

NDIS Quality and Safeguards Commission - Supported Accommodation Focus Group and Interview

Summary Report

Lead Facilitator:

Jonathon Kelleher, Inclusions Projects Officer

Overseeing the project:

Jemima MacDonald, Inclusion Services Manager

Participants:

A mixture of false and real names is used for reporting purposes for both internal and external documents. 4 participants will be referred to using the following false names:

- James
- Harry
- Simon
- Mary

2 participants will be referred to using the following real names:

- Jessica
- Judy

Background

Setting

There was 1 focus group where 2 people joined in person while another 2 people joined online.

A phone interview was conducted with 1 participant without disability on behalf of a person with intellectual disability who has complex support needs.

Participants

6 people in total were engaged with for the project. 1 person who identified as having an intellectual disability was unable to attend the focus group at short notice.

5 participants successfully engaged with this project. 4 participants identified as having a disability. 3 of the 4 identified as having intellectual disability, with 1 participant identifying as having vision impairment and physical disability.

The remaining 1 participant (Judy) did not identify as having intellectual disability and is a legally-appointed Guardian for a person with intellectual disability living in supported accommodation (Mary).

3 of the participants with disability (Harry, James and Jessica) lived in supported accommodation. 1 participant with disability (Simon) lived independently with NDIS drop-in support, and had extensive experience visiting people in supported accommodation.

Of the participants, 3 identified as male and 2 as female. 1 participant identified as being of Aboriginal background.

Considerations

Due to the specific support needs of the participants in the focus group with regards to focus and level of cognition, the facilitator used discretion in selecting and omitting questions in order to elicit responses within the session. PowerPoint slides containing Easy Read wording and photos were used to aid comprehension of the content. The facilitator used the same questions in the focus group for the phone interview, for consistency.

Interview introduction

For the focus group and interview, participants were supported to become familiar with the topic and purpose of the project, and the role of the NDIS Quality and Safeguards Commission. A discussion with participants in the focus group occurred regarding the meanings of the terms “group home” and “supported accommodation”. Some participants shared they feel there are many negative connotations and stigma attached to the words “group home”. Participants stated that although “supported accommodation” is a new replacement term, many people still say “group home”. Participants were encouraged to use whichever term they felt most comfortable with throughout the discussion.

The right to stop the discussion at any stage was confirmed for all participants. Participants were all confirmed as feeling comfortable and consented to the focus group. Participants were made aware that their personal information would not be shared and that all feedback would be de-identified. 2 participants, Jessica and Judy, consented to be identified. Jessica stated she would have liked a representative from the NDIS Commission to be present for the focus group.

Sections

The following information looks at the responses and themes of the participants involved.

The document is split into 4 sections:

- Section 1: What is working well at home
- Section 2: Supports at home
- Section 3: What could be better at home
- Section 4: Dream home and rights

Section 1: What is working well at home

Participants were asked what the best thing about their life is.

James stated that he likes where he lives now. Judy stated Mary values the stability of having a home where she feels comfortable and familiar, with a good routine and access to supports. Harry stated that his work gives him purpose as he helps to try to improve the lives of people with disability. Simon stated he likes taking care of his dogs.

Jessica stated most of her time is spent “fighting with the NDIS” and that this is “a full time job”. She said she has problems with the NDIS and advocates for herself a lot. She is aware of the role of the NDIS Quality and Safeguards Commission and shared that she has contacted the Commission before for help with her problems. Jessica indicated she was unsatisfied with the help she received.

Participants were then asked what the best thing about their home is, and what makes it good. Harry shared that the best thing about his home is the freedom and independence he has to do what he wants and make his own decisions. He likes that he can go to sleep at night when he wants. Before he moved into his group home 2 years ago, Harry lived with his mum who used to tell him when he had to go to bed. Now people at his home check-in and ask him when he wants to go to bed, instead of telling him when he has to go to bed.

James stated he likes living at his group home because he likes the people that support him. He stated the people are “friendly and nice to me”. Simon seemed proud that he does a lot on his own at home, and likes having NDIS workers come to his house to help him cook and clean. He likes that his partner often comes and stays at his home.

Jessica stated she likes living by herself with 24/7 support. She likes that “it is not in a group home setting” and she is not “stuck in a hospital, group home or nursing home” as she used to live in a group home and did not have a positive experience. Jessica shared she is happy with the NDIS provider for her home now, and likes that they are cheaper than other providers.

Judy shared that Mary’s needs are met well at her home by her staff, and the physical space is good. Judy stated that Mary has been living in her group home with

the same residents for 25 years after being placed into an institution from birth. Judy stated Mary's co-residents are like family to her as she has known them since she was a child in the institution, and living with them helps Mary feel comfortable at home.

2: Supports at home

Participants were asked what things they need help with in their home, and whether they get all the help they need.

James stated that he feels he gets all the help he needs at home. He said the staff at his home help him if and when he wants it, and the type of help he gets will "depend on what I need help with".

Judy stated Mary requires help with almost all aspects of her life at home including meal preparation, personal hygiene, finance management and cleaning. Judy shared that although Mary's basic needs are met, she does not get extra quality supports to do things like go for swims twice a week and get 1:1 community support, due to funding constraints from her service provider. Judy shared the staff at Mary's home do not get proper training about how to understand and communicate with Mary, who is non-verbal, and this leads to Mary not getting the support she needs.

Harry stated he gets help with the majority of his care and that he feels he gets the support he needs. He does not have "someone around me all the time" but he knows there are always people available to him when he needs them. Harry stated he is trying to get more support to get back into the community as he moved into his group home during COVID-19 when he was often not allowed to go into the community due to the government lock-downs and rules, and the fact that group homes often had more strict isolation rules than the general public.

Jessica stated that she needs help with her health care but the NDIS "does not want it funded" and she is currently fighting the NDIS about this. She shared that she is happy with her support workers who are "really good" and take her out into the community. Her support workers sometimes do a few hours for free because she does not have enough funding in her NDIS plan for the support she wants and needs.

Participants were asked who supports them to make decisions about where they live.

Jessica stated she previously had a legally-appointed Guardian who made decisions for her. She entered Guardianship immediately after leaving foster care in her youth and then eventually “got kicked out” of Guardianship. Jessica shared she did not like having a Guardian to make decisions for her and she now has her friends who can sometimes help her make decisions, but often they “do not know how to deal with the NDIS, so it is just me”. Jessica stated that getting support from people you trust is still important.

Simon stated his house is under Trust as he inherited it from his parents. He shared that he sometimes feel awful because “I don’t know where the money went” and that no one helps him to understand where his money is and how he can use it.

Judy stated that she has been Mary’s legally-appointed Guardian for 30 years and is Mary’s sole substitute decision-maker, and can decide where Mary lives. Judy stated that Mary had a significant amount of input into the design of her home, which Mary greatly valued. Judy noted that the communication from Mary’s home about decisions for Mary, and obtaining Mary’s consent, could be improved by Mary’s provider who do not always provide Judy with sufficient notice and information about the decisions being made.

Harry stated he has a Support Coordinator who he worked heavily with to find his current home. He said his support coordinator “knows me really well” and this helps a lot. He still has a close relationship with his mother and it is often a “collaborative approach” when making decisions about where to live. Harry emphasized that “It is all about the support networks that you develop over time – people that trust in your vision and can get you there”.

Section 3: What could be better at home

Participants were asked whether there is anything they do not like about their homes.

Judy shared that Mary “hates having lots of casual staff she doesn’t know” at her home and that when casual staff are used, Mary engages in high-risk behaviors that can escalate to self-harm. Currently Mary’s home provider attempt to avoid

employing casual staff at her home, however service funding capacity and staff under-resourcing can result in casual staff being used. Judy stated that the 24/7 support funding model for Mary's home impacts on the service's ability to roster enough staff for the support Mary wants, and on the quality of the staff employed. Judy said that Mary receives funding for only 60% of what she wants to do at home.

Jessica stated she lives in Specialist Disability Accommodation and she is not happy with the layout or location of her home. Jessica stated the laundry is located at the front of her home and this is inconvenient and impractical to her due to her mobility issues. In addition to this, her home is located on Level 1 of a building complex and this makes her feel unsafe because as a wheelchair user it would not be easy to get in or out if an emergency happened.

Jessica shared a story where a support worker accidentally locked her house key in her unit and she could not get back inside. Jessica stated this was very stressful as her epilepsy medicine was inside, and she had to call the fire brigade for assistance. She believes she should be on the ground floor level, but was not given a choice about this when she moved into her home. Jessica stated that people should have choice about the layout and locations of their SDA homes. Jessica stated this change needs to come from the NDIS as her providers are "just following what they are allowed to do" and "have gone out of their way to make it nicer than standard SDA's".

Judy stated that Mary has a restrictive practice as part of her current Behavior Support Plan, which is to have a gate that locks Mary out of the kitchen to prevent her from eating foods that could be dangerous due to a swallowing issue. Judy expressed that if there were enough staff at Mary's home this restrictive practice would not be required, as the staff would be able to be present to stop Mary from entering the kitchen or to help Mary make good choices about which foods she wants. Judy stated Mary would like more staff to be available to help her at home so that she does not have to be locked out of her kitchen, and would like all the staff at her home to be better trained on how to support her.

Harry stated that he hates when he is "not consulted or considered" when living in a group home. He believes you should be consulted if a change is going to happen at your group home, like someone new coming to live at the home, and you should be asked if the change will be suitable for you. Harry stated sometimes new

housemates arrive at the group homes without the current residents being consulted. This can sometimes lead to there being “people who don’t really gel with others” and this makes people want to leave the accommodation. Harry stated this is not fair and he is talking to the NDIS Commission and politicians about this issue. He said the NDIS told him there are guidelines that state services must consult to parents or the people who live in the accommodation, however when he has asked for these guidelines they have not been provided.

Simon shared that he spends time at his partner’s house which is government housing, and this house is going to be knocked down soon. He and his partner do not get a say about this and he believes this is unfair. Simon stated he would like things to change but does not feel he can move anywhere as his house is under Trust. James stated there is nothing big he does not like about his home.

Participants were asked whether they know where to go for help if they are not happy with where they live or the support they get at home.

Simon stated it can depend on the situation and that he could talk to the staff at his house or the service provider. Judy stated Mary has a key contact at her home that she has a strong relationship with and can ask for help.

Jessica said “it is supposed to be the service provider, but if you don’t get anywhere with that it goes to the NDIS Commission”. She stated when it goes to the NDIS Commission it is often hard for her to get the problem fixed. She knows about disability advocates but in her experience advocates “do not have much weight with the NDIS”.

Jessica shared a story of a support worker who acted inappropriately and was drug-affected when providing support. She said her service provider knew about this, and told Jessica they were unable to report this to the Commission because they are not an NDIS-registered service. Jessica found this to be a big problem for people who have complaints about a service that is not NDIS-registered, as you cannot go to the Commission.

Section 4: Dream life and rights

To conclude the focus group and interview, participants were asked what their dream home would look like.

James stated that he would live on his own “in a mansion” somewhere that is “close to everything” like shops and cafes. James stated he likes being close to things so it is easy for him to get to the community from his home.

Simon shared that he would like a big house and would like to “build it better” than the house he has now. He would like to live full-time with his partner on the coast near the water. He would like to have drop-in support like he does now, to help with things like cooking and cleaning and would like help with his money.

Jessica stated her dream home would be in a beach area between the country and city with “a nice big yard and a swimming pool”. She would like to live by herself in an accessible house, with drop-in support or no support, “but I know it is not reasonable”. Jessica stated she would like to go out and do things in the community with support workers, but right now she doesn’t have enough funding.

Judy stated Mary’s dream home would be the one she has now, “with the addition of a pool and trampoline” as Mary loves swimming and jumping. Judy stated that in Mary’s dream home she would have 1:1 support for at least 70% of the day, as Mary feels she currently does not get enough 1:1 support to do things that interest her like go into the community.

Harry would like to live near the beach with housemates and he would like a mix of having people around him like drop-in support, “but be as social as possible with my housemates and support workers”. Harry would like “endless support workers” in his dream house, but at the moment there is a “severe staff shortage” and he feels he would not be able to have this.

As the final task, participants were asked what rights they have when living in their homes.

James stated he knows he has the following rights:

- The right to come and go when I want
- The right to be respected
- The right to speak up for myself
- The right to have it the way I want it

Simon added he knows he has the following rights:

- The right to speak up

- The right to get help
- The right to do things in the community like go out for meals and play bowling

Harry stated he knows he has the following rights:

- The right to have a shower when I want
- The right to go out into the community if I want

Jessica stated she knows she has the following rights:

- The right to freedom
- The right to go out whenever I want

Judy stated that Mary knows she has the following rights:

- The right to a safe environment
- The right to have her basic needs met