

General issues around the implementation and performance of the NDIS

15th August, 2022

Chau Pham

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

Acronyms:

BCA - Blind Citizens Australia

LCS - Lifestyle Centred Services.

NDIS - National Disability Insurance Scheme.

NDIA - National Disability Insurance Agency.

SPA - Speech Pathology Australia.

VALID - Victorian Advocacy League For Individuals With Disabilities.

VMIAC- Victorian Mental Illness Awareness Council.

YDAS - Youth Disabilities Advocacy Services.

Title: Proposal for increasing the involvement of advocacy support for NDIS consumers with complex disabilities.

Government/ Department:

The NDIS is a Federal program delivered by the Department of Social Services with Senator the Hon Bill Shorten MP as the Minister. Therefore, this submission will be submitted to the Australian Federal Government and the Department of Social Services.

Summary:

There is an urgent need to transform the NDIS into a more equitable scheme. As stated by VMIAC, this can be done by providing appropriate advocacy support for consumers with complex needs. Complex needs clients are people who have multiple disabilities and/ or profound intellectual disabilities (Dowse et al., 2016). On top of their disabilities, there are also coexisting factors, such as mental illnesses, deteriorating health conditions, significant behavioural issues, alcohol or drug misuse, experiencing trauma, neglect or being involved with the criminal justice system (Dowse et al., 2016). SPA states that the current NDIA will not fund advocacy services or support (APH, 2022). Furthermore, VMIAC raises their concerns about how the discriminatory system of the NDIS affects people with complex needs. Thus, the NDIS was not designed with psychosocial disability in mind. As a result, clients and their families often express difficulties in requesting funding and navigating the NDIS system. The process of appealing an NDIS decision is anxiety-inducing and one's capacity to engage is worsened due to the lack of advocacy support (APH, 2022).

Respond/ Options:

1. The NDIA must take on the responsibility of training their NDIA plan accessors to have a proper understanding of disability while being culturally sensitive.
2. Including advocacy support as support and services funded by the NDIS.
3. Greater funding and support for existing community-led advocacy support in both urban and rural areas, for people who were denied NDIS plans or already have their plans.

Costings/ Resourcing and Implementation:

1. Develop a national training framework for NDIA's plan accessors so that staff are adequately trained around disability and cultural sensitivity to properly support consumers with complex needs.
2. Greater funding for consumers. NDIS users can take their funds and use them either at advocacy services provided by the service providers or external agencies.
3. Service providers must have advocacy support as one of their provided services. Agencies are recommended to hire social workers for those positions.

4. Greater funding and support for existing community-led advocacy support in both urban and rural areas, such as VALID or YDAS.

Impact:

If implemented, this policy proposal will affect the NDIA and its code of conduct, service providers, current NDIS users, consumers who are applying to be on the scheme, consumers with complex identities (from lower socioeconomic backgrounds and/ or from CALD communities) and consumers who are trying or tried to appeal outcomes from the NDIA.

Recommendation:

I recommend the implementation of the three aforementioned options to the Australian Federal Government and the Department of Social Services. Those options will be able to create systemic changes to make the NDIS a more equitable scheme. The first response will reduce the discriminatory nature of the scheme. Thus, educating plan assessors on clients' disabilities and being culturally competent. Additionally, option 3 will be able to target the current issues caused by the NDIS' market-based model. Non-metropolitan service users are unable to access specialist services as there are lesser demands in rural areas (Dowse et al., 2016; Loadsman & Donnelly, 2021). Having community-led advocacy services in both urban and rural will facilitate and more just system for people who face geographical disadvantages.

Who am I

I am a third-year social work student at RMIT University, an eligible member of the Australian Association of Social Workers, and a disability and mental health support worker employed by LCS in Melbourne. I am preparing this submission as an individual and do not intend to represent the views of LCS. My role as a disability and mental health support worker includes:

- Personal care: showering, changing clothes, meal prep, etc.
- Community access: going to the movies, attending appointments, getting coffee or going on walks, etc.
- Working collaboratively with clients' families and other practitioners, such as support coordinators, physiotherapists, occupational therapists, etc.

Most of my clients have complex disabilities and profound intellectual disabilities. In my practice experience, people like my clients can't excel under the NDIS without changes to the current system. As an able-bodied person, I want to highlight the experience of people with complex disabilities in this submission. Thus, calling for creating systemic change and transforming the NDIS into a more inclusive and equitable scheme.

Background and Issues

People with complex disabilities are being left out of the NDIS

According to King (2020), the NDIS prioritises inclusion and treating all disabilities equally. The scheme provides individualised support, funding packages, planning and goals based on each client's capabilities so that they can potentially transition to independent living (King, 2020). However, King (2020) states that the NDIS' construction of inclusion undermines the experiences of clients with profound intellectual and multiple disabilities. People with complex needs have great difficulties in achieving goals of independent living, comprehending verbal communication, complex ideas and social systems (King, 2020). Additionally, it requires multi-agency involvement and a sophisticated workforce to sufficiently support those participants (Dowse et al., 2016). However, the aforementioned generalisation of all disabilities also produces inadequate support for the client groups (Dowse et al., 2016; King, 2020). This causes the lack of specialised services and skilled staff for people with complex disabilities, leaving them not adequately supported under the scheme (Dowse et al., 2016; King, 2020; Wilson et al., 2022).

Nonetheless, the responsibility of navigating the scheme is being put on service users (Loadsman & Donnelly, 2021). Clients are referred to as consumers under the NDIS and are provided with choices and the flexibility to choose their support services (David & West, 2017; Wilson et al., 2022). However, the marketisation of the disability services sector prohibits complex needs clients from receiving adequate care (David & West, 2017; Dowse et al., 2016; Loadsman & Donnelly, 2021). The self-directed approach creates barriers for NDIS users who have complex disabilities, from culturally diverse backgrounds and/ or experiencing trauma (Dowse et al., 2016; Loadsman & Donnelly, 2021). This can lead to poorer outcomes when consumers try to navigate the scheme, such as the lack of external advocacy support. As a result, they are often unsuccessful at exercising their choices and benefiting from the scheme (David & West, 2017; Wilson et al., 2022).

The market-based model of the NDIS also negatively affects the experiences of non-metropolitan service users (Dowse et al., 2016; Loadsman & Donnelly, 2021). Facing geographical disadvantage, complex needs users are unable to exercise their choices and have little access to specialised NDIS-funded services and supports. Loadsman & Donnelly (2021) mention the emotional and financial stress participants and their families are under due to extensive travel to receive adequate support. Clients and their families are also responsible for negotiating and coordinating their support services (Loadsman & Donnelly, 2021).

The lack of advocacy support for complex needs clients under the scheme

SPA and VMIAC raise concerns over the lack of advocacy services for consumers under the scheme. SPA states that the NDIA will not fund advocacy services or support. The NDIS also does not support self-advocacy due to the expectations that participants will have families or external parties to successfully advocate for them. However, clients and their families often express difficulties in requesting funding and navigating the NDIS system (APH, 2022). VMIAC also illustrates that participants with complex and cognitive impairments exhibit greater anxiety when trying to navigate the scheme. For example, people with psychosocial disabilities find it difficult to demonstrate their disabilities as permanent impairments due to diagnosis uncertainty (APH, 2022). Additionally, their mental health symptoms often fluctuate. As a result, the NDIA denies access to support for the aforementioned demographic due to their disabilities not being permanent. Nevertheless, the process of appealing an NDIS decision is anxiety-inducing and one's capacity to engage is worsened due to the lack of advocacy support (APH, 2022).

Additionally, I can notice how lacking advocacy support negatively impacted my client's experience under the scheme. Vincent (client's name has been changed) has a profound intellectual disability and is profoundly deaf. He has a difficult family dynamic where his brothers were fighting for the right to be his nominee. This situation, unfortunately, left Vincent not properly supported by his family members. Being his support worker, I tried assisting him within my ability. I noted down his worries and concerns about how he did not feel supported and what he would like to happen going forward. However, my concerns were disregarded by his coordinator. Since Vincent is not non-verbal, he is expected to advocate for himself despite having a profound intellectual disability. Nevertheless, the issue was not properly addressed as Vincent felt anxious and nervous during those social interactions.

Nevertheless, he was not able to properly articulate his needs to his coordinator due to his conditions.

Policy Options

Recommendation 1: The NDIA must take on the responsibility of training their NDIA plan accessors to have a proper understanding of disability while being culturally sensitive.

I support the SPA's submission regarding the performance of the NDIS to the Parliament. The agency argues for a standardised national training framework for NDIA's planners. SPA expresses concerns over the lack of knowledge and understanding of disability displayed by NDIA's plan accessors and planners. Consumers with psychosocial disabilities and complex needs find difficulty demonstrating their disabilities as permanent impairments due to uncertainty about their diagnosis. Additionally, their mental health symptoms often fluctuate. Since NDIA planners lack knowledge of types of disabilities, clients are denied access to support as their disabilities are not seen as permanent. Furthermore, planners appear to make inconsistent decisions and/ or exhibit inappropriate remarks toward consumers. The NDIA employs people regardless of their previous work experiences due to the current inadequate staffing issue. SPA mentions that the NDIA does not take on the responsibility of training its staff. Thus, training is provided by outsourced agencies, such as SPA. This recommendation will benefit people with complex disabilities as it will make the NDIS more equitable. The NDIA must take on the responsibility of developing a national training framework to properly prepare workers when engaging with consumers under the scheme. NDIA's plan accessors must be adequately trained around disability and cultural sensitivity to properly support consumers with complex needs (APH, 2022).

After establishing a national training framework, the NDIA can employ more staff to personally train and/ or out-sources agencies who can conduct training through face-to-face and/ or online methods. An online platform, such as Etrainu (Etrainu, 2022), can be utilised to perform online training. Face-to-face training and/ or online training courses should reflect the lived experiences and voices of service users. Certificates need to be refreshed annually to keep up with changes in policy legislation and the NDIS code of conduct. The NDIA ought to provide ongoing supervision for plan assessors to make sure consumers are adequately supported and to provide ongoing feedback on the performance of the aforementioned training framework.

Recommendation 2: Including advocacy support as support and services funded by the NDIS.

To make the scheme more equitable, the NDIS ought to include advocacy support under services that it funds. According to the NDIS (2022), the scheme does not cover or fund advocacy support. Thus, it can be delivered by other agencies and does not relate to participants' disabilities or their day-to-day living costs. Similarly, LCS only provide referrals for clients to access external advocacy services. However, VMIAC mentions that participants with cognitive impairments exhibit greater anxiety when trying to navigate the scheme due to the lack of advocacy services (APH, 2022). Regardless, community-led agencies have limited or no capacity to take on new consumers as they have low funding and resources (APH, 2022). As there is no community support available, SPA also illustrates that service providers end up engaging in extensive unpaid labour to support their clients. Thus, advocacy support is not funded by the NDIS (APH, 2022). As a result, it is crucial to include advocacy support under services that the NDIS funds. This will create a more equitable NDIS system for clients with complex needs. Service providers can also properly educate and advocate for clients on their rights while putting less stress on other community-led advocacy agencies.

Recommendation 3: Greater funding and support for existing community-led advocacy support in both urban and rural areas, for people who were denied NDIS plans or already have their plans.

I support VMIAC and BCA responses in regard to the performance of the NDIS to the Parliament. They demonstrate the need for increasing funding and providing ongoing support for advocacy and appeal support services. As mentioned in the second recommendation, the NDIS does not include advocacy support under its funded services. However, community-led organisations, such as VMIAC and YDAS, are chronically underfunded. They are forced to turn away high-priority clients due to the current funding arrangement. The lack of funding has caused agencies to have limited or no capacity to take on new consumers (APH, 2022). BCA also mentions that disability advocacy organisations have been relying on short-term funding extensions and increases. Yet, the NDIS system is difficult to navigate especially for people with profound intellectual disabilities and complex needs. As a result, people with complex needs are further marginalised and decided not to appeal NDIA decisions and/ or their funding outcomes. Thereby, it is important to properly fund advocacy services to appropriately support people with complex disabilities and their carers. Thus, they can

exercise their rights, have better navigation through the NDIS complex system and influence long-term, systemic change.

Resourcing and Implementation

Develop a national training framework for NDIA's plan assessors

I propose that the NDIA must take on the responsibility of developing a standardised training framework that is centred around knowledge about disability and cultural sensitivity. As mentioned by VMIAC, people with psychosocial disabilities find it difficult to demonstrate their disabilities as permanent impairments (APH, 2022). For example, one of my clients was denied access to an electric wheelchair despite having stiff person syndrome. Her plan assessors' reasonings for denying her request was because she could still somewhat mobilise and her disorder was not affecting her quality of life just yet. To create a more equitable scheme for complex consumers, the training framework needs to focus on the long-term effects of one's disability not just on the current moment.

Additionally, the scheme ought to utilise a bottom-up approach by working closely with consumers and being proactive in asking for feedback from them. By doing so, the NDIS will improve its understanding of disabilities and make sure that NDIA plan assessors are adequately trained. Thus, properly supporting consumers with complex needs. Nonetheless, NDIA plans should be written in a more accessible language. Thus, SPA mentions that documents are often difficult to understand regardless of whether the participant has literacy or cognitive difficulties, or comes from a culturally and linguistically diverse background. Lastly, changes in the NDIA code of conduct must be communicated clearly and transparently to consumers and services providers before commencing.

Including advocacy support as services provided by the NDIS

I propose that the NDIA ought to include advocacy support as a service provided by the scheme itself. Doing so will put less stress on community-led advocacy services while making support more accessible for people with complex disabilities and profound intellectual disabilities. Furthermore, participants will not have to use their income to access advocacy services. Service providers will also be properly supported instead of having to engage in extensive unpaid work to properly support their clients. Changes in the NDIA code

of conduct must be communicated clearly and transparently to consumers and services providers before commencing.

Additionally, I propose that service providers must have advocacy support as one of their provided services. I recommend that agencies should employ social workers to assist consumers with advocacy. VIAMC states that support coordinators are not properly trained to provide advice or advocacy (APH, 2022). According to the AASW (2022), social workers have the appropriate skillsets to provide trauma-informed advocacy services with a social justice approach. Thus, transforming the scheme to be more equitable and accessible for people with complex disabilities.

Greater funding for NDIS consumers

I propose that the scheme allocates greater funding to consumers to enable more choices of support for them. Thus, making it more equitable for clients with complex needs. NDIS users can take their funds and use them either at advocacy services provided by the service providers or external agencies. Funding for advocacy services can be added to consumers' plans as 'advocacy packages'. Funding for the aforementioned packages can be reviewed depending on the client's situation.

Greater funding and support for existing community-led advocacy support in both urban and rural areas

I propose a long-term funding increase for existing community-led advocacy services in both urban and rural areas. Thus, preventing the current limitations for agencies to take on new clients. This will benefit consumers with complex needs as they are assisted with navigating through the scheme and educated on their rights. More significant funding for community-led advocacy support will also challenge the aforementioned marketisation of the NDIS. Thus, transforming the NDIS into a more equitable scheme.

Impact

If implemented, this policy proposal will affect the NDIA and its code of conduct and service providers. The NDIA will be responsible for developing its staff training framework instead of relying on external agencies. The scheme can also save more money while properly supporting its clients since advocacy support is now a part of the NDIS. According to Henriques-Gomes (2022), the NDIA has spent fifty million dollars on fighting people with

disabilities who appealed funding cuts. Additionally, changes regarding access to advocacy services will affect the current NDIS users, consumers who are applying to be on the scheme and consumers with complex identities (from lower socioeconomic backgrounds and/ or from CALD communities) and consumers who are trying or have tried to appeal outcomes from the NDIA. According to Dowse et al. (2016), people with intellectual disabilities and complex needs make up the majority of NDIS users. People with intellectual disabilities made up sixty per cent to seventy per cent of the National Disability Insurance Scheme (NDIS)'s users (Dowse et al., 2016). Twenty per cent of those seventy per cent are presented with complex needs.

Evaluation

If any of the aforementioned recommendations are implemented, an evaluation will be conducted to ensure they are doing what I intend them to do. The NDIA can conduct an evaluation by interviewing NDIS consumers and their carers on how their experiences with the scheme have changed after the implementation of my recommendations.

Conclusion

Having more involvement of advocacy services in the NDIS system would greatly transform the scheme for the better. Especially for consumers with complex needs and profound intellectual disabilities. As the scheme was not designed with the aforementioned demographic groups in mind, integrating advocacy services into the scheme, more funding for clients and community-led services would create a more just and equitable experience for service users. It will also challenge the discriminatory nature of the scheme by having a national framework to train NDIA planners and accessors.

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