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Friday 27 August 2021

Mr Mark Hoffman
Chief Executive Officer, National Disability Insurance Agency
GPO Box 700
Canberra ACT 2601

RE: Physical Disability Australia's (PDA's) Response to the Home and Living Consultation Paper

Dear Mr Hoffman

Thank you for producing the *Consultation Paper: An Ordinary Life at Home*[1] and inviting us to participate in the Home and Living CEO Forum Workshop held on Friday 13 August. We appreciate these opportunities to provide feedback on the National Disability Insurance Agency's (the Agency's) efforts to improve outcomes for participants. What follows is our answers to the questions in the Consultation Paper and some further observations and comments about its content.

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

A lot of PDA members talk to us about where and how they want to live. Primarily the issues of concern are about getting Home Modifications (HMs) approved and paid for, and finding accessible dwellings that they could move into. Some of our members, those with progressive disease that reduce their functional capacity over time and younger members who have had high support needs from birth, are concerned that they will eventually have to move into a group home or other institutional setting to get the supports that they need.

Any Home and Living situation that obliges people with disability to share accommodation with people they have not chosen to live with and share supports with them should never be their only option under an NDIS that has as part of its objective to "promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community[2]"

PDA believes there is a lot the Agency can do to provide participants with physical disability access to housing options they want without generating the escalating-to-unsustainable costs that probably underly the assertion in the *Consultation Paper* "that the NDIS cannot afford to pay for the support required for all participants to live alone." (p. 7). Statements like this and the insinuation that group homes with 2 to 4 participants are still an acceptable Home and Living option for some unlucky participants are extremely disappointing and show a lack of lateral thinking with regard to what can be achieved with different policy settings.

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[1] https://www.ndis.gov.au/media/3226/download?attachment

[2] Section 3, part (g) *NDIS Act 2013* - https://www.legislation.gov.au/Details/C2020C00392

Some of our ideas about steps the Agency can take to help all participants achieve their Home and Living goals are elucidated below.

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

and

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

Most people with physical disability have a pretty good idea about where and how they would like to live; the information they would like to get is how to achieve their desired Home and Living outcomes. The NDIA could assist in this by funding the creation and maintenance of specialised peer groups where participants with a range of impairments who are living in independently in the communities of their choice within the bounds of their funded support packages can mentor others to achieve similar goals.

PDA would be very interested in being involved in such a program.

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

Generally speaking, the NDIS website is not particularly useful for information relating to the goals of people with physical disability. As noted above, these participants usually have a good idea about what they would like to achieve and the processes involved in applying for particular Assistive Technology (AT) items and HMs.

What is less than helpful is the overly complex application processes required to get the funding for these Home and Living supports approved. The forms that need to be completed (by qualified ‘Assessors’) for general medium to high cost AT, Prosthetic and Orthotic AT, and HMs need are long and require cases to be made for them by qualified assessors if participants are going to be allowed to live the lives they want.

The *Assessment Template – General Assistive Technology* form [3], for example, requires an Assessor to “Describe, having regard to best practice, what evidence indicates the proposed AT will be, or is likely to be, effective and beneficial for the participant? (E.g. published literature, past participant experience of AT).” (p.11). This presumably is juxtaposed against the answer to a later question “Describe any potential risks to the participant/carer if this AT is not provided” (p12).

We are dismayed that these details of participants’ circumstances are required to be provided to be picked over by planners. Do planners really need, for example, to have it spelt out that the consequence of not providing a wheelchair to a person with a spinal cord injury is that they will be more-or-less completely immobile and unable to navigate their own homes let alone the community?

We are also concerned about questions about the expected impact of the recommended AT on participants’ long term support costs (for example on p. 11). This is because some impairments (such as motor neurone disease and multiple sclerosis) are well understood to be progressive in nature and reduce functional capacity over time regardless of the AT or HM secured. Are you really going to deny

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[3] https://www.ndis.gov.au/media/381/download?attachment

a participant with such an impairment a motorised wheelchair because it won't result in lower costs and/or long term independence?

There are many other questions on these forms that we consider are superfluous (such as details of participant's names, addresses, plan management arrangements, and goals) or unnecessarily prying (physical dimensions, history of AT usage, description of "behaviours of concern", etc). Planners, as we understand them, are not allied health professionals and so shouldn't be put in the position of needing to verify the reasoning of the Assessor. From our perspective, the reasonableness and necessity of AT and HM supports can be made on an understanding of the nature of a participants' impairments , their prognosis and the Assessors' recommendations alone.

The *Request for Home and Living Supports* form[4] is similarly overly inquisitive and burdensome. For the purposes of determining whether participants' supports should include assistance with living independently, improving life and household management capacity, and social, communication, and behavioural management skills (p. 1), it should not be necessary for participants to describe their current living situation and the coping skills they currently use across 27 different aspects of home life (pp. 8 to 10).

All the information a planner needs to determine the level of support a participant should receive to realise a preferred Home and Living outcome should be gleanable from their current plans, the impairments they have and the goals they have set for themselves.

PDA therefore implores the Agency to reassess and simplify its application processes to take advantage of the information it already has about participants and combine this with a more thorough understanding of the impacts each eligible impairment has on a person's capacity in the short and long term.

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

Most PDA members and participants with physical disability generally are capable of communicating their Home and Living goals to their informal supports as appropriate. Many members have let us know of quite detailed goals for moving out of family homes and out of institutional settings into a range of independent living scenarios. These people and many other participants with physical disability are hoping the Agency can offer greater flexibility in how they use their plans so that these goals can be realised soon.

Also generally, it would not be appropriate, for such participants' informal supports to investigate their Home and Living options without their active participation in such processes. The same would be true for participants with most disability types.

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

With regard to the Home and Living area, greater flexibility in how PDA members could use their funding would most likely be directed towards the purchase of better AT items and HMs. At present, and as noted above in our answer to Question 4, the process for getting funding for more costly supports in these categories is time consuming, complicated, and requires the engagement of allied health professionals

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[4] https://www.ndis.gov.au/media/2857/download?attachment

to provide justification for the supports many people with physical disability need. These arrangements are a burden to participants and the NDIS both.

For many people with physical disability, it is self evident that AT such as power wheelchairs and motorised adjustable beds, and HMs such as access ramps and renovated bathrooms[5] are reasonable and necessary supports that should be funded by the NDIS. They offer value for money in that once purchased they provide years, if not decades of service.

We hope the planned flexibility settings provide more streamlined processes and faster approvals for Home and Living supports such as those listed here. We would also like to see consideration given to funding HMs in properties rented by participants in the general market. Such an allowance would represent a large break from existing policy settings where all NDIS expenditure is closely linked to individual participant needs and outcomes. It might also be argued that modifications to rental properties would be providing benefits to landlords when they should be investing in accessibility themselves. However, there is a critical shortage of accessible dwellings in the rental market which is the most financially and immediately available option for participants, many of whom do not have the means to purchase housing that might them be modified.

Allowing modifications to rental properties would meet the needs of many participants with physical disability and we hope the Agency can consider conditional approval[6] of such expenditure.

7. Who helps you to organise your NDIS supports?

Many PDA members are self-managed. They choose this way of organising their supports as it gives them maximum control over who provides support to them and maximises the benefit they receive from their funding by minimising, if not eliminating, the overheads associated with support coordination and commercial/charitable service provider costs of doing business.

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

PDA encourages its members to interact with each other during our monthly Zoom Social Hours and Youth Network hangouts. In these settings peer support is offered informally. We would like to set-up a formal peer support network to actively match members who have achieved their Home and Living goals through self-management of their supports and clever AT and HM solutions. We hope the NDIA considers funding organisations like us to create and support networks like this for the range of disability communities that make up the population of NDIS participants.

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[5] In this context, renovations entail the creation of hob less showers, floor resurfacing with appropriate drainage, disability appropriate toilet suites, the installation of rails and hoists, etc.

[6] Some conditions that might make such a policy shift more palatable to Government and the Agency include contractual arrangements with landlords to provide long term leases to HM funded participants and commitments to prioritise tenants with similar HM needs in future leases.

9. *Who would you be most likely to use to help you implement your plan?*

PDA encourages its members to self-manage their supports if they are capable of doing this. Self-management has many advantages over using support coordinators and established service providers. The key benefit is that there are significant savings to be made by avoiding the costs of support coordination and the overheads that service providers have in employing the people who provide supports to participants.

Having said that, we are also aware that participants often need support to establish the systems and practices needed to become effective. As noted in our answer to question 8 above, We would be very interested in partnering with the Agency in establishing a peer support network where members could be facilitated in sharing their Home and Living goals and working together to achieve them.

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

As noted above, most PDA members who are participants self-manage their supports and seek their own personal Home and Living solutions without the assistance of service providers.

For those participants with physical disability that do require a service provider, we would like to see more properties created like those run by the Summer Foundation[7] that involve separate accessible apartments/units with close-to-site support workers that can be called upon when needed outside.

To deliver this, we recommend the Agency should work with other government entities to create a range of incentives to entice social-minded developers to build these in a broad range of communities around Australia

11. *Appendix D lists options for actions we could take to improve home and living in the NDIS. What other ideas would you add to Appendix D?*

PDA approves of many of the listed options for action listed in the *Consultation Paper* however, we believe the don’t go far enough.

Under ***Changing the Conversation***, we would like to see the additional training for planners and Local Area Coordinators (LACs) include more detailed knowledge about the impairments that cause disability: what they are, how they affect participants functional capacity, and their prognoses.

Under ***Supporting You to be an Informed and Empowered Consumer***, we would like to see all residents of group homes supported to find Home and Living solutions in the community and financial support (in addition to key information and communication) given to peer networks.

Under ***Expanding Support for Decision-Making***, as above, peer networks need to be supported (with funds) in addition to being promoted. We also believe you should work with the NDIS Quality and Safeguards Commission to establish appropriate safeguards for the expanded reliance on informal supports envisioned by some of the scenarios (discussed below).

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[7] https://www.summerfoundation.org.au/

Under ***Reforming the Funding Model***, rather than just “Introducing safety measures for participants to ensure they are always able to afford their supports they need from their budget”, we believe that budgets should be revisited when Home and Living Goals are changed or established for the first time. It is not appropriate to determine and strictly define a budget in advance of working out what reasonable and necessary supports are required to assist participants to achieve their goals.

Under ***Assisting Implementation and Maintenance***, as above, it is not sufficient to just ensure “Participants [are] supported through coordinated peer groups and/or access to mentors with lived experience who can help discuss home and living options” without ensuring that the peer groups themselves are supported (with financial arrangements) as well.

Finally, under ***Engaging the Market and Driving Innovation***, as argued in our answer to Question 10 above, we would like to see the Agency working with other government departments to create incentives for the development of accessible accommodation in a diverse range of communities around Australia.

12. Do you identify as:
  - ***a. Aboriginal and Torres Strait Islander***
  - ***b. LGBTIQA+***
  - ***c. Are you from a Culturally and Linguistically Diverse background***
  - ***d. Do you have a psychosocial disability***

PDA has members from all backgrounds and across the sexuality spectrum. We also have members with psychosocial impairments in addition to physical disability.

Is there something you would like to see in a Home and Living policy specific to your response in Question 12?

We have noted a trend for government agencies to ask about whether people with disability also occupy another target group of the population. In some respects, we are happy to see the Agency is aware that some people from target groups with disability face additional barriers due to language and cultural differences. However, in terms of Home and Living outcomes, and eligibility for Independent Living Options (ILO) support and Specialist Disability Accommodation (SDA) in particular, it is the nature of a person with disability’s impairment and it’s impact on their capacity to access and use the features of their dwelling that is of primary relevance. This is evidenced in the *SDA Pricing and Payments Framework*[8] where eligibility is specifically linked to a range of diagnoses (p. 13).

PDA has argued for many years now that the Agency needs to collect and use information about participants’ impairments to inform it’s policies and planning guidelines. We know from personal experience that each separate impairment has its own set of consequences and that the supports needed to mitigate their effect on participants can be quite particular. We opposed the planned changes to the NDIS Access and Eligibility Policy for it’s misguided insistence on a diagnostically blind functional capacity assessment and would like to see questions about the type of disability participants have included in questionnaires such as this alongside those associated with membership of the usual target groups.

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[8] https://www.dss.gov.au/sites/default/files/documents/06_2020/sda-pricing-and-payments-framework.pdf

With regard to the target groups listed above, PDA would like to see the usual actions to support participants that are identified in this way. These include:

- Ensuring First Nations participants are supported by culturally appropriate engagement processes that are administered by culturally aware staff;
- Ensuring Agency personnel and resources show understanding and respect for the diverse sexuality of participants, and in the Home and Living context, understanding and respect for the right of people with disability to express their sexuality with the partners of their choice;
- Ensuring resources are provided in a range of community languages and funding interpreters as required; and
- Ensuring Agency processes and the employees who administer them take into account the fluctuating capacity of people with psychosocial disability to engage in important conversations.

13. *Is there anything else you would like to add?*

- ***Lack of clear targets in the Vision***

The Agency's Vision (p. 4) expresses an admirable goal in its last sentence "to create a Home and Living Policy that supports you [participants] to make your own decisions about where, how and who you live with, just like any other Australian"… but it excuses the Agency from delivering this in an earlier paragraph with the expectation that "contemporary group homes (of between 2 - 4 people)" are still an acceptable situation for participants with high support needs.

PDA believes that just as no person without a disability would choose to live with strangers and have no control over who comes and goes, no person with disability does the same without the reduced expectations and conditioning Australia's pre NDIS disability care and support systems imposed upon them.

Therefore we would like to see the Agency's Vision state it's final sentence first and then list a range of targets such as the emancipation of all participants from aged care facilities and institutional arrangements by 20XX and the transition of all participants from (so-called) Supported Independent Living (SIL) arrangements to individualised plans by 20YY, and so forth.

- ***Lack of acknowledgement of the role played by Disability Representative Organisations***

Pages 5-6 of the Consultation Paper detail what a new Home and Living policy might mean for participants, their families, providers, and the Agency, but there is no role acknowledged for Disability Representative Organisations and other community groups. Given the key role these play in informing the Agency about participant experiences and participants about how to realise their NDIS supported goals it would be appropriate to have this acknowledged with similar commitments of support in this section.

- ***Real Life Example: Tori (pp. 8-9) and Appendix B – Scenarios for an Ordinary Life***

The examples of people moving out of a group home and family homes provided in the Consultation Paper are interesting and encouraging as they show what can be achieved by pursuing novel approaches to organising supports and developing greater community involvement for the participants involved. That being said, some of the arrangement leave us with troubling questions around how the arrangements of ‘Tori’ and ‘Moshe’ in particular have appropriate safeguards around them.

For example, with ‘Tori’, we wonder how formal the host arrangement is? Does it involve background checks for ‘Ben’, ‘Carol’ and ‘Kylie’? Are they covered by the NDIS Code of Conduct? Who monitors the support they provide to ‘Tori’ to ensure there are no unauthorised restrictive practices being used and that all reportable incidents are communicated to the NDIS Quality and Safeguards Commission? What happens if Ben and Carol find the arrangement overly burdensome? And so forth.

PDA is opposed to the notion that participants with high support needs need to successfully recruit additional informal supports to realise their Home and Living goals as it places them in the situation where they have to rely on the charity and good will of others to have their needs met. Rather, we argue that all reasonable and necessary supports should be their entitlement, and that they should be purchased from those prepared to deliver them with NDIS funding. As such ‘Ben’, ‘Carol’ and ‘Kylie’ should be paid rent and employed for a set number of hours either by ‘Tori’, if she / her family self-manage, or a service provider if this is a preferable arrangement. This way, ‘Tori’ has better control over what she does and how she is supported. She would then also have access to the full services of the NDIS Quality and Safeguards Commission and the safeguards they provide.

- ***The approach for funding a home and living solution (pp 16-17) and Appendix E – Home and Living Finding Process for Participants***

PDA is concerned about the sequence shown in these sections of the *Consultation Paper* as it shows a budget being set ***before*** there is identification of Home and Living goals and the possible arrangements that might meet them.

As we argued in our answer to Question 11 above, budgets should be set / revised with an understanding of participants goals, and that goals should not be proscribed because they do not fit a budget determined in their absence. As it stands, the process depicted in the flowchart risks participants being disempowered, if they are denied access to genuine independent living options (because it cant fit the pre-determined budget), and frustrated (because they might then pursue time-wasting internal reviews and action through the Administrative Appeals Tribunal). This could be avoided if the process started with a “Planning Discussion including Home and Living” which would then lead to a “Draft Plan”, and ‘further discussions’ before the “Approved Plan” was agreed to by the Agency and the participant.

In Conclusion

PDA hopes the answers we have given to the *Consultation Paper*’s questions and our other comments are clear and receive your favourable consideration. We also look forward to opportunities to have further input into the Agency’s Home and Living Policy going forwards.

Yours Sincerely,

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Liz Reid
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Burchill

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About Us

Physical Disability Australia (PDA) is a national peak membership-based representative organisation run by people with physical disability for people with physical disability. PDA was founded 21 years ago and we have over 1,000 members from all Australian States and Territories. Our purpose is to:

- Remove barriers through systematic advocacy to all levels of government to enable every Australian living with a physical disability opportunities to realise their full potential;
- Proactively embrace and promote difference and diversity for an inclusive society; and
- Actively promote of the rights, responsibilities, issues and participation of Australians with physical disability.