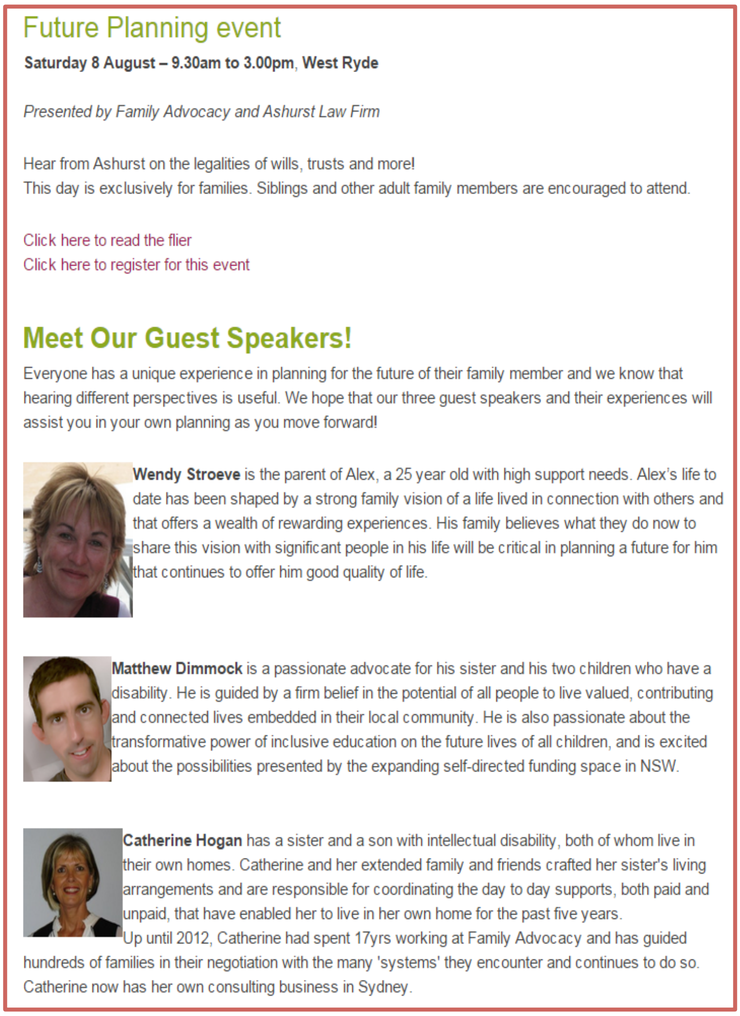
Lots of behind the scenes family advocacy has led to this place of inclusion. His mother Gina is actively involved with Family Advocacy, both personally and with systemic advocacy such as in the NSW Department of Education Stakeholder Advisory Group on Specialised Support Classes. Meanwhile, Mac (age 12) 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.

As can be seen from the above example, family advocacy is distinct from carer advocacy in that it solely prioritises the person with disability.

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 representation, 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 - as a model and in practice - 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.

Future Planning Event

Recommendations

1. That NDAP continue to recognise and support the specific models of advocacy, particularly family advocacy, and consider the benefits to people with disability of expanding our model of family advocacy as a model nationwide.

2. That the NDAP continue to facilitate and support a national networking and coordination body or bodies for the advocacy sector, and reconsider the recent funding cuts to peak bodies.

2. Improving access to advocacy supports

The availability of advocacy for people with disability is less than ideal, as expressed in the discussion paper. Family advocacy support is only widely available in NSW, despite the fact that we frequently advocate on issues at a federal level. For small organisations geographic accessibility can be a challenge, however Family Advocacy addresses this in a variety of ways.

Family Advocacy makes advocacy support available across NSW in four main ways:

- our toll free telephone advocacy support service available to families across NSW,
- traveling to regional centres to present workshops and conferences,
- funding family leaders from regional areas to take part in leadership activities,
- and partnering with culturally and linguistically diverse groups to make our material available to different communities.

In 2015-16 we made trips to 28 regional centres to present workshops as well as presenting three regional conferences ‘Harness the Possibilities: Enriching Lives in Changing Times’ in Coffs Harbour, Dubbo and Wagga Wagga. The main thing that limits access to family advocacy support for people in regional communities is funding. If we were funded to do so we could make regional trips an even bigger part of our core business. While the telephone service and website make great resources for people in both regional and urban areas, there is nothing like a face-to-face conversation to build trust and understanding, both on the part of the advocate and the person with disability and family member.

We also highlight that access must be considered along with quality, meaning depth of knowledge is particularly important. Bad advocacy advice can have very negative impacts on outcomes for people with disability. Therefore expansion of access needs to be both properly funded and monitored for quality, and in advocacy, quality requires deep knowledge and a vision of a good life for people with disability. This is something that is built up by experience of a strong community, such as family advocacy, and is an argument for the continued specificity of advocacy agencies.

One successful example of our engagement with Aboriginal and Torres Strait Islander communities was through our recent regional conferences. Family Advocacy invited the Aboriginal Disability Network NSW (AND NSW) to be part of the conference and provided space for AND to offer their sessions of Living My Way. We sponsored anyone from an Aboriginal background who wanted to attend. Dianne, an AND NSW staff member, was often in the area before the conference and we were happy to sponsor anyone she suggested would like to attend. Thus she could make a personal invitation to people who may not have registered otherwise. The Living My Way sessions were open to anybody who was interested, so a number of people from the general community went to the sessions who were interested to learn how Aboriginal people are encouraged to think about the national reforms.

Case Study: Alex and Dan

Alex is Dan's Dad. They both live in Grafton, in Northern NSW. 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.

Recommendations

3. That funding be commensurate to support the access levels that are expected by government, and needed by the population.

4. That funding for innovative methods of access be provided, on the proviso that this does not reduce expectation of face to face interaction.

3. Improving the advocacy evidence base and coordination on systemic issues

Networks and institutional knowledge of existing advocacy organisations are wide and deep. Family Advocacy works regularly with many organisations, including but not limited to: People with Disability Australia, Local Government NSW, NSW Council of Social Services, Disability Advocacy Network Australia, the Council for Intellectual Disabilities, and the NSW Ombudsman.

Family Advocacy has implemented new data management systems in the past two years in order to capture details of our work more concretely. Some key findings show that:

- education continues to be the main source of inquiries, continuously accounting for more than a third of telephone and in-person contact;
- families continue to struggle with the service sector, whether in individualised funding models or block funding.

While co-ordination may be beneficial, key advocacy organisations are established from and facilitate active communities. Their institutional knowledge is usually deep and the specificity of that knowledge is often what enables us to give sound advice. While the work we do is specific, we regularly co-ordinate with the NSW Ombudsman's Disability Roundtable, the Community Living Consultation Group (established to monitor the devolution of the Stockton Centre), the Disability Network Forum facilitated by NCOSS, the NSW Department of Education, the NSW Disability Advocacy Network, Disability Advocacy Network Australia, and many other working groups and Advisory Groups. In our experience of these networks, the benefit of the specific knowledge of the various advocacy groups comes to the fore.

We recommend further research on the impact of advocacy be funded and conducted with those who access our services. Recently, our Capacity Building project, Resourcing Families, was subject to research. The research asked initial questions of workshop attendees and then followed up with them two months later. The final evaluation report found extremely positive effects for families and their actions for their family member with disability over a period of several months after their initial contact with the project. Our view, based on this evidence from one part of our organisation, is that research on advocacy's immediate impacts and impacts over time will show the benefits and challenges of advocacy and provide a greater evidence base for our work. Family Advocacy would also support well-resourced, sector wide collection of data in the advocacy sector.

Recommendations

5. That further research on the impact of advocacy is conducted with those who access our services, and other advocacy services. This research should be funded by government, and undertaken with suitable academic researchers from the Australian university sector.

4. The interface with the NDIS and addressing the conflict of interest

Family Advocacy is still in the process of deciding whether applying for NDIA funding fits with our mission and strategic plan. Nonetheless we consider that managing conflict of interest with various funders is something the organisation has had to navigate since its inception. The primary way we have done this is through ensuring we do not provide services beyond advocacy and leadership development, and more recently, capacity building.

As a model, family advocacy recognises the conflict of interest that can sometimes be present between parents and their children, and promotes ways to recognise, minimise and protect the person with disability from this conflict. Service providers often cater to the concerns of family members, as well as economies of scale, the needs and mission of their service and so on. One of the ways Family Advocacy as an organisation does this is by being mission driven, rather than membership driven. While we do have members, and encourage their maximum involvement in all that we do, we are driven by a guiding vision of families making positive social change so the inherent value of people with a developmental disability is recognised. This vision guards against the temptation to advocate for the interests of families themselves, rather than the family member with disability.

The framework behind much of our work, Social Role Valorisation, also helps us to manage conflict of interest. Briefly, it focuses on the positive representations of a person with vulnerabilities in all aspects of their lives. We do not 'play up' worst-case scenarios for funding or any other purposes and instead represent what is possible with the power of advocacy and natural social supports. We would suggest that any organisation funded to perform advocacy should have clear guidelines about how it will present the people it represents.

Additionally, we would suggest that a tender for the NDAP should have a select tender process that disallows direct service providers, as service providers performing advocacy would present a significant conflict of interest. In this time of change we would argue that the tender should only be open to the advocacy sector. We suggest capacity development, which does not involve direct service provision or individual plan funded line items for families, does not fall into the category of direct service provision.

Recommendations

6. That a tender for the NDAP should have a select tender process that disallows traditional service providers from applying, as service providers performing advocacy would present a significant conflict of interest. We would suggest capacity development, which does not involve direct service provision or individual plan funded line items for families, does not fall into this category. We also suggest that the tender should only be open to the advocacy sector at this stage.

7. That any organisation funded to perform advocacy should have clear guidelines about how it will present the people it represents, and clear guidelines around genuine inclusion.

5. Understanding and improving access to justice

People with disability have a particular vulnerability to the criminal justice system, due to the tendency to label them as deviant, a nuisance, or a menace. Recent research led by Professor Eileen Baldry of the University of New South Wales shows that people with disability have significantly more contact with the criminal justice system than those without a disability. In NSW they are three to nine times more likely to be in prison than the general population (McCausland et al 2013: 3). This risk is even greater if the person is Aboriginal or Torres Strait Islander.

This overrepresentation of people with disability in the justice system is partly about contact with the police. Police are often the only social service that will respond to a crisis for an Aboriginal family (Baldry et al 2015). The fact that police are often the only service a family interacts with, highlights both the importance of continued funding for alternate services, including advocacy, and of access to advocacy for Aboriginal and Torres Strait Islander families.

Additionally, people with disability often struggle to get what they need from legal systems. This can be due to difficulty understanding or engaging with the law and its institutions, or the discrimination or unwelcoming attitudes they may receive if they do engage with legal processes. A person with disability may have to engage in legal proceedings regarding guardianship, disability discrimination, or for any reason others might. It is essential that support is provided for both the urgent situations involving the criminal justice system and the equally important day to day struggles. NDAP should continue to provide funding for support and representation for people with disability in all areas of the justice system, and increase this funding based on the very real need.

Recommendations

8. That NDAP should continue to provide funding for support and representation for people with disability in all areas of the justice system, and increase this funding in line with the statistics that show their massive over-representation in the criminal justice system.

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