**Deafblind Australia Response to Home and Living Consultation 2021.**

Deafblind Australia (DBA) is the national body promoting and representing the needs of deafblind people nationwide. Deafblindness, is a unique dual sensory disability that can affect an individual’s communication and their ability to receive information and express themselves. The disability also seriously impacts on a person’s social interaction and mobility. Deafblindness can affect a person’s ability to be independent, as well as making it difficult to develop social networks and is recognised internationally as the most isolating of disabilities. We exist to promote, through information, advocacy and capacity building, an Australia in which all Deafblind people live self-determined lives and can access the skills, supports and resources necessary to do so.

1. ***Do you talk to people about how you would like to live?***

For many Deafblind people the level and type of support required to remain safe in their home and actively engaged in their community is never a certainty. Our members deal daily with not being able to receive support, not being able to find replacement support when staff are ill, being severely restricted in their options for engaging mainstream supports due to linguistic limitations and ignorance/lack of training among the vast majority of the disability support industry, and express deep apprehension about the impact the degenerative nature of their condition will have on their capabilities, independence, safety and living conditions.

We also hear from members who experience extreme communication barriers and discrimination when attempting to navigate the private rental market with the minuscule amounts of support, in terms of time and sheer numbers of appropriate staff, available to them.

There are also many Deafblind community members who live with and are supported primarily by ageing family members in both metropolitan and regional areas. For these families, the lack of adequate options for living causes massive amounts of stress and anxiety as family members are left to ponder the fate of their loved ones following their own passing.

1. ***Where would you like to get information to think about where and how you live?***

The Deafblind community utilizes social media and also in-person gatherings of peer groups as the primary mechanisms for sharing information. This is due to the modifications to language and formatting that are required being most easily executable in these two spaces. Information distribution from government and the NDIA needs to leverage these channels, with content that is in appropriately accessible formats, as well as existing community groups and representative organisations nationally to ensure information around housing options makes it to the community in a meaningful way.

1. ***What information, learning and resources could we create to help you choose your home and living supports?***

All information published by the NDIA around this subject or any other needs to be published in accessible formats that follow the design advice of peak bodies in the space. Currently, the format used for Auslan videos at the NDIA is inaccessible to many Auslan users with vision impairments. Information needs to be translated, not interpreted, and presented along with captions in a layout that features the Auslan content and no other or minimal other information. Cutting to other screens or running simultaneous info-graphics/animations along with the Auslan content demands viewers spilt their attention, akin to attempting to listen to two people speak at the same time. For many Deafblind people, these videos are viewed under significant magnification which exacerbates the impact of the aforementioned techniques. The result is that most video information released is not fit for purpose and cannot be meaningfully understood. It also establishes a precedent in the minds of the community that the NDIA cannot be viewed as a reliable source of information and further compounds the adversarial attitude many community members feel is directed to them from the NDIA.

1. ***How helpful is the NDIS website to find information on home and living supports?***

DBA recommends inclusive and accessible information on the website, the content is not consistently available and the Auslan versions that do exist are not fit for purpose.

1. ***Would it be helpful if your informal supports (e.g. friends, family and carers) knew more about how and where you want to live?***

Whilst greater awareness of available options will rarely have a negative impact on anyone’s wellbeing, this question misses the bigger issue facing the Deafblind community in this and many other areas. The key issue IS NOT that people are not aware or able to connect with the type of information and supports they need, the issue is that this information and these supports do not exist in numbers sufficient to fulfill the allotted supports in most Deafblind individual’s plans, let alone to support them through huge change-of-life moments like choosing housing or in actualising the higher order goals articulated in their plans. Families, supporters and Deafblind people themselves are aware of what they need and in many cases can articulate this clearly to anyone with the cultural and linguistic knowledge and experience to have that conversation. The issue continues to be that despite campaigning vocally and consistently for the desperate drought of support workers and services to be addressed as a matter of priority, it remains unaddressed and the community continues to languish far from the minds of most decision makers in the space.

1. ***Who helps you to organise your NDIS supports?***

Deafblind community members source support in organizing their supports primarily from a small number of dedicated service providers. Currently there are 2 organisations that dominate the space whilst some vision and hearing services may also be utilized depending on how well the individual is able to cope with and navigate the operational landscape of those organizations. Private case management or support coordination through other philanthropic groups is also evident but less prevalent.

1. ***Have you ever used peer support networks or a mentor to find / access NDIS supports?***

Peer mentoring and opportunities to connect with peers are an emerging area in the Deafblind space nationally. Several states now have “drop in” style days as well as regularly scheduled meetups allowing the community to come together. These, as well as online platforms and social media groups are the primary places where peer-to-peer conversations around support take place. These spaces are cherished by the Deafblind community and are becoming increasingly self-determined and self-sufficient with the passage of time. However, these spaces and the opportunities they present are often thwarted by funding cuts, changes in operational priorities for service providers and, most recently and perhaps most drastically, due to restrictions resulting from the ongoing COVID-19 pandemic.

1. ***Who would you be most likely to use to help you implement your plan?***

At present this assistance is mostly provided by family members, Communication Guides or individuals from informal support networks such as friends and colleagues.

1. ***How would you like to encourage providers to offer new and innovative service options?***

The chronic understaffing of the Deafblind sector is the single biggest impediment to the effective realisation of the goals of the National Disability Strategy, and the goals of the NDIS both broadly and within individual plans. In response to this, there is a urgent need for Disability services sector review to their service delivery options that significantly improve the lives of Deafblind people with incorporating a robust and varied workforce of frontline professionals that are knowledgeable and experienced in Deafblindness, who have the communication skills necessary to work directly with Deafblind people, and are able to work with Deafblind people to holistically assess the impact of their disability on the goals articulated in their plan and facilitate the provision of appropriate supports. Given the high level of skills and knowledge necessary to work in the Deafblind space AND the chronic and historic undervaluing of these skills and knowledge by the community more broadly, it is necessary to actively incentivise people to train and work in this community. Similar to remote education, this needs to be treated as a national skills priority area and appropriate incentives need to be established. These could include but are not limited to: financial incentives for educational institutions to provide courses in Deafblindness; fee-free courses in Auslan (including Deafblind elective unit); financial concessions and tax benefits for recent graduates working in the space; higher renumeration rates in price guide for support workers that have undergone specialised training in Deafblindness.

1. ***Appendix D lists options for actions we could take to improve home and living in the NDIS. What other ideas would you add to Appendix D****?*

DBA supports all activities listed in Appendix D and suggests that the above mentioned incentivization should form part of the agency’s commitment to Engaging the Market and Driving Innovation.