



Inquiry into the Integrity of the National Disability Insurance Scheme.

Deafblind Australia (DBA) is the national peak representing all Deafblind people and those living with dual sensory loss/impairment.

Deafblindness is a unique and isolating sensory disability resulting from the combination of both hearing and vision loss or impairment that significantly impacts communication, socialization, mobility and daily living.

The term 'd/Deafblind' refers to people who have some hearing and vision, as well as people who are completely deaf and blind. Many Deafblind people communicate using Australian Sign Language (Auslan) and/or spoken languages. However, there is an incredibly diverse array of alternative and augmented communication methods used by others including objects, pictures, body language, gesture, key word signs and braille.

It is difficult to accurately state the incidence of deafblindness in the community due to the broadness of the classification and diversity of conditions the term captures. Based on data from the Survey of Disability, Ageing and Carers deep dive 2018 the number is thought to be around 200'000 although this is likely an underestimate. This likelihood is due to the fact that many people with dual sensory impairment do not identify as such and may not report this status and because the SDAC does not cover remote regions and thus does not reflect the high rates of sensory loss/es in First Nations communities.

The Deafblind community is very diverse. Its members have varying degrees of vision and hearing impairment and come from diverse cultural backgrounds. Some live with multiple or complex disability.

DBA welcomes this opportunity to contribute to this inquiry into the integrity of the National Disability Insurance Scheme.

Deafblind experiences of sharp practices in the NDIS.

DBA's engagement with members during both the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disabilities (DRC) and the NDIS Review often featured stories about providers and individual staff engaging in sharp practices. We continue to receive reports from all over the country of Deafblind people experiencing practices that



whilst not necessarily unlawful are plainly unethical, dishonest and not in the Deafblind person's best interest.

We have heard of over-charging for services in ways that dishonestly represent services rendered in order to access higher pay rates. For example, simple communication support that is an expected part of normal work practice for CommGuides (specialist Deafblind support workers) is invoiced as Auslan interpreting services on top of/in addition to general support services.

Deafblind people routinely report feeling like an ATM and that many people offering to provide support or services to them and their families are primarily interested in attracting or retaining the highest possible percentage of a person's plan funds rather than assisting them to achieve the stated goals of their plans. A Deafblind parent whose child is also a participant on the Scheme reported plan managers advising them to continue to seek the same levels of support for their child without a single conversation about how supports had been working up to that point.

Choice and control around supports is also frequently compromised for Deafblind participants. We frequently see people's 'preferred interpreter' lists disregarded as part of access requests because the purpose/importance of these lists is not well understood or is ignored by providers. DBA recently witnessed an instance in which a Deafblind person was denied access to the interpreters they requested because those practitioners did not work for the booking agency with which there was a supply agreement in-place. In the case of many Deafblind people, the lack of formal education given to interpreters in how to work with Deafblind people means that their preferred interpreters lists are actually definitive lists of those that have the necessary skills and experience to perform the job they require. To restrict a person's access to information and communication based on commercial agreements or other interests is profoundly unethical and costly as we will see further in this submission.

The compromised communication and information access outlined above is experienced even more profoundly by Deafblind people living in supported settings. Throughout the DRC, DBA heard from members that staff in these environments were frequently tasked with the care of people they had no way of communicating with. This amounts to a denial of essential needs and can and does have profound physical and mental health impacts.

DBA has received several reports of unethical behaviours by support workers ranging from asking participants to share supports with their children through to workers using appliances in the home such as laundry facilities without the participant's permission. We also received



one harrowing report of a support worker having keys cut to a Deafblind person's home without their knowledge.

DBA has also observed a concerning trend of state-based services abdicating their responsibility to provide supports such as Auslan interpreting, instead relying on individual NDIS packages to fund these supports. This is despite interpreter provision in specific settings, such as education or health, being a clearly defined state/territory responsibility.

It is our contention that many of the sharp practices observed in the Deafblind sector are enabled by monopolies in service provision that the market has failed to respond to since Scheme inception. It is simply much easier to get away with providing poor quality service when people know there is nowhere else to go. Investment in standing up Deafblind services across a range of providers has not materialized in the way initially envisioned by Scheme architects. The market is not self-regulating for quality. This creates issues for the quality of service provided at the organizational level and by individual staff.

Workforce issues in the Auslan interpreting space are also enabling and sustaining work that falls far short, in terms of quality, of what practitioners are charging. Lack of supply means all interpreters are able to set pricing at the maximum end of the spectrum regardless of experience. Agencies have also historically retained a disproportionate amount of fees from practitioners which has propped up inflated pricing and led to the preference for practitioners to work as sole traders which reduces visibility and quality control because they are not operating within structures where performance is easily monitored or addressed. Current professional standards and accreditations (e.g. NAATI) do not regulate for quality. Consumers of interpreting services have not reported a marked increase in quality since the introduction of mandatory recertification in 2018.

Impact on Deafblind Participants and their families.

The most profound impact of sharp practices and the service monopolies that underpin them is that Deafblind people on the Scheme remain isolated and disconnected. This makes it all but impossible to gain new skills or develop strong and lasting connections in their communities. Over time, this has profound physical and mental health impacts that not only exacerbate the existing impacts of their sensory disability but create additional, ongoing health costs.

There are also increased support costs long term associated with these types of practices. Support that doesn't meet the standard required often means a meeting or appointment needs to be repeated or rescheduled to a time when suitable support can be/is provided.



In contexts where professional support is extremely limited or not available at all (such as in many regional areas), family members are forced to provide formal supports well beyond what can/should be reasonably expected from informal support networks. These formal supports, such as interpreting, are also frequently unable to be paid for by the NDIS due to current interpretations of operational guidelines concerning the use of family members as formal supports. The impact of this is that family members also experience increased stress and associated adverse health outcomes by the repeated need for them to provide formal supports to their loved one and not be paid appropriately.

Prolonged compromised access to information and communication severely limits the ability to develop relationships and connections within local community. This has huge implications for safe-guarding and ongoing support costs. If poor quality service that costs a lot is the only option available to people then the cost of supporting and including them will remain exorbitant as their environment remains static in its rigid inability to respond to their needs.

Ultimately, sharp practices in the absence of a competitive marketplace are most profoundly experienced as a denial of access and a denial of rights realisation. There is a denial of UNCRPD rights and specific denial of access to legal or medical systems in a way that is on par with non-disabled peers. This is particularly egregious in the area of 'preferred interpreters'. Deafblind people are frequently forced to use individual practitioners or modes of delivery (such as video relay) that are not appropriate for their needs or situation and miss out on vital information and access because of this. This is frequently during high-stakes, difficult times in their lives or the lives of their family (e.g. legal disputes, loved one end of life care etc).

Many Deafblind people are also currently experiencing being denied access to services to which they are entitled because the NDIA is now forcing these to be provided by state-level services or infrastructure which don't exist and/or have been operating under the precedent of shifting funding responsibility to the NDIS for over a decade. To date, there has been little-to-no guidance or support from NDIA to navigate this change. People are just being denied supports and told their individual State/Territory services should be providing them.

The effectiveness and adequacy of successive government policies to improve scheme integrity, safeguard participants, and tackle non-compliance.



These policies have remained largely ineffective in the Deafblind sector because nothing to date has addressed the single biggest driver of non-compliance across services: lack of robust, competitive workforce/industry.

The ability to choose from a variety of providers and for those providers to be engaged in competition with one another over both quality and value for money is currently a missing lever when it comes to forcing providers to lift their game.

Lack of sufficient workforce means Deafblind people's activities and social lives are more restricted to just Deafblind or disabled spaces/activities. People struggle to become known, valued members of communities not related to disability and thus miss out on the most effective and enduring form of safeguarding: natural safeguards.

In addition to the above, a lack of human rights protections at the Commonwealth level also remains a driver of poor service and non-compliance. Providers are aware of the historic limitations of regulators like Quality and Safeguards Commission and continue to violate people's human rights with relative impunity knowing that there are little-to-no federal protections for many of these rights, especially those designed to protect access to communication and information. This has severely hampered the efficacy of attempts to lift participant outcomes and safeguarding via regulatory mechanisms.

Legislative or other reforms required to strengthen scheme integrity.

DBA firmly believes and has advocated for many years that steps must be taken to address the lack of market competition and the impact this has on integrity and quality across the NDIS.

"A free market self-regulates for quality primarily through competition and the pursuit of self-interest, where firms must provide high-quality goods to attract customers and earn profits. Quality is maintained via consumer feedback, brand reputation, voluntary standards, and the fear of losing market share to competitors." (treasury.gov.au)

Key mechanisms for regulation and integrity in a market include: Competition and profit motive; reputation and brand value; consumer choice and information; quality assurance systems; industry standards and certification. Reforms to date have failed to address 3/5 of these mechanisms and have focused too heavily on quality assurance and certification/regulation to strengthen Scheme integrity.

Much of what is currently sought as part of safeguarding, integrity and fraud/compliance reforms can be aided via market stewardship aimed at intentionally supporting innovation



and competition in this space. For the Deafblind community this as an essential but as yet unaddressed component of meaningful, sustainable reform.