

# Submission to the Joint Standing Committee on the National Disability Insurance Scheme

Market Readiness for the National Disability Insurance Scheme



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## Executive Summary

This submission addresses areas in need of improvement to allow participants to freely and confidently navigate new markets and for the disability workforce and NDIA to support and encourage this effectively. We raise the significant concern that the current facilitative operations of the NDIA and most disability services are implemented against the backdrop of economic interests. We have received consistent feedback from family members navigating the NDIS and mainstream and/or disability-specific markets that illustrates a vastly disproportionate balance of the benefits of economic gain against the rights and interests of people with disability.

This submission will respond to the following:

- 1. Participant readiness to navigate new markets:**
  - a. Participant ability to self-manage funding**
  - b. Participant readiness to choose supports freely**
  - c. Participant ability to engage supports before plan implementation**
- 2. The development of the disability workforce to support the emerging market:**
  - a. Disability service provider's disproportionate balance of economic interests and the interests of the participant**

## About Family Advocacy

Family Advocacy is a state and federally funded disability advocacy organisation in NSW, founded by families of people with disability. Our goal is to advance and protect the rights of people with developmental disability to live ordinary lives and to have access to the same opportunities and decisions that the majority of Australians have.

We have been assisting families to build meaningful and ordinary lives for people with disability for over 25 years and are dedicated in continuing this work today. We strive to build the capacity of family members and communities to realise that people with disability can engage with meaningful roles in their communities and do not need to be forced to engage only with segregated, disability-specific supports.

# 1. Participant readiness to navigate new markets

## 1.a. Participant readiness to self-manage funding

Family Advocacy has received consistent feedback from families who are self-managing and say that the process is very confusing. Further, many family members have said that there is little support provided by the NDIA or their partnering LAC/ECEI organisations to build their capacity to understand the complexities of this type of plan management. Self-management is the most effective way to build the capacity of participants and nominees to navigate new markets and support participants to have the highest level of choice and control possible. This is an entirely new space for family members to navigate, yet the NDIA has so far neglected to implement useful facilitative measures to support family members to understand the process of self-managing.

Due to the lack of involvement from the NDIA to build the capacity of participants and nominees to self-manage their NDIS plans, many self-managers are fearful that they will incorrectly use the funding in their plan and will face harsh repercussions as a result. Further, Family Advocacy has been informed that LACs and ECEI partners are discouraging family members from self-managing their NDIS plans, as the process is too confusing and overwhelming for most people. The apprehension that family members and participants are experiencing greatly inhibits on their ability to confidently navigate the emerging markets. This will axiomatically stunt the growth of NDIS driven marketplaces.

## 1.b. Participant readiness to choose supports freely

Family Advocacy has also heard from self-managers who are not able to use their funding flexibly to access the supports they wish to choose, as they were previously able to do so under the state government funding system (ADHC). The NDIS champions choice and control as one of its core guiding principles. However, the feedback we have received demonstrates that the NDIS can be limiting for people with developmental disability who

wish to engage in their communities and mainstream marketplaces, just as other Australians do.

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**CASE STUDY:**

Ellen is a woman with intellectual disability. Ellen is a strong advocate for people with disability and sometimes speaks at conferences and community events. It is important to Ellen that she attends conferences in the disability sector. If Ellen is speaking at a conference, the organiser may sponsor her to cover the cost of transport and accommodation. However, this is not always possible. Before the NDIS, Ellen was able to use her ADHC funding to pay for transport and accommodation to attend these conferences regularly. However, the NDIA has told Ellen that whilst she can use her transport funding to pay for transport to the conferences, she cannot put this money towards flights or accommodation, as she had done previously under ADHC. She was instead told that she must pay for her own flights and accommodation, yet she could use NDIS funding to pay for support staff to support her throughout the journeys. Ellen is independent and does not require assistance from support staff. However, Ellen does not have a job and relies on the Disability Support Pension for income, because of her intellectual disability. When she asked the NDIA how else she can pay for the flights and accommodation, they told her to pay for it out of her pension.

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Whilst Family Advocacy understands that the objects of the NDIS limit its scope to only providing supports that will facilitate participation in certain areas of life, rather than funding all costs required to realise this participation, we feel the inflexibility attached to this can be detrimental to people with developmental disability who wish to navigate mainstream marketplaces. It would likely be feasible for a person who earns a sufficient wage through full-time work in mainstream employment, to only require funding assistance for support staff or transport to engage in other areas of social and economic participation. However, for a person with developmental disability who relies on the Disability Support Pension, or works in an Australian Disability Enterprise, many areas of meaningful

engagement in mainstream marketplaces and the broader community are completely unattainable.

Ellen has substantial funding in the Core Supports section of her plan, which is provided to support her to engage in her community. However, Ellen wishes to engage in her community in the same way that many other Australians without disability would choose to, and the NDIS funding she has been provided with will not assist her with this.

Further, Ellen's engagement in the community and as a self-advocate are very important safeguards as they build on her "citizen capital" ([Walker, Fulton and Bonyhady 2013](#)). That is, Ellen building her self-advocacy skills by participating and attending conferences is an important safeguard if her rights are being violated. In a similar vein, Ellen's involvement in the mainstream community builds her social capital, that is a multitude of people who know her and can provide informal support and safeguards.

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#### **CASE STUDY:**

Joanne is the mother of Rowan. Rowan is 13 years old and has Autism Spectrum Disorder. Rowan has high support needs, yet he attends a mainstream school and many mainstream extra-curricular activities, including scouts, karate and piano lessons. Joanne requested funding for extra formal support hours to pay support staff to assist Rowan to engage with his extra-curricular activities. However, the NDIA have refused to fund this, saying it is not reasonable and necessary. Joanne was confused, as she is aware of many families who have been funded for the full cost of drama classes, dance classes and other activities and outings provided by disability-specific service providers where people with disability are grouped together. She is paying the cost of the classes that her son is enrolled in, she is just seeking funding for the relevant support to allow him to fully participate.

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This story illustrates that participants are often persuaded to use their NDIS funding on disability-specific services, where people with disability are congregated together and ultimately segregated from the mainstream community. This means the involvement of people with disability in the mainstream community and market place will be limited. For family members who are strong advocates, pushing for their family member with disability to have meaningful presence in the mainstream community, the processes of the NDIA in neglecting to fund this engagement have been disheartening. Moreover, it is concerning that other families who may not currently be aware of the possibilities of mainstream community involvement, will be channelled into engaging only with the disability-specific marketplaces. Family Advocacy strongly urge the Committee to recommend that the NDIA put more resources into supporting family members and participants to engage in the marketplaces of their choosing and ensuring that their systems are able to accommodate this. In order to do this, stronger capacity building for participants to pursue these opportunities and to understand the process of self-management is necessary.

### **1.c. Participant readiness to engage supports before plan implementation**

Family Advocacy has repeatedly called for a draft NDIS plan to be made available to participants, before their approved plan is formally implemented. Allowing participants to view a draft plan is imperative to facilitate plan implementation for participants choosing new services. We have received feedback from families who upon receiving their NDIS plans, have hastily begun contacting services without taking the time to shop around, as they were concerned that if they took too long to decide on new services, their funding would go unused. This is a clunky system and is counterproductive in fostering a thriving NDIS driven marketplace. Participants are forced to quickly engage supports, rather than having ample opportunity before receiving their approved plan to shop around with a clear idea of what they can expect to be funded for.

## **2. The development of the disability workforce**

## **2.a. Disability service providers' refusal to consider participant support needs as the priority**

Family Advocacy is concerned that service providers are prioritising economic interests above the rights of people with disability engaging with disability-specific services, as enshrined in the *Disability Service Standards*. We acknowledge that this common response from disability services may be inevitable given the inability of the NDIA to effectively facilitate their operations since the introduction of the NDIS.

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### **CASE STUDY:**

Linda is the mother of Janine and Belinda, who live in a group home run by a well-known disability service provider. Before the NDIS, Janine and Belinda would go out regularly on the weekends. Since the two women have received their NDIS plans, the service has stopped supporting them to go out on the weekends. The service manager told Linda that this was because her daughters' plans do not have sufficient funding to accommodate this. With the help of her support coordinator, Linda shopped around and found another service that the two women could engage with to go out every second weekend. For this arrangement to work, the accommodation service would need to assist with transporting them to a location and picking them up. This would take around an hour in total, every second weekend. Linda asked the service whether they could provide an hour of transport. She did not anticipate that there would be an issue with this, as she had been informed by the NDIA that the service has received \$125,000 of funding per year, so just one hour of individual support per fortnight for her daughters seemed reasonable. However, the accommodation service provider said they could not provide this. Linda asked if they could make contact with the NDIA so that they could fix the funding issue, and they said they could not. Linda worked with Family Advocacy to request an internal review of her daughters' plans. However, the NDIA have assured Linda that the accommodation service should have adequate funding to provide the transport. Whilst it is unclear whether this issue should be rectified with the service provider or the NDIA, what is clear is that economic interests have taken priority over Janine and Belinda's social participation. The question of whether a person should be able to leave their house on the weekends should

not be subjected to month long debates regarding whether funding is adequate. It should be a fundamental opportunity that all people are entitled to and it should be prioritised accordingly.

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Family Advocacy is deeply concerned by this practice. It is apparent that communication between the NDIA, service providers and family members needs to be clearer and more open. The NDIA as a market steward is obliged to facilitate the capacity building of services involved in the growing market. We urge the Committee to recommend that the NDIA put more resources toward responding to services who are unable to meet the *Disability Service Standards* due to inadequate funding. Importantly, we also urge the Committee to recommend that the NDIA support and assist family members to overcome issues they face with service providers. We are hopeful that the introduction of the NDIS Quality and Safeguarding Commission will facilitate this much needed improvement.

We are willing to meet with the Committee to discuss anything contained in this submission.