Submission to the NDIS Joint Standing Committee into the NDIS Quality and Safeguards Commission

> ***"The complaints system we have relies on people with disability making complaints rather than being proactive... the power differential is so great."***
>
> Eleanor Gibbs, People With Disability Australia, whilst giving evidence at the Royal Commission
> into Violence, Abuse, Neglect and Exploitation of People with Disability,
> Public Hearing 5: COVID-19, Sydney, 19 August 2020

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Acknowledgement:

Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

Introduction

Family Advocacy is a state and federally funded disability advocacy organisation that works across New South Wales (NSW) and was founded 29 years ago by families who were concerned with the rights and interests of people with developmental disability[1] (hereinafter “disability”) over the span of their whole life. This includes Australian First Nations people and culturally and linguistically diverse people with disability. Some of the areas we provide support in include education, employment, housing, guardianship and NDIS.

We provide support in the following ways:

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

Our goal is to advance and protect the rights and interests of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. This includes the right to live safely and with dignity, free from violence, abuse, neglect or exploitation. We recognise that the advocacy undertaken by families can be the greatest safeguard in their family member’s lives.

Our work includes specific funding and activities around the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereinafter, the Disability Royal Commission). As such, part of our policy and advocacy work involves being discerning and constantly questioning the quality and effectiveness of any disability service.

One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so that they have more choice and control over decisions and supports that facilitate individualised lifestyles for their family member. This includes making the most of emerging opportunities for self-directing supports through individualised funding.

In this way, we believe our purview lies in alignment with the overall objectives of the NDIS, with a similar aim to provide transformational benefits to the lives of people with a disability. Putting the person with disability at the centre of the decision making with regard to arrangements and supports is a critical component of this. And it is with this in mind, that we also are strong promoters of self-managing within the NDIS scheme. We believe this is

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[1] Developmental disability is a disability that occurs in the developmental period of a person’s life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability.

the preferred gateway to achieving self-determination, social and economic inclusion, peer support and contemporary living models including the right to a mainstream life for people with disabilities.

Family Advocacy welcomes the opportunity to provide a submission to the NDIS Joint Standing Committee's (hereinafter, the Committee) inquiry into the NDIS Quality and Safeguards Commission (hereinafter, the Commission), as part of its role to inquire into the implementation, performance and governance of the NDIS. We note the Commission is an independent agency established to improve the quality and safety of NDIS supports and services[2]. The purpose of the Commission is to regulate NDIS providers, provide national consistency, promote safety and quality services, resolve problems and identify areas for improvement[3].

Our answers and recommendations in this submission are premised on:

- nearly three decades of experience working with families who have promoted and defended their family members' interests and rights;
- our widespread knowledge of national and international research in the field of safeguarding;
- the principles espoused in United Nations' *Convention on the Rights of Persons with Disabilities* (CPRD). As Australia has signed and ratified the CPRD, any strategy concerning people with disability must be based on its principles; and
- a recent survey, undertaken during the Covid-19 period, whereby 32 families responded.

For confidentiality reasons, the names of the parent and their child with disability have been purposefully deidentified. For ease of reference, we have used the same alphabetical numbering system for the questions as per the Terms of Reference.

a. The monitoring, investigation and enforcement powers available to the Commission, and how those powers are exercised in practice

We welcome the establishment of the Commission that has powers to register and regulate NDIS providers, respond to complaints, develop national worker screening standards and oversee behaviour support and the use of restrictive practices. We acknowledge that the legislation provides the Commission with extensive compliance, enforcement, monitoring and investigation powers in many aspects, and these are critical for people with disability to have protections from violence, abuse and neglect when using supports and services under the NDIS.

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[2] https://www.ndiscommission.gov.au/

[3] Ibid.

However, Disabled People's Organisations Australia (DPO Australia) have consistently raised concerns that some elements of the Commission are weaker than others[4] and we reiterate these concerns.

"…the establishment of the NDIS Commission will not provide comprehensive protection against violence, abuse and neglect for all people with disability across a broad range of service systems and situations. We note that our support for an independent, national statutory mechanism and the recommendation from the Senate Community Affairs References Committee was not confined to the NDIS. DPO Australia has consistently highlighted that the NDIS Commission will only provide protection to the 10% of people with disability who directly access NDIS supports. It will not have a mandate to address individual or systemic issues outside of the NDIS. This means that the majority of people with disability, as well as NDIS participants when interacting with other service systems, will only have protection through existing regulatory and policy frameworks that have to a large extent been shown to provide inadequate protection."

Indeed, it is the failure of regulatory and systemic systems that have been found in the State based and national inquiries which have led to a call for and ultimately the establishment of a Royal Commission in the Violence, Abuse, Neglect and Exploitation against People with Disability. The recent tragic death of Anne Marie Smith in South Australia brings to the public's attention the failure of various service systems and oversight mechanisms. Therefore, we need urgent changes to improve the way the current safeguarding is overseen and implemented.

Family Advocacy wishes to refer the Committee to the 2018 Australian Human Rights Commission (AHRC) report, *A Future Without Violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings*;[5] and suggest the same recommendations be adopted. There is no need to reinvent the wheel, there has already been detailed work examining the key elements of effective quality, safeguarding and oversight mechanisms in the disability sector, more specifically those in Chapter 2. The 'essential elements' identified by the AHRC are:

- a human rights-based approach
- a connected and integrated system
- independent oversight and monitoring
- robust prevention and response elements
- accessibility for people with disability
- continuous systems improvement through data.

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[4] Disabled People's Organisations Australia (DPO Australia) Submission to the Senate Community Affairs Legislation Committee Inquiry: National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017 https://dpoa.org.au/tag/national-disability-insurance-scheme-ndis/page/3/

[5] Australian Human Rights Commission (2018), *A Future Without Violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings*. Available: https://humanrights.gov.au/our-work/disability-rights/publications/future-without-violence-2018.

To ensure these elements become a reality in current safeguarding approaches across the country, much work is required. This report was released in 2018, some two years ago, and it appears not many changes have been made.

b. The effectiveness of the Commission in responding to concerns, complaints and reportable incidents – including allegations of abuse and neglect of NDIS participants;

The need for more awareness and accessibility

"The actual number of people with disabilities who were abused or neglected was much higher than the number of reports… There are many people who, because of their disability or circumstances, physically cannot use the safeguard system to report." Senator Jordan Steele-John[6]

We ask the question as to why we had a relatively low response to our survey compared to our usual response rate where we ask families to share their experiences. It could be because it coincided with Covid-19 period and families were even more stretched emotionally and timewise than they normally already are. Or could it mean that not many people know about the Commission, they don't come forward as they distrust systems generally, have lost faith that they can make an impact, or that they don't know they have the right to complain, how to complain, where to complain or any right of appeal if they are dissatisfied with the outcome.

Despite the sample being relatively small, with 32 people, there was some very useful qualitative data that we have peppered throughout the submission. When asked to rate the effectiveness of their dealings with the Commission, came up with an average score of 5, with 1 being extremely poor and 10 being excellent. It is worth noting, the responses were not all average but very much skewed at either ends of the spectrum which gave the reading of 5.

A few positive comments from family members based on their experiences:

> *I found them extremely professional & helpful to achieve the outcome I wanted for my son. Their staff demonstrated thoroughness and empathy in all their communications.*
>
> Survey respondent

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[6] https://www.abc.net.au/news/2019-04-10/ndis-abuse-neglect-watchdog-serious-incident-reports/10986370 - April 2019

> *The Commission has had the single biggest impact on improving quality of service provision and the disability sector is still working to measure up. I applaud the Commission for its work.*
>
> Survey respondent

In the positive, 71% said they would use the Commission in the future. But this positive view has unfortunately been drowned out by the voices of families that have been overwhelmed with the implementation of the NDIS. Despite the good intentions of the NDIS, many feel “worse off”. They are experiencing a myriad of problems with the implementation of their NDIS plan in providing choice and control and when they seek out the Commission, they are finding the response too slow, plus there is a lack of accountability.

Some feedback is that the Commission’s process is slow, frustrating and stressful. All of this comes at a cost to families. An overwhelming number of families who responded to our survey feel their NDIS and Commission experience has been alienating, time wasting and has created mistrust and disillusionment. This highlights the need for independent advocacy to ensure that people with disability have their rights promoted and protected.

> *It should state a reasonable timeline of response from a provider on acknowledging a complaint for whatever reason from the participant or their advocate. I do not think that 2 weeks wait time for a response as stated by the NDIS Safeguard Commission is a reasonable time. A complaint should be addressed by the Provider within a day as receipt of having received the complaint and that they will get back to you (naming a timeframe less than 2 weeks).*
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> Survey respondent

> *My daughter is now with the third provider. None of my complaints or my daughter's complaints were investigated because of lack of staff. My complaint was handled in NSW when my daughter rang it was handled from WA because there was not staff available, then it was transferred to staff in Vic and went nowhere. Did not hear back.*
>
> Survey respondent

> *The numerous times that I have contacted, it was difficult to get answers and staff provided different feedback. I have had to get them to put in writing just as evidence of what was discussed.*
>
> Survey respondent

As far as we understand it, when a complaint is made by a participant, the Commission just calls the provider and believe what they say without proper, robust, balanced investigation. The person with disability is then devastated and loses all confidence in the complaints process. It places the burden on them once again to do all the heavy lifting, the system should be proactive in stamping out poor practices. The person with disability often is so devalued with a lifetime of microaggressions[7] they don't realise that how they are being treated is wrong or they have given up trying to fight for their rights as they feel powerless. The power imbalance is immense.

We are concerned with the low prosecution rate and very few charges thus far. The Committee's Progress Report 2019[8] revealed in 2018, of the 1,459 reports, almost 500 were related to the abuse and neglect of NDIS participants. Yet the NDIA had only revoked 316 provider registrations: 88 voluntary revocations due to a change in the business or personal circumstance of the provider; 39 revocations due to compliance action undertaken against the provider; and 189 other revocations that were not easily grouped under a single category but often a result of voluntary revocation initiated by the provider[9]. In the period July-December 2019, of the 69,397 reportable incidents received by the Commission, only 1,102 were reported to police. This is despite 2,665 alleged incidents being related to abuse and neglect (1,704), allegations of unlawful physical/sexual contact (779), and alleged sexual misconducts (182)[10] .

We are also concerned within the reportable incidents, 65,398 are unauthorised use of restrictive practices. There is a strong relationship between the use of restrictive practice and other forms of violence, neglect and abuse against people with disability which undermines the ability of people with disability and support workers to recognise violence and respond to it as a crime. The Commission simply monitors compliance of practices whereby states and territories continue to authorise these practices under each jurisdiction's legislation and policy, which are varied and inconsistent. This highlights one example where gaps and inconsistencies can be present when different jurisdictions' regulatory bodies or government departments fall outside the remit of the Commission. On this basis, we recommend the Commission should have the strongest powers possible with regard to the elimination of restrictive practices.

Further, we are concerned with the power imbalance whereby the onus for making complaints lies with people with disability, their families and carers (as the quote on the title page asserts). The Commission remit is limited in that it can only respond to complaints. From these observations, it appears the Commission is fairly passive as a regulatory body focused on service quality. We recommend the Commission be more proactive in monitoring

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[7] Dr Leanne Longfellow, Death by a Thousand Cuts, Disability Mcroaggressions in Education, IEP Inclusive Education Planning, https://drive.google.com/file/d/1XhcluyPmSjRQK9FNlotbkgPYU7Gvzii8/view

[8] https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/Report, (tabled 29 March 2019), Chapter 1 - Introduction, NDIS Quality and Safeguards Commission, Page 11.

[9] NDIA, *COAG Disability Reform Council Quarterly Report*, 31 December 2018, p. 31.

[10] NDIS Quality and Safeguards Commission Activity Report: 1 July 2019 to 31 December 2019 https://www.ndiscommission.gov.au/document/1921

human rights breaches, outreach to people with disability where a provider may be subject to an investigation, having “teeth” when it comes to unlawful practice and challenging systemic enablers that allow abuse and neglect to continue.

When asked if their dealings with the Commission restricted their flexibility and control, a significant 67% said “Yes”. One comment from a person with disability self-managing their NDIS funds:

> *To an extent. I have been told by a representative from the Service Provider that as self-managed I can choose another Service Provider. No negotiation with this Large Service Provider - their way or the highway. There is no flexibility nor control.*
>
> Survey respondent

c. The adequacy and effectiveness of the NDIS Code of Conduct and the NDIS Practice Standards;

Below are comments provided by our survey respondents, which suggest service providers pay lip service to the Code of Conduct and the Commission is not being strong enough in exercising its full powers:

> *My complaint took several weeks to address. I received notification that my son's support worker was cancelled at approximately 4.45pm on a Friday afternoon and he needed support at work the following Monday. The Service provider ignored my phone call and subsequent email that evening. I contacted the NDIS Quality and Safeguards Commission in response to the advice I received from a person on the NDIS hotline. The delay in the Commission's attention to this urgent matter was appalling. Apparently, the representative from the Commission did not consider this matter urgent. Although the matter was "resolved" it was not resolved adequately nor did the Commission get the truth from the Service Provider. The Service Provider was not penalised and I felt the whole matter was written off as due to COVID-19. A time when support in the workplace was of paramount importance to my son! My son has flexible supports and at the time the Service Providers on the website had stated flexible supports would continue. What does the NDIS Code of Conduct and the NDIS Practice Standards mean when the Commission does not insist that Service Providers meet their obligations under these?*
>
> Survey respondent

> *It is a clear code but I think a lot of staff that work in the industry do not take it seriously.*
>
> Survey respondent

> *Service providers do not always follow the NDIS Code of Conduct and are guilty of bullying tactics, inadequate accounting practises and restrict who they will service which is dependent on the hours a person wants. Is the NDIS Code of Conduct effective - No. It can only be effective if service providers adhere to their obligations under this code. There doesn't appear to be any monitoring of service providers fulfilling their obligations under this code. For self-managed clients the NDIS Quality and Safeguards Commission is the only forum for complaint.*
>
> Survey respondent

> *It means nothing if workers and providers don't adhere to Code of Conduct, they are not accountable to anyone. NDIS safeguards commission is useless to reinforce.*
>
> Survey respondent

Similar comments were provided in relation to feedback on the Practice Standards, expressing the lack of enforcement where breaches occur:

> *Too focussed on choice & control & restrictive practices in group home settings. Not Encompassing all the ways people with disability live.*
>
> Survey respondent

> *I complained to the Quality and Control Commission that the provider had not let me know about incidents involving my daughter even though some of these incidents were quite serious (such as removing her clothes in public). When I did eventually find out about the incidents, (the service provider) refused to give me copies of the incident reports. The Q & C commission refused to make the errant provider comply and the commission told me I would have to seek Legal Aid to follow up on this matter!!!!! There were other issues as well that the commission just seemed to find excuses as to why they didn't need to do anything. The commission even said "if the (provider) does it again then we will write a very stern letter to them" hahahaha what a joke.*
>
> Survey respondent

> *It doesn't mean anything. Just a piece of paper. Providers and many workers have no knowledge of standards, they are not enforced and no real consequences if providers don't follow standards.*
>
> Survey respondent

d. The adequacy and effectiveness of provider registration and worker screening arrangements, including the level of transparency and public access to information regarding the decisions and actions taken by the Commission.

> *I am not sure how the system works but I have dealt with staff stealing food, money and belongings from my daughter's home. Sadly, the person was never charged and left the provider before any legal proceedings. She went on to work for other providers.*
>
> Survey respondent

> *At present it seems any one can register as a provider. The provider in question seemed to know very little about the NDIS legislation, values such as choice and control rights of the clients, listening to their client needs. They were prescriptive in that they provided the services and their client seemed their last consideration. These are very concerning and so measures need to be stricter before providers should be deemed as fit to be NDIS registered.*
>
> Survey respondent

> *I'm not familiar with the screening process however I would like to see some sort of register whereby individual worker's transgressions are highlighted and available to all and become a part of the screening process. This will prevent "bad apples" from moving freely from one provider to another.*
>
> Survey respondent

> *I'm not aware of screening other than the current police and working with children's check. There is a need for a National support worker registration process, where they have to be registered and have an identification card and number. A process is needed to identify workers on a watch list. Workers that behave inappropriately, unprofessionally, abuse etc... should be deregistered for life from working with vulnerable people. Currently they just move on to another service and reoffend.*
>
> Survey respondent

> *Make first aid certificates compulsory!!!! As a matter of fact, it was mentioned in the coroner's court in the matter of the death of an aged care resident (John Reimers) that it is compulsory for Disability Support Workers to have first aid certificates (and the coroner, Audrey Jamieson, was lamenting that it also is not compulsory for aged care staff).*
>
> Survey respondent

> *More empathetic people and no boxes to tick.*
>
> Survey respondent

The comments provided above are some of the reasons why Family Advocacy strongly promote the NDIS Self-management model. From our experience, the mark of quality of a service rests with the character and tone of the interaction between a participant and a support worker. Quality audits do not sufficiently examine that interaction nor its supports. Audits are too preoccupied with items that relate to administration, policy compliance and reporting requirements that reveal little association to factors that influence the actual quality of service. Services that have met audit requirements have been found abusing and neglecting people[11]. And yet, many families we know who self-manage, tend to have great support staff in ordinary people as they have real choice and control over whom they employ and this tends to lead to less staff turnover, more consistency in staff leads to really getting to know the person with disability and their needs/interests and this ultimately leads to more trust and safety. Therefore, we recommend the Commission needs to support safeguarding more innovative models such as the families we know who self-manage, in a way that supports these models to flourish, rather than force those with contemporary solutions to fit into the Commission procedures.

f. The human and financial resources available to the Commission, and whether these resources are adequate for the Commission to properly execute its functions;

The need for more Outreach and Education

We acknowledge the Commission has only been in operation for a relatively short time, having commenced in NSW since July 2018, and is in its early period in terms of implementing its functions/role. We note the Commission's attempts to encourage people with developmental disability to complain thus far, for example, the Speak to Us campaign, and forums to engage with advocates for people with intellectual disability including

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[11] John Armstrong, Submission to Royal Commission into Violence, Abuse, Neglect, and the Exploitation of People with Disability, July 2020.

Family Advocacy. But we recommend there is much more for the Commission to do to comprehensively support and educate people with a developmental disability to enable them to engage with the Commission to make a complaint, and to help them access and understand the safeguarding and protection the Commission can provide. More resourcing may be required to do so.

The need for advocacy

It is our experience that in many cases, a vulnerable person with disability would tend to be hesitant or fearful to take a significant issue directly to an authority or independent body such as the Ageing and Disability Commission or the Disability Royal Commission. For many people experiencing abuse, neglect and exploitation their first port of call would be their community based connections through the advocacy sector. Vulnerable adults generally will only disclose abuse and neglect to people they are familiar with and/or trust. In the first instance, we would provide advice and support concerning serious issues and, where deemed appropriate, support and direct them to the relevant authorities.

We echo the view expressed in the NSW Ombudsman's report into the ‘*Abuse and neglect of vulnerable adults in NSW - the need for action’, 2 November 2018* that:

> *“There is a vital continuing role for community advocates who work with and support people with disability and other individuals who require decision-making and advocacy assistance, and who advocate for broader, systemic issues across a range of life domains.”*

With this in mind, Family Advocacy’s model provides a safeguard to continue the essential work of collaboration so as to ensure the essential multi-layered supports exist for people with disability. We submit that the Commission could access and collaborate with advocacy organisations as another support and oversight mechanism.

NSW disability funding is not guaranteed

We bring to the Committee's attention, and would like to emphasise that this inquiry is being conducted at a time when there is no guarantee of funding for NSW advocacy services post December 2020. We have discussed the need for advocacy, and much more so now during this Covid-19 pandemic. It is critical that the NSW government commit to an extension of the current funding agreements in perpetuity. This will enable any recommendations from the Committee to be considered and where applicable, adopted. It will also provide some stability to facilitate a robust advocacy sector.

g. Management of the transition period, including impacts on other commonwealth and state-based oversight, safeguarding, and community engagement programs;

Community Visitors Scheme

We suggest it is necessary to find ways to strengthen the formal mandates of community safeguards in NSW such as the Community Visitors Scheme. For example, if there were unplanned auditing that could occur, it is more likely that this would provide a higher level of protection and safeguarding. This mandate ought to be extended to private dwellings so as to avoid more cases like Anne Marie Smith's, where a person with disability can be isolated.

h. Any related matters.

Safeguards - People keep people safe and socially valued roles

Whilst we are pleased the Commission exists, it is not the panacea but merely a part of the mix of safeguarding measures of people with disability. When asking the question, "what keeps a person with disability safe?" it is helpful to realise what doesn't. The current approach in our society appears to believe the answer is a cocktail of human services, the NDIS, the government, and legal instruments.

It is not human services that keep people with disability safe. As much as we would like to think otherwise, human services are often run without considering the real needs of people, or how they are going to be of benefit to this person. They use the correct terminology such as 'Person centredness' but this is only at a superficial level, with the driving force being what suits the requirements of the business. The relationship has become transactional, the person with disability has moved into the "customer" role, the focus has moved to costs, the visions of control over one's life has been reduced to choosing from a business menu of product options[12]. In our society's service-oriented approach, we tend to focus on providing people with disability with activities to do, which are not purpose driven or capacity building. Services often coming up with solutions on how people with disability can spend their time. Whilst doing an activity, once a week is better than doing nothing at all, this is very different from supporting the same person to have a valued social role and belong in community and to join in on what is expected of a person of a similar age. Many people and professionals in disability services still carry the assumption that this is out of reach for a person with disability which continues to reinforce the parallel life for people with disability and

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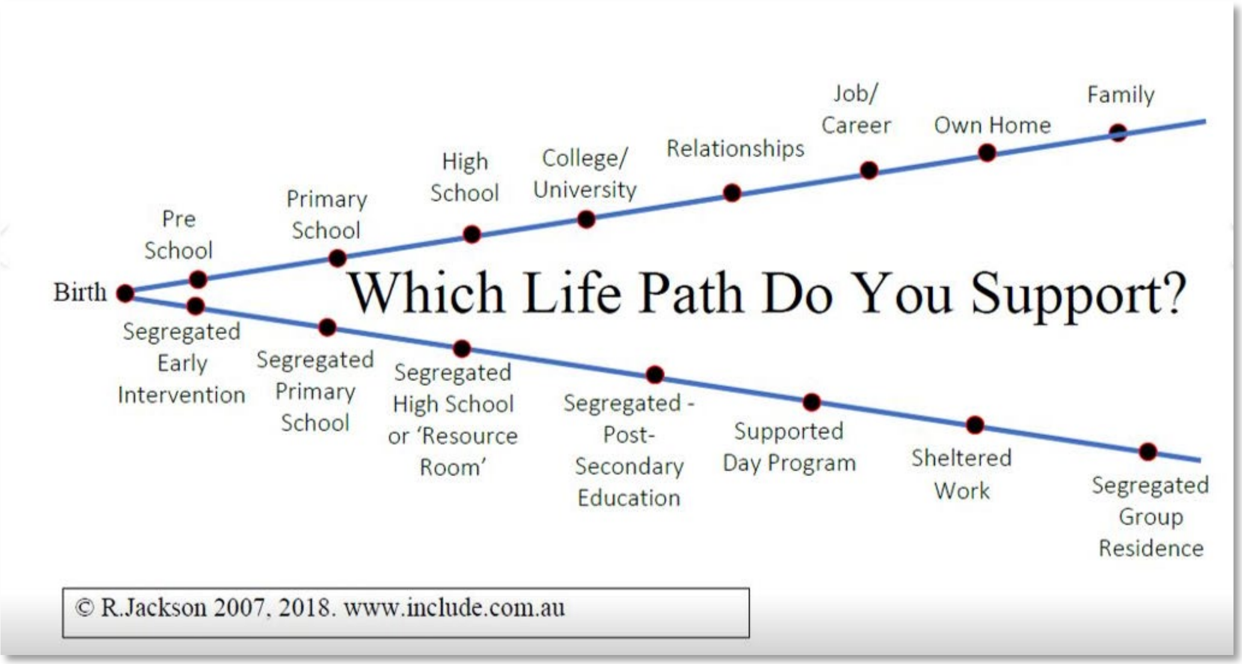
[12] Jane Sherwin, Submission in response to the rights and attitudes paper, Royal Commission into Violence, Abuse, Neglect, and the Exploitation of People with Disability, July 2020.

leaves them at heightened risk. Below is a depiction of the parallel life we refer to as illustrated by Dr. Robert Jackson:



It is not the NDIS that will keep people with disability safe. The NDIS is simply a funding scheme to provide services.

The government will not keep people with disability safe. The need to call for the Aged Care Royal Commission and the Disability Royal Commission are proof of this.

It is not Wills/Trusts that keep people with disability safe. Whilst these legal instruments can be a tool to put the vision for a good life in place, they are not ends in themselves and are inherently limited.

To reiterate, it is people who care and love the person with a disability, so freely given relationships, that keep people safe. Therefore, it is people who care about a person with disability in a freely given relationship that is the best safeguard. This is usually a family member, a work colleague, a flatmate, a friend, a member of the community in which a common interest may be shared. These relationships are a byproduct of the person with disability having socially valued roles[13] that are age appropriate.

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[13] Wolfensberger, W. *A brief introduction to Social Role Valorization. A high-order concept for addressing the plight of societally devalued people, and for structuring human services*. (4th edition.) Plantagenet, Valor Press, 2013.

The 2015 Senate inquiry[14] said that "a root cause of violence, abuse and neglect of people with disability begins with the de-valuing of people with disability." How people with disability are treated at work, at home, at school and in the community matters.

47 per cent of adults with disability have experienced violence, compared with 37 per cent of non-disabled people, according to a report from the Australian Institute of Health and Welfare[15].

On this basis, to bolster its safeguarding capacity, it is necessary for the Commission to promote the importance of socially valued roles to service providers and support workers.

The need to support contemporary innovative structures and support in NDIS Self-Management

> *"The evidence strongly suggests a wide range of positive wellbeing outcomes from self-directed funding for people with disabilities and their carers, including higher satisfaction with life, more independent living, better continuity of care and lower levels of abuse and neglect. Self-directed funding appears to cost no more than traditional models of care, and may well cost less."*
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> Inquiry Report on Disability Care and Support, Productivity Commission, 2011

One of the aims of the NDIS is to assist people with disability to live "an ordinary life" by enabling inclusion and participation in society. That means to fully realise their potential, to participate in and contribute to society, and to have a say in their own future – just as other members of Australian society do.

Family Advocacy encourages NDIS participants to self-manage. However, there are barriers such as a lack of awareness or capacity in the community, lack of positive promotion from the agency, and the onerous process for sole-traders and small businesses to become registered providers. We acknowledge that safeguarding measures are in place to protect the vulnerability of a person with a disability. For example, a speech pathologist should be required to provide adequate qualifications, have an ABN and a Working with Vulnerable People Check, and even a First Aid Certificate. But to put a business plan together makes this process too onerous and takes away any motivation to become registered. This barrier means sole-traders, such as therapists, will not be available to a participant who wishes to plan manage or agency manage as they can only use registered providers. There is no real "choice and control".

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[14] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report/b02

[15] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/justice-and-safety

Further, we have many examples where the right support worker that stays with the person with disability for years often does not have any disability specific training and this works really well in self- management. The answer to accountability is not simply compliance based policies or a particular set of training unless those who are providing the service have a foundation of worth and deep respect for the person with disability[16].

There is strong feedback from families that there is a large vacuum of knowledge about self- management on the part of LACs, planners and service providers, who often play the role of support coordinator as well. (This comes with a conflict of interest.) One LAC told a family member that she should not self-manage as it was too complicated and meant she had to get insurance. One planner told a family member at the annual review that if she wanted to self-manage, she would have to pay for all the supports upfront then apply to the NDIA to be reimbursed. Without the correct knowledge or understanding, it appears the LAC/planner/service providers are filling in the gaps and providing their own opinion on self-management, even when it is incorrect. We question whether a service provider would even give a participant the option to self-manage as it is not in their business interests. The Commission can assist in its outreach/awareness program to ensure a participant is provided with the correct advice about their options regarding self-management.

Also, more depth and breadth in training is required from those with experience based on the social model of disability, have a deep understanding of what makes an ordinary life with socially valued roles, and have knowledge of the UNCRPD (United Nations Convention on the Rights of People with Disability). Family Advocacy would be happy to assist in this regard by linking the Commission with the appropriate teachers in Australia.

> *People who self-manage have no voice. The only means to be heard is to list the complaint with the Commission. The Commission needs to address these complaints quickly and fairly. People with disabilities are already disadvantaged. The process for complaints is unreasonable and too technical for them. My son has an intellectual disability. The NDIS has become a monstrosity on so many levels. We don't need more bureaucracy, we need simplicity and understanding of their needs. The Commission needs to refocus and be a forum for people with disabilities to make sure Service Providers adhere to the NDIS Code of Conduct and NDIS Practise Standards.*
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> *Many parents are not aware of the lack of systems in place because they are just desperate for care/respite and believe that all providers do the right thing, trust me they don't!*
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> Survey respondent

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[16] John Armstrong, Submission to Royal Commission into Violence, Abuse, Neglect, and the Exploitation of People with Disability, July 2020.

The need for the Commission to support flexible individualised options

Too much of a "blanket" approach

Survey respondent

Case study:

Allan is a family member whose adult son, James, has very complex needs including behavioural issues. He had been self-managing his son' s supports directly for fourteen (14) years prior to the NDIS rolling out. To his credit, with some creative and lateral thinking, he had managed to obtain a meaningful life with great opportunities for James to achieve valued roles in his community. Importantly, these socially valued roles have also assisted James' behaviour management issues so much so that no therapy is required. Clearly, Allan knows his son best and is the natural authority on James' support needs.

When he received his first plan, his planner told him that he could not use the supports in the way he had been for the last fourteen years. This had serious implications from a behaviour management perspective. To change the routine after such a long time would induce anxiety which would manifest in a physical way thereby creating a safety issue, as James is a large adult male. With some advocacy assistance, further investigation at the senior level of the NDIA (which took several months), revealed that the planner was incorrect.

The above example highlights that the importance of the NDIA recognising that the family is the natural authority for their family member with developmental disability. Families ought to be given the power over what are the most optimal support arrangements for their person with disability. The Commission needs to remain flexible to allow for the fact that one size does not fit all and to allow for thinking outside the square. This would also assist families in rural or remote areas where options are limited.

The other important point to note here is that the above situation only worked well because the person with disability has a family member advocating for him. His father is an educated, competent, connected and confident individual. We are concerned for those who do not have a competent family representative. We strongly doubt that any service provider, with profit as their primary motive, would provide anything other than a cookie cutter approach. Where a service provider is not providing an adequate service to a person with complex needs, or where they decide to not provide them with a service at all, there is no safety net.

We also recommend that where self-management is in place, there needs to be flexibility in approaches if Restrictive Practices are utilised. The question needs to be asked, What does this need to look like to preserve the flexibility of Self Managers? Restrictive practices need to be accommodated differently for people self-managing because *it is different*. Due to the extra safeguarding that comes with this model, it is vital that self-management continues to be supported and promoted by the NDIA and the Commission. Again, the cookie cutter approach should not apply as it does not serve the participant in supporting their needs.

On this point, we question whether the Commission has the right skill set to regulate these more contemporary models of support and it needs to be asked what does the Commission need to do to ensure this. We do not want the same good practice in the service context, we want better new practices. The Commission needs to take a strong focus in supporting these innovative supports with increased expectations and if it does not do so, we are concerned that we really have the same old funding structure but just with a new name. This is problematic.

The need for the Commission to promote and support informal safeguards - Circles of Support

> *I would like the QSC to articulate a restrictive practice related to restricted access to circle of support. Group homes SIL providers routinely restrict access to people in a person's circle of support by failing to answer or return phone or video calls to a person with disability or by discouraging /not allowing unplanned visits. If these actions occur they should be required to be documented with an incident report. Repeated action to restrict access should be treated as unapproved restrictive practice. SIL providers also unreasonably limit access by claiming that access would infringe upon the privacy of housemates or contravene a housemates agreement that is primarily drafted by a SIL provider. SIL providers have a conflict of interest that discourages oversight of the SIL provider by a circle of support. This conflict should be articulated and managed by the QSC to encourage and support access to a circle of support.*
>
> Survey respondent

We recommend a national discussion is needed around the importance of natural safeguards and the proper assessment of a person’s social capital, and find ways to increase opportunities for social inclusion in a participant’s budget. One strategy we recommend as an effective for social inclusion is Circles of Support[17], whereby an intentional circle of support (unpaid) is built around a person comprising of friends, employees, neighbours, family, shopkeepers, support workers. We recommend supports be provided to enable proper access to these Circles of Support say for example, through a participant’s NDIS plan. Like all informal safeguards, this is particularly necessary for people with disability with low social capital. The danger in not doing so is that we will have many more cases like Anne Marie Smith, where people with disability have paid supports but are lonely and at great risk of violence, neglect, abuse and exploitation.

Covid-19 impacts to consider

We know people with disability may be placed in situations where they are vulnerable and profound power imbalances exist. People with disability are discriminated against, often due to unwarranted assumptions or when their needs and preferences are not adequately taken into account. This may be unintentional or undertaken unknowingly. The covid-19 pandemic has highlighted the systemic disadvantage that people with disability face in

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[17] https://www.ric.org.au/circles-of-support/

Australia in all settings. This is especially the case for people with complex needs, a cognitive or intellectual disability or who have a communication disability. The need for advocacy is greater than ever and the Commission must be real time responsive to complaints.

The need for disaggregated data collection for people with developmental disability

Approximately 10% of people with disability in Australia will receive disability support provision through the NDIS. According to the most recent NDIA Quarterly Report (March 2020), of the 338,982 NDIS participants, 72% or 244,067 of people have a developmental disability in accordance with Family Advocacy's broad definition. This consists of how people identify their primary disability: 31% identify with autism, 23% intellectual disability, 6% developmental delay, 5% other neurological, 4% cerebral palsy, and 2% global developmental delay. These are the individuals who are meant to benefit from the oversight and protection the Commission provides.

However, we are not afforded the same type of disaggregation with the Commission's most recent report, from July-December 2019. Whilst we know the Commission received 2,022 complaints, and 69,397 notification of reportable incidents[18], unfortunately, this data is not disaggregated. By having this data disaggregated, it can provide a clearer picture for example, as to nature of the complaints, where the main complaints are coming from, whether there is a pattern in reportable incidents with a particular cohort, whether there are systemic issues with each cohort, and as such properly inform the Commission as to how to make improvements to hold service providers to account and provide safeguards to people with developmental disability. We recommend the Commission provides the same type of disaggregated data as the NDIS Quarterly report.

In addition, widespread prejudicial attitudes, underlying biases, and misconceptions about disability can hamper a person with disability's likelihood of being believed or taken seriously when they raise issues of neglect, abuse and violence. Also, due to many factors including the distress the NDIS process has caused, our community have a certain level of fear and distrust in authorities, government institutions and systems. Making a complaint may risk an ongoing service for an individual, particularly in rural and remote areas where there is little or no choice over service provision. Therefore, there can be a reluctance to raise issues or concerns for fear of the negative ramifications by the service provider.

All of the points made are made worse when taking into account the intersectional discrimination for women, First Nations people, and people from a culturally and CALD backgrounds.

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[18] NDIS Quality and Safeguards Commission Activity Report: 1 July 2019 to 31 December 2019 https://www.ndiscommission.gov.au/document/1921

Culture

As discussed throughout this submission, at a foundational level, it is culture and community perception of a person with disability that needs to change in order to reduce and prevent violence, abuse and neglect against people with disability. Family Advocacy recommends the Commission more broadly, as part of education and outreach in promoting safety, educate its staff, service providers on a level that goes deeper than learning about the mechanics of the job and properly addresses the unconscious bias which lead to prejudice, low expectations, and devaluing a person with disability. It is only when attitudes towards disability change, and people with disability are given socially valued roles and included in the same ways as non-disabled people, and there are effective mechanisms to support and enable the human rights of all people with disability to be upheld, that there is any chance of this becoming a reality.

Conclusion

Despite the last half century of progress in recognising the rights of people with disability, and irrespective of what public and policy might say openly, these problematic responses from our survey and the recent case of Anne Marie Smith are an indicator of our ongoing inability as a society to consider people with disabilities as equal members of the community, with equal human and civil rights, equal claims to citizenship, and equal moral agency. This fundamental inability has potentially catastrophic consequences for disabled people in the Covid-19 global emergency. The Commission needs to be more robust and real time responsive, more transparent in its reporting, provide more proactive education and outreach, and support flexible individualised options of support for people with disabilities that choose to self-manage.

Family Advocacy welcomes the opportunity to answer any questions and discuss our ideas in more detail with the NDIS Joint Standing Committee.