Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into Culture and Capability

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Overview

Family Advocacy provides advice and support to families so they can advocate with or at times on behalf of their family member with developmental disability (hereinafter disability). Our goal is to advance and protect the rights of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. Our work also includes ensuring the rights and interests of a person with disability are served systemically through legislation, policy, and practice.

Family Advocacy was founded and is governed by family's members of people with disability and is funded by the New South Wales (NSW) and Federal governments to undertake advocacy. One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so they can support their family member to have more choice and control over decisions and supports that facilitate individualised and normative lifestyles. In this way, we believe our purview lies in alignment with the overall objectives of the National Disability Insurance Scheme, with a similar aim to provide transformational benefits to the lives of people with disability. Putting the person with disability at the centre of decision making with regard to arrangements and supports is a critical component of this as is arrangements and supports that are typically afforded to most Australians.

Family Advocacy appreciates the opportunity to provide input to the Joint Standing Committee (JSC) on the NDIS on its Inquiry into 'Culture and Capability'. Over the last three years, we have provided the JSC on the NDIS with submissions on Planning in 2019 and Supported Independent Living and directly to the NDIA on Supported decision making. Whilst there has been some attempt at improvements over the last few years, what is striking to us is that the recommendations we have made still remain current and unresolved. There is no clear movement on the issues raised which is concerning. What is critical for the JSC of the NDIS to be aware of is that all of the enquiries indicate the same issues exist in 2022.

This submission is shaped by the accumulated knowledge of families over 30 years of advocating for supports, policies and practices that value the lives of people with disability, as well as Family Advocacy's experiences in supporting people with disability and families as the NDIS has rolled out. For ease of reference, we have used the same alphabetical numbering system as per the Terms of Reference.

Our concerns and recommendations to improve NDIS Culture and Capability

NDIS Planning issues

On 20 October 2019, the JSC of the NDIS undertook an inquiry into NDIS Planning. Family Advocacy provided a detailed and comprehensive submission. Given most of the recommendations remain current, we resubmit this submission to the JSC for consideration, here[1]. From the information provided by families supporting their family member with disability, whilst there were a few good experiences, on the whole, many people with disability and/or their family member have had to face a myriad of problems in the NDIS planning process, such as:

- lack of access to much needed independent advocacy
- poor communication
- lack of genuine understanding of support requirements
- lack of understanding regarding self-management
- lack of support in the planning process
- lack of accessibility, transparency and flexibility from their planner
- poor responsiveness to their internal review applications
- lack of information on local resources.

Not surprisingly, reviews and appeals continue to be an issue and all of this comes at a cost to people with disability and their families. An overwhelming number of families who responded to our survey feel the NDIS experience has been alienating, time wasting, soul destroying, expensive, and has created mistrust and disillusionment. For ease of reference, we repeat the recommendations:

Recommendation 1: *The Joint Standing Committee on the NDIS recommend State and Territory governments provide funding in perpetuity for disability advocacy.*

Recommendation 2: *The NDIA address the need for cultural change for staff to be genuinely person-centred.*

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[1] https://www.family-advocacy.com/assets/Submissions/63468b6e1d/NDIS-Planning-submission-082019.pdf

Recommendation 3: *The Planner needs to respect the family holds unique knowledge and experience and have a flexible approach to people with complex needs that is person-centred rather than a one size fits all approach.*

Recommendation 4: *Provide more in-depth training based on values and disability rights, for all staff including LACs, NDIA planners and the 1800 help desk in order to properly understand the needs of a person with disability, treat them with dignity and respect, and have a fulsome understanding around self-management.*

Recommendation 5: *Increase the overall number of planners (with proper training) and the time they are allocated to be available for each person with disability.*

Recommendation 6: *That more supports be provided to the person with disability and their family member before an NDIS planning meeting, particularly when self-managing.*

Recommendation 7: *A draft plan is needed to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings.*

Recommendation 8: *The NDIA adopts further measures to reduce the time it takes to process reviews.*

Recommendation 9: *Use Plain English/Easy Read, as well as using understandable and consistent language in all verbal and written communication.*

Recommendation 10: *Where the person with disability and/or their family agrees, plans could be automatically rolled-over.*

Recommendation 11: *In rural areas, more flexibility in plans is required to allow for the 'thin market'.*

Recommendation 12: *Invest in the promotion of self-management of funding via the capacity building of the person with disability and their family member.*

Recommendation 13: *A Budget Breakdown sheet be automatically provided to participants along with the draft plan*.

Recommendation 14: *Create a comprehensive toolkit of local resources*.

Supported Independent Living (SIL)

On 20 September 2019, the JSC of the NDIS undertook an inquiry into Supported Independent Living. Family Advocacy provided a detailed and comprehensive submission. Given most of the recommendations remain current, we resubmit this submission to the JSC for consideration, here[2]. For ease of reference, we repeat the recommendations:

Recommendation 16: *The Joint Standing Committee on the NDIS recommend State and Territory governments provide funding in perpetuity for disability advocacy.*

Recommendation 17: *The NDIA address the need for cultural change that enables staff to be genuinely person-centred, and support individualised independent living.*

Recommendation 18: *The need for the Planners to respect that the family holds unique knowledge and experience of the life of the person with disability.*

Recommendation 19: *The Planner to have a flexible approach rather than a one size fits all approach.*

To this, we would also add:

Recommendation 20: *SIL is used for individualised and innovative home and living options.*

Recommendation 21: *Invest in ILO capacities with the NDIA and the broader sector.*

SIL is often the only option given to a person with high support needs, so no real choice. The SIL funding rarely allows for anything other than congregate living arrangements and does not take into account the relevant research in relation to the impacts of this model. We know

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[2] https://www.family-advocacy.com/assets/Submissions/281daac001/NDIS-Supported-Independent-Living-082019.pdf

that the new reform through Individualised Living Options (ILO) is a more contemporary option, however, families are consistently telling us that the lack of knowledge of LAC, Planners and service providers creates a nervousness in relation to utilizing this funding stream. ILO, however, remains an important step forward to progressive living arrangements to ensure that people with a disability can have a say about where and with whom they live with.

We would strongly suggest that relevant training be invested in across these groups to ensure all ends meet in relation to offering this as a funded option through NDIS plans. The National Alliance of Capacity Building Organsiations (NACBO) is currently delivering a project, My Home My Way targeted at building the capacity of people and their families across Australia with the last two years involving workshops and resource developments from websites, podcasts, video's and bringing together an accumulation of resources helpful to support individualised living arrangements. We strongly urge the JSC invests in understanding the depth of this work and clearly thinks through how best to invest in this collateral across the NDIS and the broader sector. These are also critical and linked to the work on supported decision making (see below).

Supported Decision Making (SDM)

On 10 September 2021, the NDIA undertook a consultation process to explore how they could implement supported decision making. Family Advocacy provided a detailed and comprehensive submission. Given all of the recommendations remain current, we resubmit this submission to the JSC for consideration, here[3]. We provide an excerpt of the conclusion as it summarises the recommendations and our concerns around the potential pitfalls when supported decision making is not done well:

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

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

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

The need for advocacy has never been greater. Family Advocacy wants the NDIS to be a success but independent advocacy funding is required in perpetuity to always be there as a safety net."

Recommendation 22: *Ensure support for decision making is available for people with disability.*

Phase out group funding for all people who use NDIS supports

Many people with a developmental disability and/or their family member share regularly how NDIA processes and practices have a funnelling effect towards accepting group funding for their supports. This must change as it goes against the intention of the NDIS to deliver individual supports for the individual needs of the person with a disability via choice and control. There are loud echoes of the old system where large service providers continue to operate with a conflict of interest, known as service capture. At several Disability Royal Commission hearings, service providers gave evidence how a person with a developmental disability that lives in their group homes, also goes to work in their ADE and uses daily supports. There is little to no independent options for support, and thus little or no choice for their supports, and little or no independent complaints process, if a problem or abuse is encountered.

As a result, we continue to hear of people with developmental disability living segregated lives parallel but not within community. This must change.

Recommendation 23: *The NDIA needs to phase out the group funding model. Invest in the sector and people and their families knowledge to support more innovative and contemporary models of support for people with disability.*

Flexible supports for transition from school to work to start from 14 years old

> ***"…Students who have access to real jobs while they are in school and plans in place to meet their ongoing needs upon graduation…have a better chance of being employed after graduation."***
>
> *Individualized Career Planning for Students with Significant Support Needs Utilizing the Discovery and the Vocational Profile Process, Ellen Condon, Michael Callahan, Mark Gold & Associates*
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> .

It cannot be overstated, that work experience and work whilst at school is absolutely critical for a young person with disability. Unfortunately, the current education system provides poor work experience opportunities, if at all, for students with disability. Work experience opportunities are often not provided in the same way as for non-disabled students in mainstream schools. We often hear from parents via advocacy enquiries and our School to Work project, that their child with developmental disability is asked to either stay home instead of doing work experience.

Another common practice is that schools will often send students with disability to Day Programs or ADE's for work experience as they have deemed that the young person is not fit for open employment. This pathway leads to poorly paid, segregated and congregated 'work' with little or no prospects for career progression. It damages the young person's prospects of seeking paid employment in the open market as statistics show only 1% of people with disability leave an ADE to enter open employment. These experiences also robs students of the joy of work in an area of interest and the potential to earn their own money.

For students deemed as not able to work, the outcomes are much worse with many experiencing their whole adult life post school with a disability program. Experienced disability employment expert, Dr David Mank made the comment at our recent School to Work National Disability Employment Conference, that these readiness programs are referred to by those working in the industry as never-ready programs because the data shows that the person with disability does not leave the program with sustainable employment at a competitive wage rate. This notion of getting ready for employment is fraught with danger. Research has shown that people with an intellectual disability learn better actually doing the job not doing a pretend job such as in a pretend café or supermarket. For this reason, we strongly recommend the NDIA does not fund or support participation in these types of mock up work initiatives but rather funds a young person to have work experience and paid employment just like other students.

Family Advocacy is currently running a School to Work Project which aims to inspire and equip students with disability, through the support of families, to seek meaningful, paid employment in the community. The conversation, thinking, and preparation for normative work experiences and then part-time or casual employment ought to start as it does with any high school student, around 13 or 14 years old. The typical path for many of us in high school is to have work experience and our first job to get a good taste of work life and also learn what you do not like. In this respect, it is important that the question be asked, what do other students of the same age do? What would really good work experience be? And provide the student with reasonable adjustments and the right supports in order to be able to achieve successful work experience. Our recommendation is to make the School Leaver Employment Supports (SLES) available much earlier, such as 14 years of age, when the student typically gets a casual job. If employment is to be realised for young people with disability then access to this vital funded support is critical in the equation.

In the video, Josh's Story, Josh was only offered a placement in a local laundry in the rural town he lived in which was an ADE. This is very common. It was only because Josh's mother had a clear vision for Josh to have a proper job with proper pay in an area of his interest, one that acknowledged his ability to contribute that guided her to push back with the school and find work experience that led to him setting up his own microbusiness in 2018, which still continues four years on. Having a flexible arrangement available to cater for the person with disability's capacity is important. The example below is such an important one as it illustrates one of our parent's experience of advocating for a flexible arrangement for her son's school work experience, which eventually resulted in paid work and then a microbusiness.

"There is generally a lack of supported and flexible work experience and this impacts their knowledge of career planning and employment prospects. For my son, I had to advocate rigorously to get the school to give permission for my child to have a flexible work experience as it was not practical for him to do it every day for 2 weeks. Instead, the school gave us permission to go once a week for 2 hours for a few months. As it was well thought through

and the right supports were put in place; this has led to future employment for my son. He now runs his own business as a mail courier. At the same time, I received a letter from the NDIA assuming the only option for my son was for a day program for work experience. If I did not have a clear vision for my son to have an inclusive life, and the support of Family Advocacy, his life would be on a very different path. I feel lucky to be educated and have English as my first language. What about those families that are not and do not know any better and do not have the support? Carole, parent."

Successful Case Study - Rhiannon's Work Experience

A great example is the video recently created by our initiative, Resourcing Inclusive Communities, Rhiannon's work experience (6.26 minutes), a story about Rhiannon's successful work experience at her local Bakery. Rhiannon's mother, Di, thought carefully about the tasks her daughter would be performing and prepared the employer and Rhiannon as much as possible prior to the work experience actually happening. Rhiannon was prepared for success as her mother collaborated with the employer and the employer was receptive to her input. We strongly recommend this video be adopted as an exemplar of good practice towards providing a system that supports genuine work experience for young people with a disability whilst they are at school, and also changing community attitudes, upskilling the capacity of parents, and lifting employer engagement. Even though this was work experience and not paid employment per se, it does highlight that supports such as the Student Leaver Employment Support ought to be offered when it is typical for a high school student to start casual employment, around 14 years old.

Recommendation 24: *Provide flexible employment transition supports from 14 years of age that fund real work experience and paid employment opportunities.*

Conclusion

This submission illustrates that people with disability and/or their family member need the NDIS planning process to work effectively and efficiently. As described, when it does not, it creates a tremendous amount of stress and takes away from utilising the funding supports in a way that's beneficial for the person with disability.

The need for advocacy has never been greater. The NDIA must provide the due diligence required to overcome the systemic barriers discussed in this submission.

Clearly, there are many issues with the NDIS planning process that can be improved upon:

- ensure independent disability advocacy is funded by State/Federal government
- NDIA communication to be clear and consistent
- provide a draft plan for all participants
- have planners with a strong understanding of support requirements and contemporary support arrangements
- be person-centred. Phase out group funding for all people who use NDIS supports. Invest in the sector, people with disability and their families and support more innovative and contemporary models of support for people with disability.
- promote, support and understand self-management arrangements
- provide support in the planning process
- have accessible, transparent, planners with a flexible approach
- be timely in response to internal review applications
- provide information on local resources
- ensure support for decision making is available for all people with a disability
- use SIL for individualised and innovative home and living options
- invest in ILO capacities with the NDIA and the broader sector
- provide flexible employment transition supports from 14 years of age that fund real work experience and paid employment opportunities.

If these recommendations were implemented, we are confident the number of internal review applications and appeals to the AAT would decline.

There is strong evidence that clear direction and capacity building is needed to ensure that self-management and the choice and control that is attached, can be successful. This can be strengthened by investing in people with disability and their families.

Whilst there have been significant problems brought to our attention, they are not insurmountable as long as the NDIA is prepared to listen to the feedback from people with disability and their families. We hope the Joint Standing Committee on the NDIS will adopt our recommendations, and they are implemented by the NDIA.