

I am writing to provide the following information in relation to the survey being conducted about the Draft Lists of NDIS funded Supports.

Q1) For the most part yes, however there are some categories of support that while they wouldn't usually be considered a disability specific expense, given a specific less common context and situation they would. Therefore **I would like to request an avenue be created that would allow participants and/or their families/nominees to make an 'exception to the rule' submission request.** Ideally with a strict set time-frame for response that would provide absolute clarity and transparency around funding and potentially propose sources for alternative support options to explore if not deemed a suitable exception.

While I appreciate the challenges of trying to identify a fair and clear list that applies to the majority, **in the complex disability sector we work with the extreme minority who don't typically 'fit the box'.** They often experience language barriers, poverty, housing insecurity, family violence and/or AOD which are all substantially exacerbated because of disability, and without the right supports they are unintentionally perpetuating and cultivating developmental delay within their households and children, which is only going to have a greater impact in the long run. And when there aren't community funded or other alternatives available for individuals with disability who have a genuine need relating to costs incurred due to their disability, having an individualised, exception to the rule pathway to request special consideration would be of tremendous benefit.

Q2) There are a few items on the draft exclusions list that potentially in certain unique and rare circumstances could be argued as being disability specific expenses. I am listing some of the scenarios below that I as an allied health provider have encountered on multiple occasions, while working in the extremely complex needs disability sector. However rather than add them on the approved list, as per my previous suggestion, having an avenue created that would allow participants and/or their families to make an 'exception to the rule' submission request for individual consideration would be sufficient.

Electricity Generators. There are some people with disabilities that are dependent on electrical equipment due to their disability – such as CPAP machines, feeding pump, Apnoea monitors, Oxygen concentrator, Suction pump and even specialised electric posture support beds for those bedridden and seizure monitoring equipment etc... The grant for life support equipment in WA covers some of the costs for additional electrical bills, **but there are no community or other funded options in WA for low income families in this situation who require a generator as a backup in the event of power outages but cant afford these themselves** (and power failures happen frequently both in summer and winter from storms and fires). For these families, they would not require a generator were it not for the disability need and dependence on the equipment. Not all of the aforementioned equipment have battery backup options built-in, and a generator is the only backup. To expect NDIS to cover the purchase of generators for all families in this circumstance may not be reasonable, but perhaps the cost of hiring a generator may be able to be covered through an 'exceptions to the rule' request, or maybe generators could be made available on loan through the NDIS. I believe other states actually have programs that assist in this area, but there are none within Western Australia.

The Western Power website in WA states that those dependent on power for life support should *"always have an alternative power source nearby - such as a battery back-up system or a generator in the event that there are power outages"*.

Home and Contents Insurance. Again this is a typical expense for the average household, but in some cases the insurance premiums of families of people with disability who also have violent and aggressive behaviour, is much higher than typical due to repeated claims for broken windows, furniture and items etc. Damage to home and contents can also impact rental options and influence housing insecurity which is already prevalent amongst families impacted by disability compared to the average population. For people in their own homes, they are able to make requests to NDIS for reinforced glass or alternatives as a safety requirement, but in rental homes this is not as easy, is not time sensitive as it needs to be and it also becomes an expensive option, especially as rentals may only be held for 6-12 months in the current market. As such, having an avenue to allow the rare but genuinely in need family an opportunity to request funding assistance to assist with a **partial** cost of insurance due to the increased amount being a direct consequence of actions and needs by the person with the disability, would be beneficial and likely far more cost effective, while also potentially helping alleviate some of the housing challenges already mentioned.

Accessible Public Transport – While this can also reasonably be expected to be a normal expense for any person, there are NDIS participants high complex needs clients requiring at least 2 people with them when accessing the community due to the safety risks they present to others. They are usually unable to access buses/trains and require transportation only via taxis and ubers which is far more expensive than typical public transport, and even with the Taxi User Subsidy Scheme (TUSS) in WA there are still significant out of pocket costs. There are also instances I know of where NDIS participants have been permanently banned from accessing Transperth services, and can only use private vehicles, uber and taxis. For many of these complex clients, when unable to access public transport, and unable to afford taxis or ubers, they default to use private vehicles from those in their personal networks, but in many cases this opens them and those they are travelling with up to all sorts of risk of harm and create unsafe environments. Please strongly consider potential individual cases around this. One NDIS participant I have supported who is banned from using Transperth and train services regularly puts himself and the community at risk by seeking to find alternative transport which includes asking for lifts from strangers, hitchhiking and even driving illegally and this has resulted in repeated contact with Justice/Corrections.

Prescription Glasses – again while this is a typical family expense not disability specific, I have encountered several families throughout my career in the disability sector, whose children with significant disabilities and complex/challenging behaviours have repeatedly broken their prescription glasses – up to 5 times a year. Many families are in a position to be able to financially manage this, and previously in Western Australia, families were able to access a grant from Theodore and Isabella Wearne Charitable Trust to help with replacement costs for families in financial crisis. However this grant is no longer available and there are an increasing number of high needs, complex families that I am coming across where they are living in poverty and a parent has an imputed or undiagnosed disability that impacts their ability to problem-solve this, resulting in the child being without eyewear for extended periods of time that has severe negative developmental implications for them that has long-lasting ramifications.

I sincerely hope these examples highlight the need for an ‘exception to the rule’ alternative pathway request option for the most marginalised, vulnerable and complex disability participants such as I have proposed.