SUBMISSION TO THE AUSTRALIAN GOVERNMENT PRODUCTIVITY COMMISSION REGARDING SUPPORTS FOR VERY HIGH-NEEDS PARTICIPANTS

June 20, 2017

I write this submission in relation to support provision for very high need participants and their primary carer givers. I have a young child with intractable epilepsy who requires 24/7 care and cannot do anything independently, requiring assistance for all daily functions. As primary carer givers and parents, it is an impossible task for my husband and I to meet her high needs and care requirements around the clock without assistance from carers who have received training in how to operate her specific equipment, such as suctioning and SATs monitoring, as well as emergency care management in resuscitation, and seizure management.

My daughter's needs are so great that she has a high-level, very costly NDIA package. Unfortunately, although expensive, her package does not meet her needs to the extent that my husband and I are unable to work, and are so tied up with her care and support that we do not have the time to just be parents to her and her 9 year old sister. At the end of the day, she is just a young child who needs love and support from her parents as do all young children, however without an adequate NDIA package, we cannot provide this.

It seems there is disparity with meeting needs for those with only minor disabilities, requiring only low-cost packages, and those with very severe and high needs, requiring very high cost packages that must be approved by the head office team in Canberra. We previously had an A.A.T. ruling that recognised and awarded us with 24/7 carers as well as emergency in-home nursing support to fill gaps where her normal carers weren't available, however, despite her condition not changing (this is documented by her medical and care team multiple times) we have constantly had supports cut from her package and are now faced with the decision of having to permanently leave paid employment to meet the gaps left by funding cuts. This means not being able to financially support our family at all.

Not being able to work is devastating for us however both my husband and I are burnt out by having access to limited support and having to meet her high care needs around the clock. We have both been diagnosed with clinical depression and I have had to be hospitalised from the stress caused by continually having supports reduced. The situation we are in is not sustainable. We have completely withdrawn from social interaction and work and are mainly confined to our house to care for her. Life is extremely difficult for our family and there is no end in sight for us let alone the possibility to have a break or time out to recuperate.

The following issues with the NDIS need to be addressed with possible legislation changes to make life sustainable so that participants and their families are not put in the very stressful and disruptive situation we face.

EXTERNAL ARBITRATION

- AAT rulings should apply beyond a 12 month plan until and only if there are significant changes in circumstance

SEPARATION OF HEALTH/MEDICAL NEEDS AND DISABILITY

- Challenge legislation on the separation of health and disability - the NDIA should not be able to simply say the health department should be funding something when there are no health funds available to provide the supports the NDIA are denying to clients - they shouldn't be allowed to handball issues to the health department when there is no Healthcare framework for supporting those issues.

- Medical needs are often intertwined with disability needs and creating a very strong separation between the two makes causes difficulty in accessing supports, creating the 'who will fund this' dilemma, often resulting in no one funding it. If there is no one to fund a required support, the NDIA should pick up the funding for the support or come to an agreement to partially fund a support in conjunction with the medical sector. Supports that straddle both the realm of medical and disability should not go unfunded just because no one wants to pick up the funding.

- The NDIA has unreasonable expectations of what the health department should fund and are creating gaps in care and finding because of it

FAIRNESS AND EQUITY

- The individualised approach taken in the current system is very unfair, with participants with exactly the same condition being funded differently, with some receiving supports that others are denied. To make it fairer, there should be baseline supports that are funded for each condition, drawn up by an independent panel of specialists in each area of disability and based on solid researched evidence. In addition to these baseline supports, the NDIA should then consider individual requirements for supports, based on evidence supplied by the participants' own specialist team. This then provides a more fair approach, whilst allowing for individualisation of plans for each participant.

- The System disadvantages the severely disabled with high needs due to a reluctance to fund high cost plans. Those with the greatest needs, often without voice or means, have to fight constantly to get needs funded and constantly live with the stress of continual coast cutting measures applied to their plans.

Participants requiring very high cost packages are disadvantaged compared to participants requiring low cost packages. High-cost packages receive a high level of fiscal scrutiny and are constantly cut down to reduce funding, with the outcome of not meeting needs. Cost saving measures such as cutting a third of the budget off a low needs low cost plans has far less impact to the participant than cutting a third of the budget off a high needs, high cost plan. Meeting needs should be based on both medical and disability need, supported by the expert team of specialists that accompanies very high needs participants (doctors, therapists, etc.), not simply how much the plan costs. Reducing costs doesn't make the plan more efficient, it makes it less effective.

- Decisions seem to currently be arbitrary, based on the limited knowledge of planners or NDIA lawyers. Decisions must instead be both consistent and evidence-based and come from a panel of specialists and experts and not left to planners or lawyers who have limited or no understanding on the disability to make decisions. Evidence should be accessible and available to participants in order to create a transparent and fair process of decision making. There should also be ability to review further or new evidence in relation to a decision if it becomes available.

ETHICAL CONDUCT

- The NDIA has an unreasonable amount of power over participants. This occurs in many areas, such as denying participants the right to record their own planning meetings, taking lengthy amounts of time to review plans which makes it impossible to take disputes to the A.A.T., not allowing participants to review plans (and dispute them) before plans are approved, denying participants information and reports directly about them, rejecting specialist evidence and not following accepted peer-reviewed evidence in making decisions, not providing any information when requested, providing inconsistent information to participants, and very limited opportunity for participants to take unresolved matters or disputes outside of the NDIA to an independent body. When taking matters to the A.A.T. the NDIA has 24/7 access to an entire legal team, whereas participants often struggle with legal aid and often even legal aid is not available to them. There are more areas where there is a power-imbalance. An independent inquiry needs to be conducted around this very serious matter as it reduces the rights of participants.

- The NDIA must be more transparent and accountable in their dealings with participants. It is currently difficult to get information on why decisions have been made. Everything seems to be done in secret, without allowing participants to have a say on their own plans. Our information was actually given to a third party outside the NDIA without our knowledge or agreement. Although freedom of information exists, we have found it very difficult to obtain reports submitted to the NDIA about our child, and were initially denied access.

- The NDIA review process should be handled independently and externally to make the system fairer. This process should (as previously stated) be subject to time limitations to allow participants adequate time to escalate unresolved matters to the A.A.T.

- Rather than putting decisions in the hands of planners or lawyers, an independent team of specialists in each area of disability should be consulted to make decisions. These experts should be able to fairly weigh up and take into account evidence provided from participants' own specialist support team.

- 'First do no harm', should apply to the NDIA. Participants should not be subjected to unnecessary stress caused by the approach of the NDIA and how they deal with participants. Participants have already been through enough trauma in their lives, and daily living is much more difficult for someone with a disability. The NDIA should treat with care when dealing with participants, rather than taking the heavy-handed, do as we say, you have no rights, DHS/Centrelink approach they currently take.

PLANNING AND REVIEW

- Plan documents should be more transparent for participants, with itemised breakdowns on how costings were devised. This would also allow for comparisons with previous plans. Participants have a right to know where funding has changed and why, as well as exactly how figures were arrived at.

- The planning process is not transparent. Participants should be allowed the opportunity to review proposals for each plan before they are put in place. It is imagined that involving participants more in the planning process would actually increase satisfaction with plans and reduce the cost and need for lengthy reviews.

- Participants should have the option of having face-to-face planning meetings in their homes.

- Participants should not be denied the right to digitally or manually record planning meetings.

- Planning and Review - the NDIA should be bound by time limitations, just as clients are, to prevent unreasonably lengthy planning and review periods, during which clients can't access funds - this severely disadvantages clients

- Plans should last longer than 12 months - it is costly to the NDIA and stressful to the client revisiting a plan every 12 months

SERVICES

- The NDIA are currently trying to set market pricing on already existing services, such as cleaning, agency carers, food preparation, etc. This does not create greater pricing efficiency, but instead reduces quality of service.

We have had funded cleaners, who are actually personal carers with no training on how to clean and have done things like ruin polished timber furniture because they don’t have any training on cleaning basics. We have had funded cooks, who are actually personal carers with no training in food safety and handling, who have left cooked food out on benches for hours, putting our family’s health at risk. Much worse than this, it is really expensive to train each of our carers in the specialist care they need to provide in order for us to be able to leave our daughter in their care (so that we can work etc.) and we are unable to retain carers due to the inadequate costing structure NDIA have put in place which means that our carers can have better pay and conditions (such as permanent-part-time employment instead of casual employment) in the commercial sector. In our case, it would actually be cheaper to provide carers with adequate pay and retain them long-term, rather than continually having the expense of training new carers, furthermore, continuity of care is really important for participants, particularly when they are young children.

The NDIA must provide an adequate price point for services as the attempt to dictate market pricing and driving costs down is harming participants.

SUPPORTS

- Supports must take into account supporting the family unit as a whole - if we aren't supported we can't provide for our families physically or emotionally

- Supports should include allowance for primary carers who are family (such as parents) to take meaningful breaks, such as providing in-home care so that family take time out from care to have holidays or mini-breaks, as is expected when you are in the workforce – i.e. 4 weeks break per year. Never being able to take a break is unsustainable.

- In this day and age where people work past retirement age, it is unreasonable to expect extended family members, such as grandparents, aunties, uncles, etc. to take on support roles. Australia's current social structure is not such that we have support from a village community to raise our children (i.e. the old adage that 'it takes a village to raise a child'), and extended family should not be considered as supports, nor should they be expected to forego their lives and employment to help care for disabled participants of the NDIS because the NDIS wants to cut agency-funded carer support costs.

- Supports shouldn't be lessened/reduced in new plans for existing clients if there are no changes in circumstance

- The NDIA should not expect parents of disabled children to take on more than parents of non-disabled children - and this needs to account for all the extra appointments and organizing parents of disabled children have to undertake which in reality leaves little time and no energy just to be a normal parent - the whole issue around expecting parents to do more needs to be challenged - because we are already doing more

- It is not a luxury to provide adequate support to allow carers to re-enter the work force and adequate support must be put in place to allow primary carers, such as parents and family to work outside the family home if this is desired

- The NDIA needs to realise that it is more economically feasible and better for clients, especially children to remain in the home environment and out of externally facilitated care, including hospitals and should fund plans accordingly with measures that keep clients in the home. Externally facilitated care should be a choice, not a necessity.

- Evidence - we shouldn't have to keep supplying extensive evidence that has previously been supplied - once evidence has been provided, unless circumstances have significantly changed all that should be required is a confirmation of 'no change in circumstance'