**Home and Living consultation submission**

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**How do you identify:** A participant currently receiving home and living supports

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

Yes

## **If not, why not?**

* I’m happy with my current arrangements:
* I don’t think I have the money to make changes:
* I don’t know where to start:
* I’m comfortable thinking about it on my own:
* I don’t want to talk about it:
* Other – please describe:

## **What kinds of things do you talk about / would want to talk about?**

* Who I want to live with: Yes
* Where I want to live: Yes
* What supports the NDIS funds: Yes
* What options are available: Yes
* What other people have done: Yes
* Not sure: No
* Not Applicable: No
* Other – please describe: No

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

* Internet: Yes
* Social media: No
* Service providers: No
* Support Coordinator / LACs: Yes
* NDIS / NDIS website: Yes
* Friends and family: Yes
* Other participants / peers: Yes
* Government websites: Yes
* Peak bodies / advocacy groups: Yes
* Other – please describe: No

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

* Examples of what options other people with disability might have chosen: Yes
* Someone to talk through my options with me: Yes
* Information that I can take away and read on my own: Yes
* Information given to providers: Yes
* Opportunities to talk with NDIS representatives on new options: No
* Other – please describe: No

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

Not at all helpful

## **What would improve the helpfulness of home and living information on the website?**

Explaining all the options available clearly and how you qualify, and how you apply, and all support coordinators being checked for knowing and offering these options.

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

Yes

## **How can we work better with your informal supports to help them know more?**

Make it simpler, and make each step for each choice clearly documented.it is too complex and too hard to find the information, so unpaid people refuse to help. As it’s too time consuming, thus we get only snippets of what is available, or told the completely wrong thing.

# **If your NDIS funding was more flexible, would you purchase different support/s for your home life than what you have now?**

Yes

## **Such as?**

Equipment, furniture, decor, electronics, faster more capable internet, and assistive technologies that a. Cost more than the low cost threshold for initial outlay, or b. Are labeled every day items-when if I didn’t have my disability I’d not need the, every day, so regardless if other people need it, if I need it due to my disability and it will change my world, better than uninspired disability labeled items at ripped off, out of date stores..I’d get more out of it. I’d also get a sauna, swim spa and cable weight machine and have a sensory room, and a spare room for all my disability related equipment to help keep it organised and to have a place to meet with staff and therapists, to reduce so much stress, wasted time, and hazards. And the items mentioned, would allow me 24/7 pain relief as needed, increased mobility, fitness, wellbeing, a way to increase my social opportunities, reduce stress and meet me where I’m at..unable to leave the house, comfortable and safe at home, so willing to try here, and the need for support workers, travel, program fees, admin fees, invoicing, plan managers, support coordinators, at to cope with leaving the house etc etc would all be drastically reduced not just during the one plan it would take to buy the expensive things, but for all the years they should last, approx ten years. We know what we need, better than the experts, books, or experiments can tell u, as we all are affected differently, cope differently, react differently, need different things to be as undisadvantaged as someone without the disability.

# **Who helps you to organise your NDIS supports?**

* Formal support, such as a support coordinator / LAC / NDIA planner or delegate: Yes
* Informal support, such as family / friends / carer / peer support networks / mentors: No
* No one / I self-manage my funds: No
* Other – please describe: No

## **How helpful is using formal supports?**

Somewhat helpful

## **How helpful is using informal supports?**

No answer recorded

## **How helpful is using other supports?**

No answer recorded

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

No

# **Of the following options, who would you be most likely to use to help you implement your plan?**

* Peer support networks: Extremely unlikely
* Mentors: Very likely
* Specialised home and living support coordinators: Very likely
* Support coordinator / LAC: Unlikely
* NDIA planner / delegate: Very unlikely
* Family and friends: Very unlikely
* Other – please describe: Extremely likely

Advocates specialising in the disability I have and the ndis, and myself, as I need it and it affects me the most, so only I will put in the enormous effort and time needed to navigate, learn, evaluate options etc that are in my best interest

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

* Pricing incentives for providers: No
* Recognition of innovative providers: No
* Newsletters: Yes
* Showcases: Yes
* Participant reviews and ratings: Yes
* Other – please describe: No

# **Appendix D (see consultation paper) lists options for actions we could take to improve home and living in the NDIS. What other ideas would you add to Appendix D?**

Just allow invoicing under 5k to be drawn up as per normal invoices in the real world and stop all the wasted time and confusion getting the codes and current rates and having things refused cause u used last months price not realising it had changed, then get plan managers to convert it to the codes ndia need. Self managed upload invoices how we get them, ndia figure out what codes to enter it as

# **Do you identify as:**

* Aboriginal and Torres Strait Islander? No
* From a culturally and linguistically diverse background? No
* Living in a rural and remote area? No
* LGBTIQA? No
* Having a psychosocial disability? Yes

# **Is there something you would like to see in a home and living policy specific to your response in previous question 12?**

To stop thinking it’s rubbish, and understand it can be more disabling than physical disability, and to realise mental, brings on physical ailments and vise versa, u can’t untangle them, u can’t tell asd depression or anxiety is not part of their funded disability. And u have to allow new different and plain weird to u, treatments or supports, when anxiety or depression are present as we can’t cope doing the normal treatments in the normal ways. So we miss out altogether on what would help us

# **Is there anything else you would like to add?**

Asd is proved to go hand in hand with ptsd, anxiety, depression, adhd, learning delay, speech issues, memory issues, dietary issues, sensory issues, communication issues, fatigue, tight muscles, lax muscles, food allergies, everything else allergies, insomnia, dehydration, ocd, etc etc etc. please educate all staff to know this, the whole rest of the world knows this.. It's even on many of our states webpages for asd advocates, government assistance or info etc. but conveniently ignored by all ndia staff, planners, support cooordinators etc etc, they ignore the full definition in both diagnoses definitions uk and us..and the wealth of peer reviewed , government sanctioned, experts in the fields reports and publications from the entire uk, us and everywhere else. even our own university published works on what asd entails, what out of the ordinary treatments show more success, and that adults have no treatments, it’s all aimed at children, meant to “fix” them with early intervention. reduce costs..problem solved. but asd is perm condition, and all the children that missed out growing up on early intervention, all those u couldn’t “fix” need life time supports to be at less of a disadvantage, and there are none tailored to us. So supports need to focus on increasing our wellbeing, however we will find it, that will reduce costs if we are happy, supported, free to make choices and be living a life we are proud of fulfilled in and that addresses all our unique needs in ways that speak to and are accessible by the type of personality we are.