22 September 2020

The Hon Stuart Robert MP

Minister for the National Disability Insurance Scheme

By email

cc. Hon Anne Ruston Minister for Social Services

Dear Minister Robert,

Deafblind Australia (DBA) is the national peak body representing Australians living with deafblindness. Our community is diverse, dynamic and determined, but has historically fallen through the cracks in many areas of support/service provision.

A lack of consultation when designing services, lack of awareness around accessible technology and its interaction with online interfaces and a legacy of underinvestment in the sector leading to a scarcity of professionals in the field means that deafblind participants in the NDIS are frequently required to cobble together services from disparate providers as best they can as a fit for purpose service/support simply does not exist in many life domains, or exists in so few numbers as to not sufficiently meet the demands of the community.

Recent focus groups run by DBA have also demonstrated a lack of knowledge and skills in the area of deafblindness amongst NDIA staff resulting in less than satisfactory experiences for deafblind participants and their capacity to exercise choice and control in the pursuance of their articulated goals being limited by market conditions beyond their control.

With the NDIA roll out of Independent Assessments beginning from 2021, the manner in which preparations for this roll out have been managed leave DBA and its membership concerned that the historical lack of awareness around deafblind issues that has for so long left this community out of service design and provision, looks set to continue. Our specific concerns are articulated below and we invite representatives from the NDIA to address these in order to ensure the function mandated in the NDIS Act, namely the effective realisation of the UNCRPD, is carried out in such a way that takes into account the specific needs of the Deafblind community.

***Issues of Consultation:***

As a member of the Australian Federation of Disability Organisations DBA is well positioned to survey the disability landscape and has been shocked to discover that not only have we not been consulted in the lead up to the launch of this program, but that this experience has not been unique to us and our members. We are inundated with testimonials from Deafblind participants speaking to the level of complexity of the supports they require, and the disturbing lack of professionals within the NDIA and service providers more broadly who have the requisite knowledge and experience to understand this complexity and provide support accordingly.

The context outlined above illustrates the importance of consulting with the Deafblind community around the design of a scheme such as this and its many and varied policies, procedures and systems. Our community is already marginalised and left out of many information and service offerings and it is vital to ensure inclusive, consultative design is used by the NDIA as a mechanism for managing the thinness of this particular market. Given the lack of consultation to date we remain concerned that this program will take into account the needs of the Deafblind community in any area from its policies to its practices and call on the NDIA to address this lack of consultation immediately to ensure the stated aims of the program of making “…the NDIS simpler, more consistent and easier to use” are a reality for ALL participants.

DBA is also deeply concerned about the specific “recognised, standardised tools” that will be used as part of the assessments. Who has endorsed them? Given the specific needs of our community and the lack of consultation with us or other peak groups on the issue, how can the Deafblind community trust that these tools are appropriate and accessible to them? In the current context of information distribution, accessible formats and Auslan translations are provided selectively and sporadically by the NDIA, and are often inaccessible to Auslan users who also have a vision impairment. It is our concern that historical issues of vital information not reaching deafblind people in ways that are accessible and understandable to them is likely to continue and worsen given the lack of consultation undertaken by the NDIA around all aspects of this program.

***Lack of recognition of market realities:***

The aforementioned lack of consultation has also resulted in several stipulations regarding the operation of the program being completely inappropriate for participants with deafblindness.

Of particular concern is the stated policy that participants will be prevented from engaging their own, regular health professionals for the purposes of assessment. In the context of the Deafblind community lack of incentives for specialization in this area has resulted in a thin market where often a particular health professional represents one of very few and perhaps the only professional in that sphere with a comprehensive and practical knowledge of deafblindness essential to making the sorts of declarative statements and recommendations that form part of this program. This is the market reality across several domains including allied health, direct support, employment support, support coordination , advocacy and language access (interpreting, captioning, notetaking etc).

Of further concern to us is the statement “Independent Assessors are qualified health care professionals” and the implied gravitas connected to this medical knowledge as being an indicator of the regard in which their assessments should be held. For our community a statement such as this reflects the reductionist medical model of disability and is troubling as historically this approach has missed the mark terribly in servicing this community. This statement further evidences the extent to which market realities have not been factored into the design of this scheme. For Australians living with deafblindness the impacts of their disability primarily manifest in areas of access. Access to services, to information and to other community members and services necessary for active citizenship are the primary domain in which our membership continues to express frustration. This is not an arena in which the knowledge of a healthcare professional is particularly applicable or appropriate. A suitability qualified professional with a background in community community development, lived experience or understanding of disability engaging CALD populations particularly sensory impairment would be a much more appropriate choice in this context.

Independent Assessors will not “create a complete picture” if the assessor does not fully grasp what they are looking at, or take a holistic approach to assessment based on the social model of disability. A “focus on function rather than diagnosis” must take into account the limiting or enabling influence of the environment on an individual’s capacity to function. This includes their physical, linguistic, cultural and digital environments; the physical, linguistic, cultural and digital environments of the service providers/supports they wish to engage and the respective challenges of both.

DBA can support the NDIA to access the Deafblind community for the purpose of consultation around accessible design. Without consultation and engagement our community will once again be forced to operate within a policy and service framework that does not adequately account for or support their needs. Given the stated goals of the Independent Assessment program it remains unclear how this will be achieved for NDIS participants without consultation. The Deafblind community contains within it an incredible capacity for growth and a membership that is vastly more limited by the way our society is structured than by anything pertaining to themselves or their disability. This lack of recognition has been and continues to be one of the biggest challenges facing Australian’s living with deafblindness and until it is addressed, any and all programs of this nature cannot and will not be truly inclusive or successful in achieving their stated aims.

If you have any queries or would like to discuss, please contact me on email below.

David Murray

Executive Officer/ Company Secretary

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