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To: NDISConsultations@dss.gov.au

# Consultation on draft lists of NDIS supports

# It has been a long time since I have felt the need to respond to the government in relation to disability as I felt that many out there in the disability community have managed to get their say which often reflected our needs and appeared to have been listened to.

# But not this time.

# This arbitrary list of items pulled from a small selection of NDIS claims with no statistical backing as to whether these are broadly misused or if they are genuine needs after a client has gone through the whole ‘is it reasonable and necessary’ depending on their individual needs because of their disability is a massive step backwards.

# I have been fighting for my twins for 17 years – from the initial diagnosis at around 8 months of global development delay to PDD-NOS, ASD and intellectual disability. I have had to fight the NDIS process a number of times to ensure sufficient funding for their needs but this attack has placed all participants’ choice and control at great risk.

# I have been denied community health services after one was deemed ‘too complex’ at 4 years old and was referred to a state department that told me ‘we have no funding for therapy – hope you have something put aside’ whilst my other child became eligible for HCWA. Luckily the assessors (a team of three Allied Health professionals who assessed my daughter over three days) realised they had missed signs and she became eligible for HCWA – at 7 years old.

# This ran out when they turned 8.

# We then funded their Allied Health needs for years privately, drawing down off our mortgage, before the NDIS became a reality.

# The NDIS gave us an opportunity to build on our children’s needs, however, poor management from the government not recognising that there were just not enough providers out there, delays in paying the service providers leading to many closing, and deciding my children’s second plan needed to be slashed by 2/3 causing unnecessary stress. It took 11 months for NDIS to review their plans and acknowledge it needed to be increased. This meant that I lost contracts with service providers and had to go back on waiting lists, and treasured disability support workers found other jobs as they couldn’t wait around and not get paid.

# I had to fight to get them appropriate education whilst being denied specialist education because we lived in NSW rather than in the ACT and there was no appropriate schooling for one of them in NSW. I had to fight with the NSW Department of Education because the Principal didn’t want the other twin at her school because she felt they didn’t have the capacity to support him (I won and he thrived).

# I have always wanted to make sure my children were included, accepted and welcomed into ‘mainstream’ society. We looked outside the box to work on issues and give our children opportunities. We closely worked with individuals, groups and schools to make sure they were ready to take on our kids.

# This list will take away this choice.

# I implore that the government move beyond the use of an arbitrary ‘list’.

# There will never be enough ‘lists’ to recognise what can be used to make NDIS participants’ lives better. It needs to be individualised, discussed with experts who understand the disabilities (not LACs), talked over with the participants or their carers, nominees or guardians. This is the way that NDIS planning was always supposed to look like and not fobbed off to a Local Area Coordination agency that often have no relevant understanding of participants’ needs.

# We can’t sleep at night worrying about what is going to happen to our children and I know I am not alone having spoken to many parents of our age with children who are approaching adulthood. The push away from individualised plans, the move towards group day options, short term accommodation and SIL homes with group ratios of 1:3 up to 1:8, the loss of independence through appropriation of almost all of their pension if they move into SDA leaving them nothing to purchase basic needs like clothing or medicine, plays on our minds constantly.

# I acknowledge that the NDIS must change and must find its way again to protect our most vulnerable people. There has to be a better way than applying a sledgehammer to everyone.

# For your information, I have attached a document highlighting the specific supports/non supports list that will impact our family, giving examples of how we have used these services in the past and how they will impact our children if these are denied.

# Yours sincerely

# Jodi Wood

# ATTACHMENT

# NDIS supports list

## Supports that are ‘NDIS supports’

The below contains 36 categories of NDIS supports, a description of the category, and any carve outs to the description that are not ‘NDIS supports’.

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| NDIS SUPPORTS | COMMENTS |
| *Assistance In Coordinating or Managing Life Stages, Transitions and Supports**Description**Supports to establish assistance within the participant’s home or community to develop skills. Includes support coordination, mentoring, peer support and individual skill development such as attending appointments, shopping, bill paying, taking part in social activities and maintaining contact with others.**Active involvement in planning and transition supports on the basis of a person having reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) wherever there is a need for ongoing maintenance support.**Carve outs that are not ‘NDIS supports’**N/A* | My biggest concern is the focus on ‘develop skills’ with the assumption they will require less assistance – some participants may require this support for the rest of their life or will require more if there is physical or mental deterioration. There needs to be more focus on identifying the difference to give participants more dignity. There is too much emphasis on ‘let’s fix this’ rather than ‘what can I do for you at this moment to ensure your needs are met and please let me know if you need less or more assistance from us’. I am tired of explaining to organisations that – yes – I have pretty much tried most things with my daughter and we are at a stage where no amount of therapy, social stories, PECS etc are going to make her do certain things. Sometimes this is a waiting game, sometimes with lots of repetitions she finds she would prefer to do it herself, other times nothing is going to change and she will possibly need help for the rest of her life. I don’t want to have to beg NDIS for supports when they arbitrarily decide at 20 that she doesn’t need the support we have been using because ‘she should be able to do this now’.I also don’t want to have to continuously justify why she needs individual support rather than at the 1:3 ratio in all aspects of her life. We have been intimately involved in her development and growth for 17 years and if we say it is safer for her and her workers to be at the 1:1 ratio there are reasons for it. Her primary school agreed, her high school agreed. Her Positive Behaviour Support plan written by an expert who did a deep dive into her life for months agreed. Even when I send her to programs (disability or mainstream), events, activities or just out into community, she requires 1:1 unless we have exhaustively worked with an organisation to increase the ratio. And even then if things flare up she will go back to 1:1. This will potentially affect her for the rest of her life. Is Positive Behaviour Support going to ‘fix; it? No. Will it help organisations and their staff understand how to work safely and calmly with my daughter? I hope so – but only if they read it. Will she improve? I hope so, she is only 17 with a lifetime of experiences to absorb. But if those experiences are negative or she is placed in situations that make her feel vulnerable, she will only regress further in her behaviour to protect herself. |
| *Assistance With Travel/Transport Arrangements**Description**Transport assistance, including training, activity-based transport, provider travel, and costs associated with the use of taxis/private transport, where the participant cannot travel independently or use public transport due to the impact of their impairment/s on their functional capacity.**This includes transporting participants to funded supports and other activities including school, educational facility, employment, or the community.**Carve outs that are not ‘NDIS supports’**N/A* | We live on the outskirts of Canberra in NSW in the country. There is no public transport. There are only two taxis and they will not transport people with complex disabilities. Uber does not service our area. My daughter requires another person to travel with her due to complex behaviours and her disabilities. She does not cope well in group situations and needs to be transported in private vehicles with trusted workers or parents. I need the NDIS to understand that to get her out into society I need appropriate funding to cover these costs. This may even include the cost of someone coming out to our place which can be a 30-40 minute drive to pick her up as there are no local workers.  |
| *Assistive Products for Household Tasks**Description**Specialist products to enable cooking, cleaning, washing, home maintenance and other tasks.**Carve outs that are not ‘NDIS supports’**N/A* | My daughter currently lives with us (parents) and two siblings. We do almost all household tasks for her. Our hope is to identify equipment that is safer for her to use, encourage her to prepare simple meals, clean up after herself. We understand that some products would be standard in any household. However she has difficulty with fine and gross motor in her hands, has severe sensory reactions to noise, light and touch, and requires products that will help her to avoid these situations. At the moment we purchase these so called ‘mainstream’ products that would assist her (eg. Microwave with handle, lever taps, auto vaccuum etc) but these are often more expensive than standard products. In the long term when she may be living independently or with support, my hope is that NDIS do not prevent participants from claiming these types of items if it lets them live with some dignity and they would not have purchased the items otherwise. |
| *Assistive Products for Personal Care And Safety**Description**Specialist products for personal care or safety including beds and pressure mattresses, toilet and bathroom equipment, specialised clothing and continence needs.**Carve outs that are not ‘NDIS supports’**N/A* | My daughter has always had issues with toileting including occasional incontinence, encopresis, refusal to wipe after toileting and has just started her periods at 17. She had an incontinence plan when we transferred onto the NDIS. She detested the feeling of nappies and pull ups. We were purchasing standard underwear and often had to throw them away if they became too soiled, and she was embarrassed if she had an accident at school and it leaked through to her jeans. We were thrilled when NDIS covered the cost of Modibodies (her preferred brand after trialling several period underwear) to assist in both her incontinence and now her periods. She wears these pants every day unlike ‘mainstream’ users. She may have to change them a couple of times a day if she has an accident but they wash well. We usually have at least 12 – 14 pairs at one time to allow for washing, drying etc. These give her dignity, she likes wearing ‘normal’ looking underwear, and the boyleg design helps contain any accidents. However if NDIS refuses them due to them being considered for menstruation, this will create an additional financial burden as they are expensive. Continence underwear will not be suitable as they do not deal with periods and my daughter’s cycle is still very erratic and can happen with no warning. Similarly we purchase Jettproof singlets and long sleeved tops. She will not wear bras or crop tops and for her dignity we have her wear these. They also provide sensory input (unlike a bra) and help to settle her. |
| *Group And Centre Based Activities**Description**Assistance for participants to access and participate in community, social and recreational activities provided in a group setting, either in the community or in a centre.**Carve outs that are not ‘NDIS supports’**N/A* | This reeks of institutionalisation – I had hoped the NDIS was moving away from the day option program to a more mixed model where there were supports in a more mainstream setting for participants. I am concerned that this appears to be separate from ‘innovative community participation’ and I am looking for more details on both of these to see how they work with each other. |
| *High Intensity Daily Personal Activities**Description**Assistance with and/or supervision of tasks of daily life to enable a participant with complex needs to live as autonomously as possible in a range of environments, including but not limited to, the participant’s own home.* *These supports are provided by a worker with additional qualifications and experience relevant to the participants’ complex needs.**Carve outs that are not ‘NDIS supports’**N/A* | I have heard that this may only relate to physical / medical complex disabilities. My daughter has complex behaviours with her ASD and ID diagnoses and we have learned over the years that there are specific traits in workers that are essential to ensure her (and their!) happiness and safety. We need NDIS to recognise that participants such as our daughter also require specialised and experienced supports which may require a higher salary and additional qualifications. |
| *Innovative Community Participation**Description**Activities not included under other community participation registration groups; for mainstream providers who want to enable participants to access mainstream activities.**Carve outs that are not ‘NDIS supports’**N/A* | We need more details and examples on what ‘community participation registration groups’ and what this is actually used for and who receives the funding. The purpose of the NDIS was to remove the demarcation between these (which I am assuming are disability specific such as day programs) and ‘mainstream activities’.  |
| *Specialised Driver Training**Description**Driver training using adapted equipment or vehicle modification.**Carve outs that are not ‘NDIS supports’**N/A* | My son is currently trying to obtain his P licence in NSW. I have employed a highly experienced driving instructor who is familiar with his disability and our desire for him to obtain his licence as we live out of town with no public transport. The instructor has been open in his assessment (including having an OT sit with them). He is going to need well in excess of what a ‘neurotypical’ teen would need in structured lessons, but he also said that my son – with sufficient support – would become a very capable driver. I understood NDIS was funding up to 10 additional lessons to help young people achieve this (we have already paid for an excess of 20 lessons as the instructor said he is not ready to drive with us yet – we have put in a request but have not heard back yet). I hope NDIS continue to fund this for young people with a disability as it is vital for their mental wellbeing to have the freedom to drive and not rely on parents or support workers to take them places. |

## Supports that are not ‘NDIS supports’

The below contains 15 categories of goods and services that are not an ‘NDIS support’, a description of the category, and any carve outs to the description that are considered an ‘NDIS support’.

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| *NOT NDIS SUPPORTS* | COMMENTS |
| *Day-to-day living costs**Description**Accommodation and household related:** *Rent, rental bonds, home deposits, mortgage deposits, strata fees, rental bonds and home deposits.*
* *Standard home security and maintenance costs, fencing, gates and building repairs*
* *General furniture removal and services, unwanted furniture pick up*
* *Pools, pool heating and maintenance, spa baths, saunas, steam rooms*
* *General home repairs, general renovations and maintenance.*
* *Water, gas, and electricity bills, council rates*
* *Water filters, purifiers, or aerators.*
* *Electricity generators, solar panels, and batteries*
* *Standard household items (dishwasher, fridge, washing machine, non-modified kitchen utensils and crockery, fire alarms, floor rugs, beanbags, lounges, standard mattresses, and bedding), replacement of appliances, including hot water services, solar panels, etc.*

*Finance and payments related:** *Donations, tithes, gifts, and political contributions,*
* *Fines penalties, and court-ordered amounts*
* *Travel insurance, life insurance, home and contents insurance, car insurance and excess insurance for Novated vehicles (Salary Sacrifice).*
* *Superannuation for participants or related parties (exceptions apply for arm’s length Employment arrangements)*
* *School / education fees including TAFE and university.*
* *Legal costs*
* *Child support fees, debt repayments, gift cards*
* *Business development costs, business skills development costs*
* *Debts, liabilities, and taxes, other than those necessarily incurred in the receipt of supports*

*Food, Beverage related:** *Groceries (except for modified foods required as a result of a person’s your disability e.g. PEG feeding),*
* *Fast food services and takeaway food*
* *Alcohol*

*Lifestyle related:** *Cigarettes, vapes and smoking paraphernalia, legal cannabis*
* *Gambling*
* *Internet services, land line phone, mobile phones, mobile phone accessories, and mobile phone plans and smart phones.*
* *Gaming PCs, consoles and games, subscriptions for streaming services*
* *Standard toys, balls, racquets, uniforms, membership costs and other costs associated with recreational sports*
* *Wedding, honeymoon, funeral, other events.*
* *Musical instruments, music production, social media production*
* *Tickets to music, theatre, cinema or sporting events, and general conference fees*
* *Sex work*
* *Sex toys*
* *Surrogacy, Menstrual products, IVF*
* *Trampolines*
* *General play equipment, indoor or outdoor.*
* *Membership of a recreational club*

*Clothing related:** *Jewellery, watches (including smart watches)*
* *Makeup, cosmetic treatments, wigs, and cosmetics*
* *Standard clothing and footwear*

*Travel related:** *Cruises, holiday packages, holiday accommodation, including overseas travel, Airfares, passports, visa, meals and activities.*
* *Tickets to theme parks, tourism and entertainment operators.*
* *Motor vehicles, motorbikes, watercraft, all-terrain vehicles and other recreational vehicles, mechanical repairs, tools, vehicle registration.*
* *Petrol*

*Pet Related:** *Animals (other than approved NDIS funded assistance animals),*
* *pet food for animals other than for approved NDIS assistance animals,*
* *veterinarian costs, pet boarding, pet grooming, taxidermy, pet cremations/funeral*

*Carve outs that may be considered ‘NDIS supports’ for certain participants* *The following day to day living costs may be funded under the NDIS if they relate to reasonable and necessary supports:** *Additional living costs that are incurred by a participant solely and directly as a result of their disability support needs*
* *Services delivered in a gym or recreational club related to the participant’s disability support needs (excluding the cost of membership, entry, or basic equipment).*
* *Play equipment where it is specialist sensory equipment could be funded under Assisted Technology*
* *Additional insurance costs that arise from modified vehicles*
* *Additional costs to upgrade standard household items to household items that include accessibility features*
 | From a parent’s perspective I find some things on this list insulting that they even need to be pointed out as inappropriate. If some of these things are being purchased NDIS need to focus on the individual participants and not tar all participants with the same brush, especially through the media.However, some items (menstrual products, sex services, smart watches, electricity generators, land lines or internet) that have been targeted in this list are a concern and should be considered on an individual basis. As discussed above, we use Modibodies for both continence and period requirements. Smart watches can keep participants safe and organised in their daily lives or if they have falls. Rural participants may require a land line if mobile signals are weak or non existent. Participants on overnight respirator machines need a generator in case power fails (and I don’t think I need to remind NDIS of people who have died because the power went off and they were unable to breathe on their own in WA).Sex services is an uncomfortable topic but must be discussed in relation to how our participants still need love. However they may not have the discretionary spending especially if they live in SDA/SIL/ILO as fees where up to 85-90% of their pension are often absorbed, leaving them with very little discretionary spending money. I completed a Certificate III in Individual Care (Disability) and our tutor had worked in the disability industry for decades. She recalled that many of their clients in the institutions would save their pension for trips to the brothels. NDIS need to look at WHY a participant is left with nothing out of their pension to purchase basic human needs such as a meal with their day option group, a warm coat, having their hair cut or washed, sexual services or companionship etc |
| *Not value for money/not effective or beneficial**Description**Alternative and complementary therapies:** *Crystal therapy*
* *Tarot card reading, Clairvoyants*
* *Cuddle therapy*
* *Reflexology*
* *Aromatherapy*
* *Sound therapy*
* *Yoga Therapy*
* *Wilderness Therapy*
* *Alternative or complementary medicine*

*Wellness and coaching related:** *General massage*
* *Sports or athletic supplements*
* *Life/wellness/career coach/cultural coach*
* *Hypnotherapy*
* *Neurofeedback*
* *Gaming therapy*
* *Mastermind coaching*
* *Somatic therapy*
* *Kinesiology*

*Energy and Healing Practices related:** *Reiki (including intuitive reiki), Scalar Lounge, Frequency Healing and Energy balanced massage, Deep Energy Clearing, Spinal Flow Technique, Shamanic Healing*

*Beauty Services related:** *Hair therapy, hair and beauty services including nail salons*

*Carve outs that may be considered ‘NDIS supports’ for certain participants* * *Therapeutic massage that is directly related to a participant’s disability support needs*
 | Gaming Therapy:My children have no friends. They are 17 years old. No one asks them to go out to the movies, hang out at the mall, come over to their place to game. This is due to many reasons but ultimately it comes down to the fact their disability makes it difficult. We have been fortunate to use a number of these ‘gaming therapy’ services and it has been amazing. They are with experienced moderators who help with the social interaction between the participants, encourage them to join in, talk, laugh, learn. I had tried mainstream gaming groups and even with a support worker my daughter did not fit in nor were they accepted by the others in the group so we continue to use these kinds of services. My son became confident enough after being with a number of disability supported gaming groups to move to a mainstream group and is now thriving. NDIS need to be more judicious in targeting these groups as some have made enormous changes in our children’s lives.Beauty Services:My daughter does not like to shower, will not wash or brush her hair. She is now 17 and it is inappropriate that I have to force her whilst in the shower as it distresses her. This has always been a struggle since she was a baby. Prior to 2020 her support worker and I set up a weekly hair washing session with our community hairdresser. This has taken years to get to a point where she will let her hair get washed and conditioned, and only recently will she allow the hairdresser to comb it out and now lets us know if she wants it cut. I cannot provide this kind of service at home nor can a support worker do it in the shower as the hairdresser has the equipment to wash her hair safely in the basin without getting her face or body wet. At the moment she pays for this service out of her pension. However, if she is ever required to move into an SDA it is unlikely she will have sufficient pension left over for these services. If she doesn’t get her hair washed, she is guaranteed to develop hygiene related health issues. I would not have my hair washed once a week by a hairdresser – I can do it myself. My daughter can’t. That is the difference. |