

**Consultation in Support of The NDIS Quality and
Safeguards Commission's Own Motion Inquiry into
Aspects of Supported Accommodation in the NDIS**

NDIS Quality and Safeguards Commission

Consultation Report

People with Intellectual Disability and Family Members

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Background

The NDIS Quality and Safeguards Commission's is in the process of gathering information to conduct an Own Motion Inquiry into aspects of supported accommodation in the NDIS. As a component of this process the Commission is gathering feedback about supported accommodation from people with intellectual disability and the families of people with intellectual disability.

The NDIS Quality and Safeguards Commission has contracted the Victorian Advocacy League for Individuals with Disability (VALID) to conduct accessible and inclusive consultations with people from within the target groups identified above, including people living in group homes and families of people living in group homes.

VALID has operated as the peak advocacy organisation in Victoria supporting and representing adults with an intellectual disability. VALID has a long history of providing opportunities for inclusive processes for people with disability and their families.

The feedback gathered from the consultations will inform a report that will guide the Commission's Own Motion Inquiry into supported accommodation.

The aims of the consultation process will be to explore:

- What 'good' looks like in supported accommodation
- What are people's experiences of how NDIS providers respond to their complaints
- Incidents that may affect people living in supported accommodation settings
- Suggestions for changes for how group living is delivered by providers
- What the Commission can do to support any proposed changes

At the conclusion of the consultation phase VALID staff had conducted four focus groups and consulted with twelve people with intellectual disability and six family members.

VALID has completed all the consultations required and the transcripts are included in this report.

As VALID has only provided the raw data for this project no analysis has been done on the feedback.

Throughout the transcripts the names of people, places and services have been replaced with words that protects the identity of the participants.

Note - All feedback and opinions in this report are from conversations with participants during the consultation process. They do not reflect the views and opinions of VALID Inc or the staff of VALID Inc.



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NDIS Quality and Safeguards Commission Consultation Focus Group

Cohort # 1

The first consultation cohort is a group of people living in group homes within the community in Victoria.

The group consisted of four people with the following demographics:

Gender of group members

two females

two males

Age of group members

20 - 30 years - two people

40 - 50 years - one person

50 - 60 years - one person

Disability

All members of the group have intellectual disability, some people have comorbid disabilities including: Down's Syndrome, Mental Health issues

The following is a transcript of this consultation

Question 1 - What is the best thing about your life?

Person 1 - Living in (Suburb), close to the shops.

Person 2 - Getting a job.

Person 3 - Family, friends.

Person 4 - Well, I'm attending a day program called (service provider) and it's in (Suburb) near the station. I go there three days a week and I do pizza making, Wednesday's I do music at the Salvos place in (Suburb), and Thursdays I go to the city to have lunch. So, life is pretty good for me, it's really turned around a lot. I've been there almost a month and a half, by the end of this month - would have been there two months.

Question 2 - What is the best thing about your home?

Person 1 - The staff and residents.

Person 2 - They know how to look after me properly, so that's a really good thing and the staff are pretty good.

Person 3 - I have my dog here, my dogs living in my house. I've got nice staff here looking after me.

Person 4 - I've got wonderful cooks, all the time they cook for us. I've got Foxtel in my room to watch. I've got nice friends and life's pretty good in the house. We've got wonderful staff. It's all worked out well. I've been living here six years next month, next year will be seven years.

Question 3 - What are the things you need help within your home?

Person 1 - Showering and cooking

Do you get all the help you need in your home? - Yes

Person 2 - I have a diet plan, which is for staff how to support me. I also have help with cleaning when required. I do have some help with washing my clothes sometimes, only to sort them out into piles to put away sometimes or somewhere, I may have had a lot of clothes and it's just easier to have extra hands.

Do you get all the help you need in your home? - Yes

Person 3 - I've got a diet plan. I've got diabetes, so I show staff my sugar levels and that's all I need a hand with. I help with cooking and things like that.

Do you get all the help you need in your home? - Yes

Person 4 - I don't need much support because I shower myself and I wash all my own clothes. The only problem is I always leave a mess in my room when I'm cleaning out my room and stuff but It's not too bad at the moment, but it gets very hazardous for the staff to help me they might slip, or I might slip over. So, I've got a woman, (name) who comes in and helps me clean up, but she tells me once my room is clean if it starts piling up a bit, I should just ask one of the staff to help me clean up a bit to keep it clean at all times. We have to work as a team together, sometimes I can be a bit of a slob. They cook for us here; I've helped with the vegetables a bit a few times and the potatoes, but they mostly do it because they're very well trained. I can cook, I just don't cook in this house because I did a cooking program years ago in the year 2000, I got a certificate.

Do you get all the help you need in your home? - yes, I do, they're lovely people and they support me pretty well. When there's a problem with somebody else, we chat it out in the office, we all calm down, and one by one they speak to the other person and I go outside, I just walk out quietly, so everything's fair and done.

Question 4 - Something you do not like, something that you would like to change?

Person 1 - No, nothing that I can think of.

Person 2 - I would like to cook food.

Person 3 - Nothing that I can really think of. I do occasionally get people put down. I've got just two people that can't talk and I don't sleep well, but I'm moving soon so I'll be happy. I have one person that has seizures at night and that wakes me up and I don't go back to sleep until four or five in the morning. And one just puts me down, just asking me to do stuff and I said no, and that makes me get upset a little bit. I've got pretty nice staff now, I used to didn't have a nice staff, but now I've got a really good staff now and I really liked that, so I had about three not nice staffs.

Person 4 - Just a little one, just a few problems with two others who are a bit obsessive. It's just two and it's not much, but it gets worked out pretty fast, that's all nothing else.

Question 5 - Who supports you to make decisions about where you live? Who would support you?

Person 1 - Mum would and the staff.

Person 2 - My family

Person 3 - My mum and my dad.

Person 4 - Well, most of the staff do, including (house supervisor name) in my house. They help me with supporting and decision making. We don't really have a resident meeting anymore, but they have their private meetings for staff, and they bring up issues and problems in our names, that's all. But that's it really

all major good things and stuff about the rest of us except for one but I can't mention his name. If I had to move to another house, (house supervisor name) the supervisor, she would support me.

Question 6 - How much choice do you have with the things that happen at home?

Person 1 - I play bingo twice a week online Thursdays and Sundays and the staff help me find that. I'm independent, I go out in the community. I have to let staff know where I'm going and what time I'll be back, but apart from that I'm independent.

Person 2 - I get to choose what I can do one weekends. We have a resident meeting monthly. And me and another resident have an activity that we do on the same day every week, which we got a choice to make that decision, which I thought was really cool.

Do you have the freedom to do things you want in your own home? - Yes, yes, so if I have like a social event I go to, I'm allowed to go to that. I can go out to meet friends when I want to, that kind of stuff. I can leave the house when I want to and come back when I want.

Person 3 - Sometimes I don't get my own thing in the house that I want to do. Some weekends we don't really go out, but I'd really want to go out some weekends. I go out on Sundays for church, but I get bored on Saturdays. I'd just like to get out and about, go for a drive, not to be bored in here.

Do you have the freedom to do things you want in your own home? - I've got things I can do in my time. I go to church, I have a staff take me to church and I've got freedom to go for walks, to take my dog for a walk.

Person 4 - Yeah, I do, I've got a lot of freedom and choice. I've got a choice of going out with my one to one of doing my day program and going out on Sundays for a drive. I got things to do too, like cleaning my room where I get support with, and we all get along pretty well. We watch movies together; we go out for lunches and sometimes we go for walks in the park. I would like to go for a walk on my own, not at the moment because staff walk with me, but I have gone for a few walks down to the shop to get a drink on my own, they trust me. But I don't pick up any sneakers on the way anymore like I used because I've stopped all that, I'm just being honest. Freedom and trust goes both ways, do the right thing and they put their confidence in me, and I do the right thing.

Question 7 - If you are not happy with where you live or the support you get - who can you go to for help.

Person 1 - Go first to staff and if that didn't work, talk to mom, and if that didn't work, I'd go to VALID

Person 2 - I'd go to my family cause they're pretty supportive, I would talk to staff there. If it wasn't something staff would be able to resolve, I would talk to mum and dad

Person 3 - I'd go to my support, my boss in the house, the supervisor

Person 4 - Well, I'd talk to the staff first and if that doesn't work out, I'd talk to the head boss of the house. (House supervisor name) or if it's too much of a hand to work things out I can go higher like (house supervisor name) got a boss named (Name) and (Name) got a boss named (Name), who is the big boss of (service provider). But I take it through the right channels, I always do the right thing. But they are lovely people, and they support us a lot all the staff are good here and they sort out any dramas or upsets. I use my breathing techniques to calm down, you know I stay out of things, that's all. They're great staff, I've been living here six years and I'll probably be living here until I get old. I never get my parents involved when there's a problem. I talk to the staff only, because that's what my parents told me you needn't ring us up, you can sort that out as an adult.

Question 8 - If you could choose the dream home what would it look like?

- **Who would you live with?**
- **Would you want to live with other people with disability?**
- **How much support would you want?**
- **Where would you live? A busy city town/country other places that you might think of, why?**

Person 1 - The house would be a castle and I'd choose my friends to live in there. The castle would be in the country in New South Wales. I wouldn't want to live with people with disability. I would not want any support to live there.

Person 2 - My dream home would be a nice place where I'd have internet and enough spots for DVDs and I'd live with my partner, just the one other person. I would like to have support at night time and during the day so we can get to where we need to go. I'd want to live somewhere close to public transport and a Shopping Centre.

Person 3 - I don't really have a dream house that I really want, but I can imagine me in a cool house, a beautiful house with a swimming pool. I would live with one client, not three or four clients. The person would have a disability and they would be someone that I could talk to and have more chats to and spend more time having chats. I wouldn't need much support just for my diabetes and my diet, that's about it. Just to live where I am because I don't want to leave. I don't want to leave this town too far, just to live where I am.

Person 4 - A mansion with a pool, spa, sauna and a tennis court and I'd probably be living with the same people here and the staff too. That's just my dream home. I'd need very little support. The rest of them get showered except for me and (other resident) and probably just support with cleaning my room and that's it. I do my own clothes washing. I'm pretty good. Well, I live in (Suburb) now but maybe the city in a big place, but there's a lot of hotels there where you can stay but they're not permanent they're just for holidays. There was a big house up for sale here, just for an example, a huge place with lots of rooms, a spa and sauna, or even a room for a billiard table and a cinema sound system that'd be great. I'd still live in (Suburb). It's not far from the city, it's very close to the city and not far from my day program either, or my parents.

Question 9

How would you rate the following rights in your home

- The right to be safe - 1st
- The right to privacy - 2nd
- The right to speak up - Equal 4th **
- The right to complain - Equal 4th **
- The right to dignity - Equal 3rd *
- The right to freedom Equal 3rd *
- The right to make choices - Equal 3rd *
- * Equal 3rd
- **Equal 4th

NDIS Quality and Safeguards Commission Consultation Focus Group

Cohort # 2

The second consultation cohort was a group of family members of people living in group homes within the community in Victoria.

The group consisted of two people with the following demographics:

Gender of group members

two females

Gender of family members

both male

Age of group members

60 - 70 years - one person

70 - 80 years - one person

Age of family members

20 – 30 years

40- 50 years

Disability

Both members of the group are related to people who have intellectual disability and may have other comorbid disabilities including:

Prader-Willi Syndrome, Mental Health issues

The following is a transcript of this consultation

Question 1 - What is the best thing about your life?

Family member 1 - I retired recently from the workforce, the paid workforce and so I used to be doing two jobs if you like my paid job, and then after work I would come and do all the advocacy for my son, so now I can actually do some of this kind of thing during business hours. So after five o'clock I'll actually have my own life back, so obviously, retirement gives me more choice in what I do with my free time in terms of picking up hobbies and visiting friends and all those kinds of things.

Family member 2 - Twelve months ago, I moved to a retirement village, so I have a lot more social interaction with people. and it means in terms of supporting my son I have more time because I can just shut the door and walk out basically. I don't have to do all the maintenance and all sorts of things as probably the best thing but I'm freer to pick up all the issues that are going on in the accommodation, so I think that the best thing right now.

What is the best thing about your family members life?

Family member 1 - He has enough funding for what he wants to do, and this has come about through massive diligence and vigilance on my part from the get-go of the NDIS. I could see the writing on the wall, so from gathering all the reports, writing here, there and everywhere, so that the first plan was adequate. And maintaining through subsequent plans making sure that I read all the draft reports that all the service providers are going to submit to the NDIS that kind of plan report because I don't think I've ever seen one that's been right in the first cut, they leave out, something that could result in, it's a loophole for the NDIS to

say, okay that the funding could be cut. He does have enough funding at the moment, and he does lots of things in his life. He's pretty proud of himself and he's achieved a lot more than what we thought he would, he's in a very good place himself at the moment.

Family member 2 - That he has 24 hour support high intensity support, he's actually got funding to support that 24 hours a day, that's probably the best thing that the funding is there for that level of support.

Question 2 - What is the best thing about your home?

Family member 1 - Oh, well, you can do whatever you like here, decorate it the way we want to. We can do what we want on our timetable, we come and go when we want all that sort of thing. We've had people over when we want to.

Family member 2 - It's an apartment, it's my place and I make decisions about what I do, I can come and go as I please. I can interact with other people or not. I can have people here. I can watch whatever I want on telly. I live on my own. I've got my little dog here, it's very comfortable, it's got everything I need.

What's the best thing about your family member's home?

Family member 1 - He does have quite a lot of choice there within the constraints of his disability because there are some restrictive practices there, but he is accepting of that because he realizes it saves his life. He can do what he wants in his room, he can't do that in the open space for various reasons which are to do with incidents. He can come and go when he wants to as well when he lets the staff know what he's up to. I'd say that he feels he can do pretty much what he wants except have a pet, that's probably his main disappointment.

Family member 2 - It provides 24 hour physical safety. It provides support for his usual activities of daily living in terms of meals, housework all of those sorts of things. My son is very dependent on staff support, they would be the best thing. He has his own room with a television in there and has a little support dog. That's probably the best I could say about it.

Question 3 - What are the things your family member needs help with in their home?

Family member 1 - My son has massive dependency on the staff. It's not mobility that's the issue, it's the planning and organizing, he can do a certain amount of that himself. If it wasn't for that scaffolding he wouldn't be able to do all the things he wants to do, because he can't organize himself, the laundry wouldn't be done, the food needs to be looked after. He's a diabetic managed by exercise and diet plan. So the support staff are there to help him do that as well. He does get himself up in the morning but in terms of all these different activities that he does, three different programs, daytime activities and then he has a sports team which he's got to go off to training and then a match at the weekend. Not to mention all the medical appointments and various other life administration, to keep track of all those things and make sure they happen on time and that he's taken the right sports gear, he's got his packed lunch, he wouldn't be able to do all these things if it wasn't for the staff. They're supporting him, in other words, it's all the prompting and the motivating and the reminding and actually they're supposed to be doing things with him to keep him going. So let's say he really needs to be spending some time doing some exercise every day. Will he go out for a walk for an hour by himself if they say time for you to go off for a walk? No. Whereas if they said to him, something like it's pretty boring here isn't it, it's a really nice sunny day outside Hey, let's go out for a walk then he'd be up for it. Definitely because he could go and have a bit of a chinwag with the staff member and whatever. He needs it for all these other service providers through the NDIS let's say the exercise physiologist or the dietitian or the OT or whatever. He needs those SIL staff to help deliver that in his

ordinary day to day life. And that is one of the risks of the SIL staff they seem to think at times that will that external provider said do these exercises that external provider is responsible for making it happen, whereas it's not the case. These things happen as incidental activities in my life, and they need to happen daily in his life, and he needs that SIL staff to help him. Transport is another big they help him with.

Family member 2 - He needs support with all hygiene needs, he's not totally dependent but he needs prompting with that. He can feed himself, but they provide all the meals in (Family member) house the residents don't have any input at all into meal preparation, which for my son is a good thing, having (named disability) he's not responsible for any food intake at all, for him it's psychological security as well that it's all done by somebody else, and he doesn't have to manage that. He needs support for all other household activities, it's pretty much like a mini institution, I would say a few of the regular staff and some of the other residents all came out of the (Name of institution) and I think that has continued on. Most of the residents in the house, including my son are all very dependent, so very little that they do on their own. The SIL staff don't provide any community participation I have another provider that does all of that. (Family member) needs support to access anything in the community. He doesn't come and go, and the front doors are locked, and he has to have a support worker to come and take him out, which is the same support worker that takes him out daily. So he's pretty much out of the house six hours a day, either at day program or out and about but even at the day programme he requires one to one intensive support. He is mobile so he doesn't need support with mobility, having said that he's got a walker, so he does need support going up and down stairs and things like that. He has a hearing impairment, so he needs support in terms of giving him his hearing aids, making sure that they are clean and that they've got batteries in them. He needs a lot of support with behaviour management, he has severe anxiety and mental illness so needs a lot of support around keeping routine, predictability and all of those sorts of things.

Do they get all the help they need in their home?

Family member 1 - He gets the support that he needs with involvement from me. I have serious concerns that if I wasn't there keeping all these people accountable at the SIL staff. You know, for example, I have to say when there's a casual staff on shift, what are the rules about making sure they understand the needs of my son before they actually start interacting with him? I feel like there's a risk of hotel style care with the SIL staff unless someone's there. Even just by, speaking to my son on a regular basis, how was your day? How was work? How was cricket training or whatever It'll come out if he says the staff didn't take me to training, so that in itself is a bit of a motivator for the staff to keep up with what's supposed to be happening. Otherwise, I feel the temptation would be, oh no, sorry we're too busy today to take you or oh no, sorry we've got to look after this other resident. We can't spend the time to drop you at cricket training. Also with my son and the medication side of things, medication taking is supported but when it's tablets, yes, that seems to be done reliably, but when it's another kind of medication, let's say he's got a rash and he's supposed to put anointment on it three times a day or whatever, that really falls down badly. They will give him the ointment and let him have it in his room, but will he remember to put it on or not, that's a completely different story. Will they supervise? They need to see with their own eyes, or they can't you know, you cannot trust that it's happened because he will easily forget or think that he's done it and say I have when he hasn't. It comes down to quality, the SIL staff are intending to help support him with these kind of medications. But is it done properly and effectively with the desired outcome? Not necessarily.

Family member 2 - I think if you had a bit of paper with a tick box against these things that need to be done you could probably tick a lot of them, but it's the quality of the support, I would say the biggest issue for me is around a false economy of some of the funding stuff within the NDIS and with SIL. An example of that

being probably in the last four years my son's funding would have included up to close to \$100,000 on behaviour support, intervention, planning, all of that sort of stuff, so you get wonderful plans, lots of assessments he has all sorts of other health plans bowel management, mental health management, all of that. However, because the level of staffing within SIL houses have quite minimal qualifications and experience, these plans do not get implemented the way they're supposed to, so to my mind it's a false economy and this \$100,000 spent in behaviour management when the plans are not always implemented, and it's not a deliberate omission of doing it. I think the workers simply do not have the training, the experience or the capacity to do it. Currently there is just a stream of casuals coming through the houses, I'm sure our house is not the only one because of the situation, which means they're in and out for shifts with very little time to read all of these things. The quality of support particularly around the mental health issues and behaviour support is minimal, I'd say bordering on being unsafe.

Question 4 - Something you do not like about your house, something that you would like to change?

Family member 1 - I had a choice about where I live, so it's got what I need, it's got public transport, it's got you know, pleasant environment. Nice neighbours, all amenities nearby. I'd change the interior decor that's about it, but we haven't been here for very long. I can't say that's why I don't like it because you know, it was a very recent conscious choice to be here.

Family member 2 - I don't think I'd change anything, actually, because it's brand new, so I can't complain about what it's like. It's in a great area. I have access to everything. I need so I don't think there's anything I would actually change.

Something you do not like, something that you would like to change about your family member's house

Family member 1 - Well he lives in (suburb) so it does have probably similar amenities, but in terms of his lifestyle, as I mentioned before, he can't have pet, which of course we can do here and also his co residents, some of them cause him distress at times, and he doesn't get a choice about that. So in terms of where he lives, that would be one of the, physically I don't think he'd necessarily want to change it, but what goes on inside he would want to change.

We've got a vacancy in our house at the moment, and I certainly haven't had any input from the house supervisor as to how the next resident is going to be chosen, so I don't know whether the existing residents are going to have a meet and greet to decide whether that's the new person they want to have as their housemate or what, that's again, a lack of transparency and poses a risk. There's already some irritation amongst some of the residents, not all of them, some do go out and do things together, but from a quality point of view, there's quite a gap there. I haven't been included in that at this point, maybe it's just not the right part of their process to include, a mother and my son hasn't mentioned anything about it. Not sure what's going on there.

Family member 2 - I think the major thing would be that when (Family member) first went to that house, there was no choice, he went from a hospital situation, and it was like, any vacancy type thing. So he was put in the house where he's been there eight years, but he virtually has nothing in common with the co-residents, they don't have similar interest. So other than sitting at the meal table together at night, which is about it, there's no interaction pretty much between the residents. If there was anything I could change, it would be, I guess, more compatible residents or residents of similar interests that could actually do things together, that would have been the major thing. The actual physical house itself, it was purpose built quite a while ago so it's adequate in terms of the layout of the house and all of that. Its location is, although it's in a pretty grotty area It's close to hospitals and transport and things like that, I wouldn't complain about that. I

think the main thing would be the lack of choice of who you actually live with, and that means that he spends when he is there, he spends most of the time just in his own room because there's nothing to entice him out into the living areas, because what the other guys want to do or watch on telly it's not the same as him, so he pretty much lives his life in his room, or at the dining table when they have meals but not the rest of the house.

Question 5 - Who supports your family member to make decisions about where they live?

Family member 1 - If it wasn't for us, the family, I don't know how it would work. Theoretically, there's a Support Coordinator but they don't know my son it's very superficial administrative sort of, they're just like a service broker, they don't know him and his interests and all that kind of thing. I suppose if we weren't here to support him in his choices then it would have to be one of those staff those support coordinator type specialists, in which case they might try a bit harder to get to know him with that targeted service in mind, but otherwise, it would be very fraught situation.

Family member 2 - Going back to the time with my son, there was no support in the sense of where he lives, it was a situation of he was in hospital, the hospital said he no longer requires our medical care he has to be discharged, with me saying he doesn't have an address to be discharged to because he's been on a waiting list for years for accommodation back and DHHS time. So it was pretty much hospital wanting to get rid of him and DHHS saying, well, we don't have any vacancies and when one did come up, it was there, you're going there. In the last probably couple of months there has been some discussion with our provider about is this the best place for your son, would you be happy for us to consider other places or what that might mean? And I said, Yeah, I'd be happy to think about that process, obviously it would involve (Family member) along the way if it were to happen, other than that, there's no other support for this.

Who would support them to make decisions in your absence

Family member 1 - We have nothing formal in place, but my son has a sibling and some aunties and uncles, so I would envisage that they would be involved to some extent, but there's no chance that they could be involved to the extent that me and my husband are involved.

Family member 2 - Well, probably be my sister or her sons. I have set up a thing for two of her sons who are same age as (Family member), middle aged people, to have enduring power of attorney and to manage everything and so my sister and her family are pretty well aware of everything with (Family member) so they would definitely take over but wouldn't have the same capacity that I have being retired and they've got families of their own so that's what would happen. A decade or so ago it was pretty much in my mind that I would definitely outlive (Family member) because he's exceeded the life expectancy for people with his condition already. So I just thought, it's not going to be an issue I will live longer than him type thing, but now as I get on, I'm quite healthy at the moment, but I am 70 and he's living longer, and this needs rethinking this is not as obvious as I thought. You know at our age when you start to move into the one in the three and the one in four get this and that and you think, oh dear.

Question 6 - How much choice does your family member have with the things that happen in their home?

Family member 1 - In terms of his activities he's got quite a lot of choice. The SIL staff do make some effort to go out and about with the residents so there can be some spur of the moment activities, oh it's a sunny day, let's all go for a walk down the beach or something like that. So a number of the people in the house might go and do that at once. But also one of the residents might say, like one goes to church sort of thing and the staff member will take him to church, rather than having to be a third party provider because that's just absolutely absurd for spur of the moment, you know that aspect of choice that we have in our own

home, where you can just decide to go and do something, we'll just go out this afternoon and do blah, blah. You've got to book these other service providers two and three weeks in advance, and then you might not feel like going at that particular moment or it's raining or whatever. It's good that the SIL staff can do some of that stuff with my son, and yes, he does have some choice about that. The staffing is where he doesn't have any choice and some of the staff are more hands off than others and because they aren't quite verbal in this particular house, sometimes the staff members will be talking amongst each other about things that are going wrong in the house and then my son comes home and says, Oh, this is happening and so and so has complained about all the staff, and the staff breaching other residents privacy because they've said so and so's got this illness. They've gone to hospital for this, and I think sometimes the staff are used to working in houses where the residents are nonverbal and they can just you know, rabbit on about whatever they want in front of the residents, the residents might understand, but they're not able to pass information on to others. And I know that sometimes what he hears does cause him some anxiety. Because when the staff don't agree with each other, then that's not helpful for anybody, so he doesn't have choice about that.

Family member 2 - That's difficult in terms of with my son because of his severe anxiety, and mental health issues he functions the best when his day is absolutely predictable and routine like the timetables there and this is what you do at this time every day and he functions better in that. So whilst he does have a choice about being out of the house six hours a day he has chosen to be out rather than in because he likes being out doing things and not just sitting in his room at home. Within the house itself it's very institution like, I'll give you examples they all have to put their pyjamas on at four o'clock and then they have dinner just after five and then they go to bed, and I think that's what used to happen, and they're all used to it. If I said to (Family member), if you don't want to put your pyjamas on you don't have to no one would say oh yes you have to, but it's so in a routine but that's what you do that's the rule that's what you do. Their meals, sometimes they get asked and particularly on birthdays, have they got favourites, they might like to have. As far as other choice about what goes on in the house, I guess he doesn't have the free choice just to go out in the lounge and watch whatever telly he wants to watch because the others don't want to watch what he wants to watch, he's told you have to stay in your room and watch whatever you want to.

Do they have the freedom to do things they want in their own home?

Family member 1 - Largely Yes, I don't hear him often say I wanted to do such and such, but I wasn't allowed, very rarely would I hear that. It's not a locked house, it's more there could be something else going on like one of the other residents escalating that acts as a deterrent to him wanting to say he might want to watch TV out in the open area but someone else's you know is having a difficult time and that's a deterrent for him into go and do what he really would have wanted to and so he stays in his room. It's probably some of those social interactions that reduce his choice rather than physical and planned activities.

Family member 2 - It's difficult to say, no, he doesn't have any choice, but the staff would probably say, well, he does, it's much better if he has a routine, if you provide my son with choices he finds it very difficult, and it provokes anxiety. So be limited would you like to do this or that, like two things and you can choose from if it's an open ended, what would you like to do this afternoon? Well, that would just be over the top. I can't answer for the others it's probably similar for them, they've been there a long time so that's just the way.

Question 7 - If your family member is not happy with where they live, or the support they are getting who would they go to for help?

Family member 1 - I wouldn't know what the options were, if you said I really don't like to live here anymore, can you please help me find somewhere else which he wouldn't be that articulate? But let's say he

was struggling and then I realized we need to do something about this. I wouldn't really know the process. Well, I guess I'd know sort of what the process was because you go to the NDIS, and you get a special housing coordinator or whatever. But in terms of being able to find other places, and I know about the disability sector, I guess, you know, all these years. Being able to get this transparency about what's on offer is you just can't do it. You know that they won't share with you what the service is in any great detail.

Family member 2 - I know, my son, I would just know that things were not right, not good or I'd ask him about things, but in his mind, I don't think he'd be aware of having any choice or any alternatives, this is the way it is. It just comes to me basically, that I know when things are not going right.

Question 8 - What would your family members dream home look like?

- **Who would they live with?**
- **Would they want to live with other people with disability?**
- **How much support would they want?**
- **Where would they live? A busy city town/country other places that they might think of, why?**

Family member 1 - That's a good question, because sometimes I think if he had a unit on his own where he could have a dog and be independent and have SIL workers coming in, I have that horror of Anne Marie Smith there, because if the support worker was sick that day, who was going to make sure that someone else came in and if no one else came. Who would know and all that kind of thing. But then I also think he might be a bit lonely because quite often, like with the SIL staff, occasionally they'll bring their own dogs to work, then my son will say, oh, you know so and so brought their dog in and we went for a walk,. He'll say, oh, you know, so and so is getting married and so and so's kids are graduating from school, so he obviously has some social discussions with the staff and the other residents. He has got a very limited social life otherwise, and I feel like if he was living in his own place, could be a risk, and I think that's what some research shows that people with intellectual disabilities actually can end up more isolated, even though there is this sort of theory that living independently like an ordinary person is better, is that really better? That would have to be tested out in our situation.

I would prefer it was in the country for him because I know the support that country communities offer and yes I just think the lifestyle would be better, but I realize the service provision would probably be more difficult to get. Also he might not want to do that because he is connected with a lot of things that go on in the city where he's grown up, his sporting clubs and programs and all that kind of thing. But I feel as he matures he might broaden his horizons about what he wants to do, but I think in the longer term, country would be preferable, but it would need to be near family so that that would be a significant proviso, not a random country area.

I think if there was one other person that he was compatible with that would probably work pretty well because then there's extra eyes from that person, another disabled person or maybe not, but I think a non-disabled person would find it pretty hard to live with the sort of chaos that comes with not having good planning and organizing skills.

More than likely I would want him to live with another person with disability because that way there would be extra support workers coming and going and I think the safety aspect would be there then. As I say, with more eyes involved and the other person who lives there, their family would be coming and going as well, and then if something wasn't working there's more likelihood of that being realized rather than him being isolated, but it's very hypothetical.

I would say that we're talking SIL support specifically I guess because it's on the assumption that 30 hours a week he's out doing programs or whatever, then the only time that there wouldn't be support needed might be for maybe a six hour block during the middle of the night or maybe eight hours during the middle of the night. I don't know what that means by support, let's say it was electronic support, let's say there was some kind of sensor in the house, which would alert a carer from some remote location that (Family member) is up and about and distressed about something, that might be enough. I mean most of the time, like for me most of the time I, have a good night's sleep and fairly routine and all that but occasionally I can't sleep, and I get up or I'm feeling sick, and I have to get up. How do we accommodate that circumstance if there was literally no one rostered ever in the middle of the night. Otherwise the 24/7 has still got to be there, still needs to be a lot of prompting around hygiene and planning, getting ready for the next day and making sure the washing is done and all that kind of stuff after programs.

Family member 2 - I think it would still be a house that would be an SDA. It would be staffed 24 hours a day, but maybe with only one other or maybe two other residents who had similar interests, for example my son loves sport, and when I say loves sport, not playing sport, watching sport, particularly the AFL, cricket, things like that. He would love, I think to actually have some friends or peers that he could enjoy that with, like watch it on telly, go to games with. Currently he has no peer friends at all, all his social outlets are either with family or support workers and you know, from time to time, if I ever said to him something like for example, one of his support workers is (name) that he really gets on extremely well with, I've heard that your friend (name) and he will say he's paid to look after me, he's very on the ball and he knows if you're not a family member everybody else is paid to look after you or do things with you. He doesn't actually have any peers that he does things with, so yes, to have one, possibly only one other person in house that had similar things that they could do stuff together, maybe share some of their support time out of the house, so that wouldn't necessarily be the SIL aspect.

To be perfectly honest, I don't think a person without a disability would tolerate living with (Family member) all the time, having said that, the only type of thing that I know works like that, which is very few and far between. I don't know if you know about the Larche Communities, they can work they're few and far between and they do rely on non-disabled people living with disabled people and it's a very difficult situation. I don't think a non-disabled person would tolerate (Family member) behaviours and narrow interests and need for strict routines and things like that.

I don't think he could any have any less support, currently he sleeps most nights, but they have active night support in the house and there would be times when (Family member) is mentally unwell, where he's up roaming during the night, psychotic or whatever, and that's not predictable. You would have to have somebody there, whether it's a asleep over would probably be sufficient for one or two people rather than active nights, I think the active night persons asleep most of the night anyway.

At (Family member) age, the way he is and his dependence on a lot of the health system, tertiary specialist health care, I think he has needs to be close to that. He'd ideally be close to sporting venues and things that he could go to, but what he does most days when it's not at the day program, he goes out walking with his support dog and a support worker, where they walk five or six kilometres a day in parks, and he just loves being close to easily accessible parks. There would have been a time decades ago where I would have said country because I belonged to an organization before we moved down here that was looking to set that up a farm type situation where there was a central community area for meals and getting together and separate little units where they live but they're involved in farm work and get involved in the local community, that would not be suitable for (Family member) right now.

Question 9

How would you rate the following rights in your home

The right to be safe - 1st

The right to privacy 6th *

The right to speak up – 4th

The right to complain - 6th *

The right to dignity - 2nd

The right to freedom 5th

The right to make choices - 3rd

* Equal 6th

NDIS Quality and Safeguards Commission Consultation Focus Group

Cohort # 3

The third consultation cohort is a group of people living in family homes or in their own homes in community settings in Victoria.

The group consisted of eight people with the following demographics:

Gender of group members

four females

four males

Age of group members

18 - 20 years - one person

20 - 30 years - one person

30 - 40 years - three people

40 - 50 years - two people

50 - 60 years - one person

Disability

All member of the group has intellectual disability, some people may have other comorbid disabilities including:

Autism, Cerebral Palsy, Down's Syndrome and Mental Health issues

Living situation of group members

Four people live in the family home

Four people live independently in their own home

The following is a transcript of this consultation

Question 1 - What is the best thing about your life?

Person 1 - My best thing about my life is being with family and being with friends and having the opportunity to do different things and do different sports and try different things.

Person 2 - One of the best things in my life is my family. Just being able to be with them. Spend time with them. And many more things such as like my job and my education. I'm really grateful for those. And I guess just the life I lead.

Person 3 - I do (place name), it's like a community house, I do volunteer gardening and I do (activity name) which is a theatre group. And I've been looking after my mother.

Person 4 - I just like being busy, because I'm very busy all the time, looking after my auntie, looking after my cousin she's unwell, looking after my kids, I enjoy working and doing consults. I really enjoy it. And I learn every day, being positive and getting out there and helping people. I really enjoy what I do and put a smile on other people's faces, and I do (activity name) like Person 3.

Person 5 - Being with my family and being on committees. Going out when I can, I do different things, social things.

Person 6 - I actually got told this morning that my big trip that I've been planning is finally getting sorted. I'm very excited about that because I was supposed to get away overseas in COVID and as everyone knows, no

one no one went away overseas, so finally, everything's coming to a head and I'm very excited about that. So I'm off to Alaska.

Person 7 - One thing that's good about my life is that I'm here today to actually discuss some of my experiences and some suggestions as well. I've gone through a lot of psychosocial trauma over the past few months, but I suppose one thing that's keeping me here, motivated and moving forward is things are actually finally working out for me and I'm now just a name attached to the number not just a number by itself. I also play soccer with Person 3.

Person 8 - I think the best thing about my life is having people around me and in my life.

Question 2 - What's the best thing about your home?

Person 1 - A very good location and very easy to get into and a very good area and like lovely houses and everything. I like the animals and the type of house it is.

Person 2 - The thing about my house is that I have a comfy room and I have a nice bed.

Person 3 - It's close to transport. It's a good area, nice neighbours and I get along with my neighbours and the street is the best street in the whole world.

Person 4 - Doing my prayer stuff. I like going into the lounge room and having some meetings there, prayer meetings from church and I just like sometimes not being around people and just having your own time when you need it when you're so busy.

Person 5 - My house is accessible, and we have a vegetable garden.

Person 6 - I suppose access. My home is very peaceful for me, very relaxing, but it's also been set up for me, so I know that it's safe. I know that I'm able to live here in that way.

Person 7 - I suppose the best thing that's about it is that it's accessible if you're in a wheelchair or on a scooter. I suppose the other good thing I could say about my home is that it's got a balcony and faces north so it's good for plants and vegetation growth. I suppose I could also add the good thing about my property is that I have got the view of what's around me So if you're kind of worried about who's in your street, have got bird's eye view of properties west, east and north of me.

Person 8 - The best thing about my home is about safety, being safe in my house. Another thing about the place I'm living in I've been renting, next year I will be moving into a new apartment that is part of the (apartment block) housing which I am part of and which they are still building which is next to (name) Station.

Question 3 - What are the things you need help with in your home?

Person 1 - I get help with cooking and reading and filling out forms. I get help from my mum and my dad and my whole family.

Person 2 - I have flat footedness on my right foot, so I need physiotherapy assistance, sometimes that can be at the gym or sometimes it can be at home. I also need ankle support shoes to be able to help me walk around places I need to go properly, that's what the podiatrist recommended for me last year. So what I need support with is just getting my legs to work properly which is working really well now. Another area I might need assistance in is understanding some tasks properly, because sometimes I may be told something and I just say, yeah, I understand it, but in actual reality sometimes I don't. So I tend to ask for clarification just to make sure that I'm on the right track with stuff that I need to do.

Person 3 - I don't need any help in my house. I do the dishes every day.

Person 4 - Just help with different things like cooking, washing and cleaning. I'm trying to find a couple of support workers and that's quite hard, but I never give up. I get the help that I need, but sometimes it takes forever to find the correct person or the two support workers if one is sick and they can work along with your family and you know, they're not over standing, you know, they don't feel in, you know, they get on well with the whole family you know, they don't feel uncomfortable to give you the right support so they can walk alongside you and not talk for you. Capacity Building, do you know what I mean, with your housing issues, domestic violence issues, or other issues, they can walk alongside you but not do it for you.

Person 5 - I have carers that have to look after me for 24 hours for day to day duties and at the moment I'm not good with the NDIS for travel and other stuff. I don't get the support I need. I'm living with my parents but that doesn't help with the issues, we have a theory about a carer, to not feel embarrassed to look after you.

Person 6 - Yeah, I get support every day to do tasks around the house, such as cleaning and help with cooking and a few other things. What I do is I have three private staff, I have them plus two other agencies that I can go to for backup services if those staff members are unavailable. It seems to be with the NDIS, that if you live at home, they expect informal supports to do a lot. Whereas if you're out of home, you know, your parents aren't there or if you live out of home they look a bit more favourably on that.

Person 7 – There's a lot of things that I kind of need a hand with at the moment. I'm usually a pretty independent person with a heart condition and what I call a learning difficulty. What I need support with is the administration side of things. Managing COVID 19 logistics for your doctors or NDIS Support Workers or coordinators not being able to attend those kinds of things. And I've also been a recent victim of domestic violence and I'm trying to get security assistance for my apartment, but I'm not having much luck with state housing at the moment or any other facility. When I do request for support work, 80% of the times to get the help that I need. There's just been over the past few months where I've had some service disruptions due to unavailability of support workers or support coordinators. So I've been left scrambling trying to work out what to do. Regarding the NDIS and NDIA in general, yes, there is a lot of flaws or cracks in the system as we speak, in theory, it's a beautiful system. Although I suppose we've got so many people who have got vested interests with the NDIS and NDIA. But their agendas are just to satisfy cost of living and that they're not really passionate about their work that they're doing. And one thing that I'll be arguing in my plan review coming up in a couple of weeks is the next support worker or coordinator that's going to be looking after me how much work can they guarantee themselves to participant and the agency that they're employed with to provide services for that participant before they take on personal leave? I understand why people need to take personal leave. I discussed the original statement to one of the supervisors this morning. Their comment is that sick leave is also now considered as personal leave unfortunately, in the industry, so it's pretty hard to actually justify why workers take on leave. But I suppose that it affects me because when they're sick, what I need to get done gets disrupted because I have issues with catching public transport independently. And the long weekend that we just had last week, congratulations for people that were getting public holiday rates, but also good on them for actually not being there for me when I needed them this week, because apparently they needed a few extra days off from work because they're sick.

Person 8 - There are some things that I need help with, when there is a clothes line that is outside in the backyard, I can't actually reach the line, so I'll ask one of my support workers to help and I ask them to help me change the sheets on my bed and help me make my bed. I've got two new support workers and they help me out.

Question 4 - Something you do not like, something that you would like to change?

Person 1 - My room is very small, and I still live at home and I'm still very young, but I don't really want to change much only my room is too small

Person 2 - I would say the handle on the shower. In one of the showers for example, in my house is a little bit too high. And sometimes people who need disability access because someone elderly might decide to go into it, and they may want to have a shower. The showerhead is a bit too high, someone like myself or my brother would be able to reach it but my Nana, she won't be able to reach it. So I guess rearranging the showerhead to become lower.

Person 3 - The tap in me shower, every time you bump it, it goes hot water.

Person 4 - There's a lot of not nice people where I live, and a lot of people don't feel safe, and I don't feel safe either. I spoke to someone in Parliament and the (local council) to make it change, so people with disabilities and non-disabled people agree with everyone so they can feel safe, I don't feel safe really either, but I've had to say something and go to the (local council) to see if there's any other type of housing because I don't feel safe. And we don't say anything it can be scary; we have to say something.

Person 5 - I don't like when carers are touching my stuff or when the carers come to me late and it's hard to find someone else if they don't turn up

Person 6 - I wouldn't change anything apart from like it's my own fault but there are little bit of holes in the wall because I can't drive properly, and I keep putting holes in the wall. That's the only thing would change otherwise its fine

Person 7 - There is a lot of things that don't like about my current building. Now, I've always been a fan of the following principal that beggars cannot be choosers. However, me being born with a heart condition and me going through trauma as a child and teenager I suppose what I'm actually asking for is not really that extreme and that I'm not complaining about the little cosmetics of the actual apartment but the fact that everything is wheelchair accessible for me and I'm not in a wheelchair. And the fact that I should break my neck every time I need to see who is outside my door or the fact that it's actually taken my state housing office to fix them or after two years and seven months to fix up my stove. There has been a lot of issues and I'm actually tired of everyone using COVID-19 as a reason why they cannot fix up things within due time. And I'm tired of COVID-19 going to the way of things. Yes, people may have been affected by COVID physically with the virus, but not just physically it's also affected them mentally, financially and emotionally. That's what I'm actually quite tired of and the fact that there's so many responsibilities that the state housing office passes on to me, when quite frankly, if they are a housing officer it is their job to take on what's actually happened in the premises and to state to that tenant that they need to fill out an incident form and send it to them. It's very easy for them to say if they do not have disabilities, or if they do that they've got the supports right in front of them. It's very difficult for me though, because I may not have an email right in front of me. And I'll definitely not have that fancy incident forms on access so by the time they send them to me and then by the time I send them back out, I've forgotten what time the incident happened. I'm tired of them passing on all the responsibilities to what they're supposed to work on to people with disabilities like myself. Now I may sound a capable human being and I may be verbally articulate, but it doesn't mean that I did not have a disability.

Person 8 - One of the cafés which has been abandoned in the community has been graffitied. And I got in touch with (Council name) because there's a lot of history there and they got back, and they are going to take action on it.

Question 5 - Who supports you to make decisions about where you live? Who would support you?

Person 1 - My whole family supports me with making decisions, like our family makes the decision where we live.

Person 2 - That's a difficult question. I guess it comes down to all of us it's like a democracy. What we would do is that our family would look at the houses. Then later on, we would tell each other our thoughts and see what we are happy with about the house and what we are not and then if we're not happy with it we would talk about another place we can basically live.

Person 3 - I support myself.

Person 4 - I make decisions myself. I do talk over things with my advocate and my mentor and sometimes the people at my church It's about my life and my best interests of going forward and making really good, positive, proactive change.

Person 5 - My family, my case manager and my staff.

Person 6 - I chose where to live or choose how to live my life, sometimes I get help from my parents or colleagues to talk to me and sit down and say, Okay, well, you do this decision, but, you know here's the consequences sometimes, but a lot of times, it's just me.

Person 7 - Well, that would be really myself at the end of the day. Regarding supports now I suppose the more people that you have involved in your support team the more overwhelming it can be, and we may often find ourselves overwhelmed with what to do and who's doing what.

Person 8 - Sometimes I do make my own, sometimes my mum and dad.

Note – Person 3 left the meeting after question 5 and was unable to re-join.

Question 6 - How much choice do you have with the things that happen at home?

Person 1 - I make all the decisions myself, but my parents help me too.

Person 2 - The answer to that question is yes, I've got the power to choose what I want at my home. Just only in my room though because the rest of the areas are obviously belonging to different people like my brother, my two parents. As for how much freedom I got to choose, basically I can put anything I want in there, I could even ask for my room to be rearranged. Just to make it more accessible for me, so I have pretty much a lot of choice in my house. I can have access to the facilities like the oven, the kitchen as long as I clean up after myself, that's fine and even the computer study area too.

Person 4 - I can do things. It's my choice and control but my support workers help me do a lot of things, walk alongside of me, don't do it for me, like with transport and doing clothes and lots of things, they walk alongside of me. I communicate my activity or what things I need to do. But one thing I don't like them talking to their boyfriends on FaceTime, and I said, you can't do that while you're working with me on an eight hour shift. And when they are late, it's not good time management, they should ring up or you know.

Person 5 - I've got a lot of freedom to do what I want as long as I've got carers, if I don't have carers then I I'm stuck. I need twenty four hour care and I have carers every day and every week.

Person 6 - I choose what goes on in my house because I live independently and obviously if there's something I cannot do then I get my support workers to give me a hand to do it such as ironing for example or something like that.

Person 7 - I've got full control over the choices that I make from my home, but unfortunately, I'm not given that much freedom, because I live in public housing and if I wanted to put in an electric stove the answer is no, if I want to drill some holes to mount a TV frame, the answer is yes., but please wait four weeks after you've taken a photo wherever it is. If I want a pet dog, the answer's yes, but questionable because it's also dependent on the cultural benefits, the cultural barriers, the garden and the other tenants in your building. I feel that I have little freedoms and I can't get things done because I've got to wait for a bureaucrat to make his or her decision.

Question 7 - If you are not happy with where you live or the support you get - who can you go to for help.

Person 1 - I talk about it with my family and my parents and I'd talked about it just with most of my family and people at work.

Person 2 - Probably my psychologists who would just talk about what the issue may be. If it was worst case scenario I would probably go to a hotel or something like that, I would also contact the police if there was any issues with robbers, people like that. Beyond that, I'm actually quite happy where I live.

Person 4 - I'd go to the DHS, I'd go to advocacy group, or I'd go to the Member of Parliament. I'd go to my support coordinator or go to the disability commissioner or ring up the NDIS.

Person 5 - My family and my plan manager for NDIS.

Person 6 - I would go to my area coordinator and try and sort it out that way or I'd speak to the services myself.

Person 7 - First, I'd be running to the Department of Health and Human Services Office. Closest to me and then second of all I'd have to contact doctors, nurses, and I suppose whatever I generally need might not be able to be facilitated but I have to seriously wait just like the rest of the other people. Because I'm a publicly housed tenant, services like a crisis centre will not really help you out because you have to be housed. But apparently, it's considered that you're at risk of homeless when you've been a benefactor in domestic violence or gone through psychosocial trauma, or depression and there's not many services out there for people with disabilities.

Person 8 - Normally I will talk to my mom. She self manages my NDIS support.

Question 8 - If you could choose the dream home what would it look like?

- **Who would you live with?**
- **Would you want to live with other people with disability?**
- **How much support would you want?**
- **Where would you live? A busy city town/country other places that you might think of, why?**

Person 1— I'd like to live in a mansion with a pool, a Spa, a basketball court. I like to live in Gold Coast in hot weather. I would live with my friends from my service.

Person 2 - My ideal dream home would be to be a single story house or a two story house whichever works with disability access. The people I would live with would be either my family or my girlfriend if her and I end up teaming up at some point. And I would be open to living with people with disabilities because I just love the individual person. It would either be there's a lot of places I have a few ideas. Greenville, Williamstown, Somerton, Brunswick or even Geelong Maybe as well.

Person 4 - I think I'd either live in Dandenong in six or seven bedroom place with disability access and I'd live with my children and people from the church and just be disability friendly and have a swimming pool and just be a really nice positive place and I'd live in Geelong or Toorak or Brunswick or in Ballarat.

Person 5– A good house with good access, friendly neighbours a nice shopping centre with good access for my wheelchair. I'd live by myself with support.

Person 6 – I could say here but in a dream scenario maybe Oakleigh or Bentleigh. The house would be accessible, nice and bright and I'd just live by myself.

Person 7 - I suppose my dream home is like the old song that one Australian artist once sang "Give me a home among the gumtrees, with lots of plum trees, a sheep or two, a kangaroo, a clothesline out the back, veranda out the front". Now, that would be my dream kind of home. With relation to living with other people with disabilities, I'd like to refer to a yes I'm wanting to live with people no matter what their issues are. And so as long as they are getting the support that they need but disabilities and so long as privacy and headspaces are a given from time to time, then I've got no objections with living with another person with a disability. I'd like to say that I'd be here in Australia, this is the country I was born in, and it is the country where I would like my body to be laid to rest

Person 8 - I think about dream home would be in New York or somewhere overseas somewhere or just an island, a Greek island somewhere on the beach by myself with support.

Question 9

How would you rate the following rights in your home

The right to be safe – 4th

The right to privacy – 5th

The right to speak up – 1st

The right to complain – 6th

The right to dignity – 7th

The right to freedom and - 3rd

The right to make choices – 2nd

NDIS Quality and Safeguards Commission Consultation Focus Group

Cohort # 4

The fourth focus cohort is a group of family members of people living in the family home or independently in their own home within the community in Victoria.

The group consisted of four people with the following demographics:

Gender of group members

three females

one male

Gender of family members being represented

two females

two males

Age of group members

60 – 70 years - one person

70 - 80 years - one person

Age of family members being represented

20 – 30 years

40- 50 years

Disability

Both members of the group are related to people who have intellectual disability. The family members being represented may have other comorbid disabilities including:

Autism, Down's Syndrome, Mental Health issues

The following is a transcript of this consultation

Question 1 - What is the best thing about your life?

Family member 1 -The best thing about my life, well, I've got the (Family members name) finally back to his day program after 18 months at home. That's the best part of my life. Just having that few hours in the day to myself.

Family member 2 - For me. At the moment I'm on holidays. With all my children, which is sometimes good, sometimes bad. That (Family members name) is on holidays as well. So it's nice to actually just reconnect with them all and spend some time with them.

Family member 3 - The best thing about my life at the moment is that I'm having opportunities to take my wife out to a few different places. She's disabled and we don't have the opportunity a lot. But at the moment, she's physically able to go out and have a good time for a small period of time, it makes it happier for her and that translates into the family, and everybody feels a little bit happier.

Family member 4 - I'm retired.

What is the best thing about your family members life?

Family member 1 - He used to take part in quite a few things, just before COVID he stopped and when he stopped one, he stopped quite a few and he just got into the habit of just doing nothing, and it's just been really, really hard for him. And for me, and it's just having as I said, him back it's made him a little bit happier. Because he's got a routine and when he's here it's only the two of us and so he's here all the time and he doesn't have any interest in things, you can't get him to join anything, you know, he doesn't really have any friends and it's just he doesn't want to do anything at the moment. So that's the hardest part really, that's what we're trying to establish with him just you know, now very slowly getting him back was the biggest challenge that we had for a year and a half, that was really hard to do. Now we're just treading softly is what we're doing now and trying to make a few changes. He can't deal with change. You can't even really talk to him about changes because if he thinks it's happening it stresses him out. He is a really funny character and everything but he just, yes, I think just going to the centre I think it's mainly with the staff that he really likes to interact mainly. He is so much older than all the others because he's just turned fifty, a lot of the others coming in, they're only eighteen, nineteen or twenty, so there is a big difference there. He has tried a few things over the years, and I know he's well capable of working but he wouldn't, his anxiety would just take over and any kind of any kind of criticism and you've kind of lost him, so he is a bit of a challenge.

Family member 2 - At the moment, she's just started working which is amazing. This year has been fantastic for her because she's also doing the Special Olympics National Games in Tasmania in 19. days, she keeps reminding me so. It's just seeing her develop and grow and seeing the things that she still needs to learn and experience. How she's still young and has a lot of interest in so many different things. This year has just been amazing for her, and it because she's just gone out. This is a first year away from school, so it's a huge change for her, a massive change, she's still finding her way she's usually a chatterbox and you can't stop her talking and at the moment, she's still a bit shy and sort of gone into herself a little bit in certain areas, which has been really interesting that she's also come out and is developing this whole new adult life, It's amazing.

Family member 3 - I understand what (Family member 1) is saying about consistency, you know, COVID was a big destroyer of engaging with people at different times particularly face to face. We've found that it's so important for the kids to actually be face to face with people and engaging and you know the possibilities of a love interest or a friendship developing or going out to the movies is mostly only available if you are actually speaking to the person, because it's so hard, the nuance of interaction is quite difficult unless you're actually speaking to them personally. But they're big on their computers and their iPads they love communicating that way. At the moment, the most exciting thing for (family member) other than completing his Certificate Four in Community Work is going to work at his new job that he's doing once a week, one day a week and he's very excited about that and he goes to (service provider), which is a place where he can do, it's open several days a week and there's a couple of them one is in (location) that's where he goes and he uses their 3D printer and creates things that you know like little models of Star Trek and Star Wars. He burns pictures on to balsa wood and stuff like that, he just loves engaging with them and learning how to do things like that.

He loves going out to dinner when we do that and he and his brother just went out for the first time together to a really swanky hotel the other day for dinner and they went out the day before and bought themselves a jacket for going out and then they went and saw Hamilton straight after that, and they would not stop talking about how good it was.

Autism is difficult sometimes finding their way out of the shell, you know where people that are autistic often see themselves encapsulated or trapped is a difficult thing, you need to find springboards for them, that they're interested in, that they can bounce off and keep going with.

Family member 4 - I think her independence is and the stuff that VALID's done with her. She loves it. She loves being consulted and she's also doing the (service provider) Employment Training and she loves that too. We've seen a lot of a lot of changes in her, increasing maturity or confidence or whatever. She doesn't argue as much, if I make a suggestion, in the past she would have just dug her heels in and said, no, and now she will consider it and give her reasons why she thinks it's not such a good idea. So I think it's a combination of the VALID and (service provider) because she has to actually consider other people's perspectives in the process.

Question 2 - What is the best thing about your home?

Family member 1 - I'm trying to think, it's really convenient here to everything, and it's a beautiful block of land and the garden is beautiful. (Family members name) is not somebody that you could actually just leave inside while you went outside, you can't even go upstairs and leave him downstairs so I would have a room downstairs the same as him. He wouldn't adjust to moving anywhere, and that's what we're in the process of looking at now. I think as he's getting older and I'm getting older, we need to do that. But the house itself is nice, but with (Family members name), you've got to really watch him 24 hours a day, so it's very different, very restrictive, put it that way.

Family member 2 - We've just moved recently which is nice in one way, bad in another, it's just nice being in a different environment. All the children have their own rooms now, although they're not that big. It's nice being in a new home and being able to start working in the garden and have a bit more of our own space, everyone's getting their own space, which is nice.

Family member 3 - At the moment, we're putting all the boxes of books that we've had from different places, and we're putting them into bookshelves, like a library sort of putting it together and really enjoying doing it. The boys help us because they've got good eyesight. The other thing is we're doing a garden as well outside and pots and trying to make our outside sort of an entertainment area where our grandchildren can come over and play, they are four, and six months old, but they just love coming over and we love having them and their uncles are overjoyed when they come over. That's one of the best things about living in a house or living in a place, that you make it nice, and people are happy to do things and keep it clean, that's one of the big issues too. And one of the best things about it is having a home to live in. I guess there are many people in this world who don't but yes, we do.

Family member 4 - It's a good size, we downsized to come down here, it's near the beach, it's close to supermarkets, banks, library, pub, bowling club and everything's within walking distance. That's what we wanted. and it's a great community

What's the best thing about your family member's home (who lives independently in her own home)?

Family member 4 - It's super cheap, it's a friend of ours, daughter and she doesn't need the income. She's quite happy for (Family members name) to stay there as long as she likes. The mum of the young woman who owns it has worked in disability for many years and has known (Family members name) for years and she only lives a block away, so she acts as the landlady, whenever there's a spider in the bathroom or something (Family members name) calls (name) and then (name) comes round and gets a spider out.

Question 3 - What are the things your family member needs help with in the home?

Family member 1 - He's really quite independent, there'd be very little things I'd have to do for him, and he'd do it you know. But it's the autistic trait that comes in because you've got to watch him, he loves cooking, we used to cater a fair bit, so he does love that, but you could be there cooking with him and if you turned your back on him he could turn it up or down. He's very independent, but he thinks he's got his own way and you might not know he's turned it up. That's where it's really hard with him and just got to completely watch him all the time. But really he would even know bills, I mean his memory is brilliant he can remember things right back 50 years, he even knows people's names. He knows how to put the washing machine on and hang it out and bring it in and he knows how to fold it.

He's pretty good with dishes and everything like that, but he doesn't wash the floors or do anything like that, but he would mow the lawn, so back to the same thing you know, you have to watch him because then he could unplug something on the lawn mower, there's a 1% chance he might, you've got to eliminate that. He's very capable, there would be very few things he would need really guidance with. He listens to everything and he's very perceptive, he was also told he would never read and really, he was well into his 20s even before he strung sentences together and it's incredible the way he speaks now, and he's all self-taught even his writing and reading is really all self-taught. You know, he just used to get the newspaper, he might not know all the words, but he'd be able to piece together the sentence and things like that from just looking at it.

I have to choose his support workers and I'm very particular because he is the way he is and he's good, but you got to watch him. So therefore I can't have anyone that I know wouldn't really be keeping a little eye on him if you know what I mean. So I do struggle to get somebody that's qualified enough to know just to keep an extra eye on him when they're out and stuff like that. As I said, most of the time he is fine, but you've got to eliminate these little things. He only has somebody once a fortnight at the moment because he's been back at (service provider).

Family member 2 - She needs reassurance all the time because she can't sequence things or remember things. She repeats things over and over again to make sure she's got it right, she talks a lot, so she needs reassurance all the time. She needs help with reading and if she gets mail or emails she needs help. Sometimes you know with belts, fine belt buckles and things like that, she's okay with dressing and showering and stuff, but she still needs to be reminded to you know, really wash her hair properly. Every day things she'll tell me that her teeth are clean and flossed. She's becoming more independent with food, but I mean it's very basic. She can get the food out, but she needs help cutting bread or she can make a cup of tea, but she needs help with the stove with cooking. She likes to help out, but she does need guidance as well for safety. She has support, she's got some lovely carers that come over and support her, that is that through her NDIS plan and you know, travel training, that sort of thing, she's just starting to get right into that this year, so she needs a lot of support with that. She thinks she can do everything, but then when she thinks about it, just like oh, can you help? I can't do this; how do I do that? She's pretty good at asking most of the time. She'll give things a go, and once she understands something and gets it, then she's able to do it. It's stuck in her brain; it takes a very long time for her to be shown over and over and repetition over and over again until she gets it and then she's okay. But you know, with reading it's taking a very long time, it might not happen which is okay, she's got the basics and she tries a lot, she's always reading of a night time. They're the sort of family things because we're all together still. The boys help out and give her a helping hand all the time too.

She's been doing speech therapy since she was about 18 months old and as soon as she turned 18 that stopped because we were with a kid's speech pathologist and we tried to get her into an adult one and haven't been able to, we got funding through NDIS, but it was for literacy, which they were going to help her with her reading and what have you, but the NDIS wouldn't cover it. They wouldn't have a bar of it because it's literacy, it's not speech. So we're starting that in January and when we found out we couldn't get funding for it we had to close up shop and we've been working ever since. It's hard to get speech unless you've had one for all your life practically since birth. So that sort of support of speech therapy has sort of gone away. The carers and what have you still sit with her and go through with you know, reading and what have you. So we get that support. But when you really want a specific type, and it doesn't come under the NDIS guidelines, then it's sort of like we've got the money, we want to spend it, we want to use it and you can't get anybody

Family member 3 - He suffers with his anxiety, anxiety is the greatest influence in in his life and getting a hold of that and dealing with each instance of it, as it comes along is probably the issue. It leads to self-doubt, so we try and help him to overcome each issue as they come along. A lot of the time he finds ways of getting past it or over the hurdle as it comes along, but there comes a time when he needs to be able to talk with somebody, and now that he's 21 he likes to actually speak to somebody separate. So a behavioural therapist, and he's finally found one that's really great. And, they have good relationship which is wonderful, and NDIS will pay for that which is great.

They try to cut the anxiety stuff out of his plan every time it's reviewed. But we try and find ways around those issues. It's becoming very difficult the NDIS is becoming smaller and smaller and smaller in their in their scope, not broadening.

Family member 4 - I think it's actually seeing what needs doing like, I'll go into the bathroom and the floor is pretty grotty where she hasn't scrubbed and washed the tiles, she won't see that. You know there's a bit of mould around the shower recess. She needs a routine like change the sheets once a week, she needs help making the bed. There's just a few bits and pieces she needs prompts and reminders.

If I know a support workers coming and I happen to be talking to (Family members name) that morning, she rings me every morning, I'll say make sure the floors are swept, things like emptying the fridge, the bottom crisper of the fridge, the soggy green things that are growing there. One of the support workers she had would go through the fridge and say that's past its use by date before they went shopping. That's part of her NDIS program to support her in her own home.

We had a couple of really good workers and then they were doing study, so they had to leave and do their placements and whatever. We have new workers on at the moment, and I'm more than happy to give them three or four visits before they actually get to know (Family members name) and get to see what I'm talking about, they're young and they don't see things the same as a grumpy old woman sees, like dusting the top of the kickboard. Which I've told her to dust because I'll say they're not there to do all the work, (Family members name) needs to do it and they have trouble convincing her that she needs to do it and that in itself is a skill. People have what they don't have, they can do it, or they can't do it. And I've seen that over the years and years of people working with (Family members name). I'm just sort of waiting to see how these newbies go.

Question 4 - Something you do not like, something that you would like to change?

Family member 1 - I'm sort of renovating this and have been for the last 15 years because that's something we used to do and my youngest is a builder so everything as you can imagine is half finished. We actually bought the house next door thinking that would be ideal for (Family members name) later on, it just didn't work out. That's when we started to realize he couldn't live there, because he was working at that time for a disability organization for seven years. And we thought oh he'll be alright, to live there, we'll just keep an eye on him, but he used to disappear overnight, and we didn't know this. So in the end we ended up moving back to where we came from, and I had bought the house next door to my mother's and then when my mother passed away we bought my mother's house and they're very big properties and the idea was that we would build a disability place on those two properties because they are the bigger blocks of land like a retirement village

Family member 2 – I'd really like a dog flap so the dog could come in and out without scratching the doors. I would really like to have my own house. We had a property just before (Family members name) was born and then we decided to sell up because everything was booming, then we had (Family members name) and realized when she was about three weeks old that something wasn't quite right because she had delayed hearing, delayed vision, tactile sensitive, the whole kit and caboodle for her. So then from three weeks onwards until she was 16 we did everything speech, OT, kinesiology, shiatsu, you name it we did everything with her and had support groups and what have you, so everything went into her which we don't regret whatsoever. And then I had another child, but we never got back into buying a property we've been renting ever since and ideally I'd love to have my own home to be able to do things like paint the walls, knock out walls, not having to put up with things going wrong and waiting for the real estate to get back to us, that sort of thing. And it'd be lovely to own our own place, but in saying that, we've just moved and it's a lovely home and the kids seem to be enjoying it, but it'd be nice to own our own house.

It's nice to just have the family unit working together all the time, in that you don't walk into the kitchen and there's crumbs everywhere, there's cups and if you use it just put it in the dishwasher and you're finished with it or you know you're hungry, make something but then put it away, and the washing drives me up the wall because we're in a dip so this house is very cold and the backyard is quite sludgy and we can get anything dry, so I'm constantly having clothes everywhere trying to dry things and then it's a big fight as to who will put the washing on the line or who can take the washing off the line.

Family member 3 - Realistically, we're not a very financial family, but we get by, if we had money to we'd like to make the showers more accessible and we'd like for there to be something smaller than we could exist in and manage, that's what we'd like about the house.

Family member 4 - Can't really say my husband because that a bit rude, he doesn't do enough around the house, it needs painting and I need a window put in but that's all.

Something you do not like, something that you would like to change about your family member's house (who lives independently in her own home)?

Family member 4 - I find that its cold because it's a double brick but then she doesn't mind, she's got the heater to use if she wants to. The owner who is very tall renovated the kitchen and things are up really high and it's a tiny kitchen. (Family members name) doesn't have any cupboards down low they're all up high and she can't reach them, so we've got sort of bookshelves everywhere for her to put her pantry stuff on.

Question 5 - Who supports your family member to make decisions about where they live? Who would support them to make decisions in your absence?

Family member 1 - Me it's just me, my daughter was living overseas, she came back a couple of years ago, she's a couple of years younger than (Family members name). So it's been really quite good because I'm kind of trying to train her because she had her own opinions on (Family members name) as well that are different to mine. I think she's finally realized that I do know him better and what she really has to do if something happens to me.

Family member 2 - My husband and I, we sit with (Family members name) and go through it with her, so she understands what it's about in a very basic structure and then she decides if she likes it or not. She interviews her carers. She helps me look through the Hire Up app to see what carers are available and if she likes them or not. We have a good group of friends from (Family members name) School, from (School), and we talk about a lot of stuff together as well. So they help me in making certain decisions about you know, what was the next stage after year 12. I just had a parent today ring me asking about where (Family members name) goes at (service provider). So we support (Family members name), but we also have external friends that support as well.

Family member 3 - We support (Family members name), we hope his sisters will at some point, if whenever we are not here or you know, so we're in a jet and that jet falls out of the sky. We're prepping him to be on his own. I guess his sisters would support him They're both older and their mother plays a very large part in in both all four of the kids' lives as I do. But their mother particularly provides the wisdom of the family.

Family member 4 - I guess It's me, except when I suggested (suburb) she was quite strong about no thanks.

Question 6 - How much choice does your family member have with the things that happen in their home?

Family member 1 - (Family members name) has a lot of choice really the whole structure is around him, because if he doesn't want to do it, we don't do it. I would like my grandchildren to come over and stay the night, they've got rooms upstairs, but he would be a little bit funny about that. It's too stressful and it's terrible because I can't have them come over and stay even though they love him to death, and he loves them. The very fact that they are coming into our house can cause a problem, so it's really everything is around (Family members name).

Family member 2 - She has a lot of choice. We're quite structured in what we do, but she's very much a get up and go out, she's happy to do anything and everything. Every weekend we go for a walk in the morning, she's up at six. She's keen to do things and if she wants to do something usually she ends up doing it, more so than the boys. We do have limitations on some things, but we try and get her to experience and do as much as possible because she can't sit and just watch TV or anything that she just needs to be moving all the time doing things, so I think if she wants to try something we're all for it. But with some things it could be a financial, it could be just physically we cannot do it because we don't have time because we're doing six million other things as well. She has quite a bit of freedom, especially with having two carers which is great because she gets out with them, and she works out what she wants to do with them. she does have quite a bit of choice and freedom, but she does have to work in with the family, being at home and she's quite happy to do that most of the time.

Family member 3 - He has a lot of choice if he involves himself in what's going on. If there's something that needs to change in a particular room, or the garage needs to be clear cleared out, or something needs to be put together, then if he's involved in it, then he'll be very happy to be here and present. He makes choices in his life depending on what he wants, just like we do. It's just a matter of the motivational thing in the right

direction. It has to come from us sometimes and reminding him if he hasn't done it for a time. he needs to go back to it and doing that will help him, like finances, you have to remind him to save money as opposed to spending it.

Family member 4 - I would say probably 90%. She has a routine based on her daily activities, but she chooses what she watches on TV and what she downloads on her computer and when she does things. She comes and goes as she pleases. Apart from the fact she's learned that if she has made a commitment to be somewhere at a certain time she has to be there, but in her own home, she does whatever.

Question 7 - if your family member is not happy with where they live, or the support they're getting who would they go to for help?

Family member 1 - My daughter would, (Family members name) knows that's what we're looking at in his plans now and I've told him that if he's not happy with anything in the house that he knows he has to speak up and tell his sister or one of his brothers because if he doesn't nobody will know he's unhappy, then his anxiety comes in and that's when he will start doing things.

Family member 2 - If (Family members name) wasn't happy she tells us, she'd probably come to me first before her father and she'd probably talk to her friends or a couple of her friends' parents. She's very comfortable talking with adults and yes she would probably go to me first or communicate it to her friends' parents. She's a happy go lucky girl, so at the moment she's quite happy apart from her room is so small. She is thinking about down the track and what she's going to do, but she'd like to move in with her friends.

Family member 3 - If he has an issue regarding his NDIS or things that he needs assistance with he speaks to his support worker who is very helpful and if they need extending that further for each issue, or place that they need to get assistance with he can go to the specific person for example a counsellor or personal physio who meets him at the gym or an OT who comes to the house or goes to the coffee shop and they have a chat about what it is or the way that he is the way he does certain things or his exercises. And when it comes up for review they put in the extras. He knows that he can talk to his mother as well his mother gives him great assistance with about if he's not happy he they lives. They can go to each other for help because he's got brothers or sisters, but definitely their mother.

Family member 4 – If she was not happy with her support she would probably talk to me or her friends, but if she wanted to change something she'd talk to me, she's not too scared of me.

Question 8 - What would your family members dream home look like?

- **Who would they live with?**
- **Would they want to live with other people with disability?**
- **How much support would they want?**
- **Where would they live? A busy city town/country other places that they might think of, why?**

Family member 1 - I don't think (Family members name) would really care where he is because he will never go anywhere else except to his day program wherever it is. You'd have to be in the vicinity of that because I could never get him to change. He's been there for too long.

I don't think the House would matter. I wouldn't want him in a tent. I wouldn't want him in a townhouse or anything that was with others because I think the noise from if there was little arguments and fights going

on it could actually you know, get his adrenaline going. Though I'd prefer if it was in a quieter like a semi-detached or something.

He'd be just quite happy; all he wants is one other person. I think he'd be better off with a female a male would be too much competition. Because he's a very caring person, I often think that somebody that needs help whether they're in a wheelchair or what because he loves helping like that. I think he'd be the kingpin in his own mind. That to me would really benefit both people, but he definitely would need a carer 24 hours. He would need somebody, even though he's really capable he's unpredictable. He would need somebody there.

Family member 2 - (Family members name) would like to live in Queensland, she would like to live in a big house, with her other friends that have disabilities. She be quite comfortable having a carer, we only just spoke about this a couple of days ago, someone that could possibly stay overnight but could come and check on her other friends that have different needs. Because I don't need that sort of support, but I need other support. Yep. So Queensland, it has to be a big house. It would have to have a pool it would have to have a gym and a sauna, all that sort of thing. It would have to have the basketball court and be near the beach. She likes walking on the beach and loves all that sort of stuff. So I know that Queensland would be the top of her list and being with her friends and having a carer not necessarily stay overnight, although that's not for her but for her other friends. They would probably need a carer to stay overnight but Queensland has to be close

Family member 3 - I think he'd like to be married with children. Is it's more about who's with him and the environment around him. I don't think it really matters where, he wants to be loved, like mum and dad love him or like mum and dad love each other. He'd have to have a Lego room and he'd have to have the ability to use his Xbox and computer and stuff like that. Location would be wherever we live, that's where he would like to live as well in that state or close in that town. I have a feeling that there'd be a dog, or a cat involved as well.

Family member 4 - I think what we're working towards with (apartment block name), because she doesn't need a yard, she doesn't do any gardening, she can barely look after the two pot plants she has. The community would be great. I'd prefer a two bedroom, but we could only afford a one bedroom and it's a huge bedroom. She will be close to public transport, it's right on the train station, near (Street) with trams and the bus goes along (Street). I think it's perfect. I think that's she's really excited about it. And it's across the road from her boyfriend. He's in the other (apartment block name). I know she'd like to live with her boyfriend, but that ain't gonna happen. They've been on and off on and off since he was 18 and the off was really off, they both stuffed up severely. If she wanted to and she found someone that she liked to share with sure and I think if you had two families involved it could be quite a good collaborative thing.

Question 9

How would you rate the following rights in your home

The right to be safe – 1st

The right to privacy – 3rd

The right to speak up – 4th **

The right to complain – 5th

The right to dignity – 2nd *

The right to freedom and – 4th **

The right to make choices – 2nd *

* Equal 2nd

** Equal 4th