**Home and Living – public consultation**

Feedback from a family member (mother) and delegate on behalf of my adult daughter with a disability

**Submission questions**

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

 a. If not, why not?

b. What kinds of things do you talk about / would want to talk about?

1. *She lives and what is going on. We hear about who is doing what, who is ill or*

 *perhaps taken to hospital and whose birthday it is.  She loves living with her*

 *family of friends and is very anxious about not being removed by the*

 *authorities. They eat every meal together, play board games, play bingo, draw, paint etc and most importantly interact and laugh together as a family.*

1. *She once left Mary Macaulay House (MMH) to live independently in a unit with a friend and this turned out to be a disaster.  Despite having outside help,*

 *my daughter found she could not manage looking after herself and the house and slowly she became very agitated, anxious then very sick.  Eventually she couldn’t sleep or eat and ended up in hospital for some weeks.  Going back to*

 *MMH and her “family” proved to be a huge relief and she has never wished to live elsewhere again.*

*c My daughter talks about everything that happens within the group there* *and feels quite special when she helps someone else to do* *something, ie, peel the vegetables for dinner, and when she* *shared accommodation with a long-time friend who used to have fits, she always keep an eye on her and my daughter would pick up* *the phone and ring the person on duty and let them know she was fitting. She* *has always enjoyed being with the other people she lives with.*

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

 *My daughter  lives in a group home owned and cared for by SCOPE Australia where all residents use wheelchairs and have very high support needs.  Now there are plans to relocate to another location and to sell the property which my daughter and the other five residents have told everyone who asked that they strongly  wished to stay together and stay in the neighbourhood.  Hampton is where they have established their support and friendships with shop-owners and banks over many years .*

*Four of the six residents have lived together in this same home for between 35 and 45 years, another resident has been under Scope care since early childhood.*

*We would like more information from NDIS about how we can ensure the voices of our loved ones are heard and they are not caught up in the plans to phase out group homes.  Although we understand this policy is the We best for a lot of people, NDIS must realise that group home living is working well for some people.  My daughter and her housemates wish to continue to live together as an established family, especially as they age*.

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

*We would like more information about other options and what innovative ways could be found to enable all six residents to stay together as a family who know and love each other (yes, even though they argue at times just like any other family)  They have heard talk of splitting them up into smaller units and they have said this is not what they want, they value the opportunities they now have to come together for meals, recreation activities and just to hang out together in a shared home space either in smaller groups or all together.  This means they have the privacy of their own space when they want it in their individual rooms.*

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

*Not very helpful in our situation: we need to find a site close to the current home or the ability to re-develop the existing home, although an older building, family members of the residents think there may be a possibility of bring it up to the NDIS standards.  We are hoping that the NDIS can be flexible and be able to meet the various needs of participants with respect to their wishes*

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?

a. How can we work better with your informal supports to help them know more?

*We were unaware of this public consultation until four days before the deadline to submit feedback.  Our SDA and SIL provider (SCOPE Aust) did not let us know, even as NDIS participants we were not informed of the consultation.  This is a valuable opportunity to provide feedback for such an important aspect of our loved one’s lives.  The NDIS is life changing for so many people living with disability and their families.*

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

*I am extremely happy with the care that SCOPE gives to my daughter  and the other residents.  The staff know and care about all of the residents and have taken my daughter to medical appointments including hospital procedures which they do for all the residents.  Even though we have been told there are plans to separate services, in our case SCOPE has been doing both SDA and SIL very well for a long time and the six residents have all said if they had the choice they would want this to continue.  I understand it is a good idea in theory to separate services, but in this case it doesn’t need fixing*

7. Who helps you to organise your NDIS supports?

a. How helpful is this support?

*The Support Co-ordination has been extremely helpful especially in chasing up equipment delays and following up when reports have not been submitted properly by the NDIS Planner (no system is perfect)*

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

*No, just the Support Co-ordinator*

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

*Me (my mother and delegate), the Support Co-ordinator (Uniting Wesley) and the various therapists especially the OT to arrange and Co-ordinate equipment.*
*To find a suitable solution to SCOPE’s plans to re-locate the home, we hope to use an advocate from VALID to assist participants and families.  Family members are working together and advocating at various levels to give our loved ones a voice: we are listening to what they are telling us*.

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

*My understanding is that SCOPE will be passing the responsibility of providing SDA to another provider (unknown to us) who will use taxpayer’s money to build the new home with SDA funding in a less costly area well away from the residents established supports.  This will allow SCOPE to make a big profit from the sale of the property and not be required to put anything towards the new home for the residents.  This seems like crooked logic to me and I would hope there is a better way.  The DSA funding model seems to have unintentionally opened up this opportunity, I am hoping SCOPE can see what a bad look this is for their organisation.  We are talking about vulnerable older people who like to get out and about in their wheelchairs, independently and safely in the community they know, where they are known and supported by their neighbours, local business people and nearby services*.

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?

 *Keep the flexibility and choice for participants, even if this choice is different to what the Quality and Safeguard Commission thinks is best for people.  No one size fits all.  If people can choose their providers they should be able to choose to have the same provider for different services if this is their wish.  Please don’t throw out group homes as not desirable when it is still clearly working for some people (although admittedly not that many) especially where people have been together for decades and are functioning as part of a family.  What happens when these people become too old for NDIS funding? Their disability does not suddenly change, they should still be able to live with the people they see as family while they age in their familiar surroundings.  If the alternative is to go into Aged Care, this may be putting people into a much larger group home type setting rather than maintaining a smaller well-functioning group*.

12. Do you identify as:
a. Aboriginal and Torres Strait Islander
b. LGBTIQA+c.

Are you from a Culturally and Linguistically Diverse background |
Do you have a psychosocial disability

 *No*

13. Is there something you would like to see in a home and living policy specific to your response in Question 12?

 *n/a*

14. Is there anything else you would like to add?

 *I suspect there is a long way to go to address the issue of the aging population of people living with disability.*

 *We would like to see some form of transition so that people can have the company and support of a number of others in a household of pre and post NDIS participants rather than restricting to groups of up to three. They could share resources and care support with a mix of NDIS and Continuity of Support (CoS) clients who have similar interests and needs or who have forged bonds with others in their household.  As people age it is important to remain as much as possible in the community where they have developed networks and established their supports and services: a familiar place where they feel secure and confident to move around in safety.*

 *I am hoping SCOPE can come up with a way to keep our loved ones in their local neighbourhood, this will take additional money on top of what NDIS may contribute through SDA.  How this money is found needs to be negotiated.  50 years ago SCOPE was set up by families who fundraised and lobbied for better care and services for their children with CP.  These CP children are now older adults and another generation of their family is advocating on their behalf for a better life for them as they age* .

*Eve Burchell*

*Sandringham*

*Mob: 0425 717 728*

*Mother of and Delegate for Katrina Pirrie*