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**TRANSCRIPT OF PROCEEDINGS**

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**THE HON RONALD SACKVILLE AO QC, Chair**  
**MR ALASTAIR McEWIN AM, Commissioner**  
**MS ANDREA MASON OAM, Commissioner**

**THE ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND  
EXPLOITATION OF PEOPLE WITH DISABILITY**

**PUBLIC HEARING 25**

**WEDNESDAY, 13 JULY 2022 AT 10.01 AM (ACST)**

**DAY 3**

**MR PATRICK GRIFFIN SC, Senior Counsel Assisting**  
**MS AVELINA TARRAGO, Counsel Assisting**  
**MS REBECCA McMAHON, Counsel Assisting**

CHAIR: Good morning, everyone. Welcome to everyone who is present in the hearing room in Alice Springs and to all those who are following the proceedings on the live stream. This is the third day of Public hearing 25, of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. And at this hearing, we are examining the operation of the NDIS for First Nations people with disability in remote and very remote communities.

I shall ask Commissioner Mason to make the Acknowledgment of Country.

COMMISSIONER MASON: Thank you, Chair. Werte. We acknowledge the Arrernte people as the original inhabitants of the traditional lands on which we are gathering today, Mparntwe, also known as Alice Springs. We acknowledge their ongoing spiritual and cultural connection to Mparntwe. We acknowledge and pay our deep respect to elders past and present. We extend that respect to all First Nations people and acknowledge their enduring connection to land, sky, seas and waterways. We pay our deep respect to First Nations people here today, and who are following this public hearing online on the mainland and on islands, including in the Torres Strait, especially elders, parents, young people and children. So -- with disability. Today we are joined by witnesses giving evidence from Broome and Fitzroy Crossing in Western Australia. We acknowledge the Bunuba, Gooniyandi, Nyikina, Walmajarri and Wangkatjungka peoples of the Fitzroy Valley, and we acknowledge the Yawuru people of Broome. Thank you, Chair.

CHAIR: Thank you very much, Commissioner Mason. Those who are in the hearing room will know that there is some wonderful artwork that is being displayed. Prior to commencing the taking of evidence this morning, I would like to express our very sincere thanks to the Bindim Mwerre Anthurre Artists as well as the Bindi Mwerre Anthurre Studio for providing this room with the artworks that you can see or those in the room can see at present.

For those that may not know, Bindi Mwerre Anthurre Studio provides a means for Aboriginal artists with disability to develop and receive recognition for their artistic practices by providing supported studio spaces, a national exhibition schedule, design contracts, multi-media collaborations, art fairs and art award opportunities. One particular artwork by the Bindi Mwerre Anthurre artists which you can see directly behind me is by Adrian Jangala Robertson and the piece is titled 'Yalpirakinu'.

Adrian won the Alice Prize this year and is a finalist for the Hadley's Art Prize in Tasmania. He was also a finalist in the very prestigious Sulman Prize that is on show right now in Sydney. The Sulman Prize, as I'm sure many people know, is awarded for the best subject painting, genre painting or mural. For those who haven't been able to participate in the proceedings in the Alice Springs hearing room, and as you may already have seen, the artwork of the artists will be displayed on the live stream during adjournments for the duration of this public hearing, that is, for the rest of this week.

So, again, our thanks to the artists for the privilege of having their artwork displayed in the hearing room during the course of this week.

Yes, Mr Griffin.

5 MR GRIFFIN: Thank you, Chair. As mentioned by Commissioner Mason, today the Royal Commission will hear evidence from five First Nations people with lived experience of disability, and one First Nations organisation from the Fitzroy Valley in Western Australia. The Fitzroy Valley is a collection of connected communities covering an area of the central southern Kimberley of Western Australia. It's the home to five predominant language groups, and there are at least 45 distinct communities within the valley.

10 You will see on screen a map of the Kimberley region, and particularly the locations of Broome, Derby and Fitzroy Crossing and then across to Halls Creek. Fitzroy Crossing is the service town for the Fitzroy Valley and is situated on the banks of the Fitzroy River, around 400km east of Broome with a population of around 1,300 people. Can I indicate that data produced by the NDIA to the Royal Commission recently indicates that, in Fitzroy Crossing,  
15 there are 183 First Nations participants with active plans during the 2000-2001 financial year.

20 There were 152 First Nations participants who received payments against their plans. Preliminary analysis by the data team at the Disability Royal Commission suggests that Fitzroy Crossing participants in the NDIS are not utilising their full plan funding. It suggests that participant spending is, on average, 28.4 per cent of their committed supports and, most importantly, that 31 participants have not spent anything from their plan.

25 Plan utilisation is consistently lower across all age groups, irrespective of First nation status when compares to what appears to be the national average. As I indicated, Commissioners, it is a preliminary analysis by the data team within the Royal Commission, and after this public hearing there will be an opportunity for the Commission to liaise with the Commonwealth in terms of making submissions on any of these matters. But I wish to raise these matters this morning to give you, Commissioners, an understanding in which the  
30 context can be placed.

35 The first witnesses you will hear from and the ones I will call immediately are Geoff Davis and Marmingee Hand. I understand Marmingee will make an oath and Geoff an affirmation. Before that happens can I indicate, Commissioners, that these two witnesses currently have three young men in their care: Tristan, aged 23; Tylon, aged 18; and Quaden, aged 16. Each of these boys have been diagnosed with fetal alcohol spectrum disorder, known as FASD.

40 Marmingee has provided a statement for this public hearing dated 4 July 2022, identity number STAT.0567.0001.0001. This statement is in Hearing Bundle number A at tab 39. Geoff Hand has provided a statement for this public hearing dated 15 June 2022, ID number STAT.0555.0001.0001. This statement is in Hearing Bundle A, tab 40. I will hand over to your associate, Chair, for the swearing of the witnesses.

45 CHAIR: Yes, thank you very much. Can we see the witnesses on screen? Is that to happen?

MR GRIFFIN: It is intended they will be on screen.

CHAIR: All right. We will just give it a moment to bring up the picture. We can see you now. Thank you very much for coming to the Royal Commission to give evidence. Thank you very much for providing the statements. I hope it's okay if I call you Geoff and Marmingee. Is that okay?

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MR DAVIS: Yes.

MS HAND: Yes, that's fine.

10 CHAIR: Thank you to both of you for your assistance to the Commission, and we are looking forward to hearing your evidence today. Now, I understand, Marmingee, you wish to take an oath. So, what I would ask you to do is to follow the instructions of my associate, who will administer the oath. And then, Geoff, I understand you wish to take an affirmation. My  
15 associate will then administer the affirmation to you, and, if you don't mind, just follow her instructions. Thank you.

**<MARMINGEE HAND, SWORN**

CHAIR: Thank you, Marmingee.

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**<GEOFF DAVIS, AFFIRMED**

CHAIR: Thank you, Geoff. This, I'm sure, has been explained to you, but just to be clear, I am obviously in the Alice Springs hearing room. With me is Commissioner Mason, who is on my  
25 left, and on my right is Commissioner McEwin. We are the three Commissioners who are participating in this hearing. I will now ask Mr Griffin, who is Senior Counsel Assisting the Royal Commission, to ask you some questions. Thank you very much.

**<EXAMINATION BY MR GRIFFIN SC**

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MR GRIFFIN: Chair, before I ask any questions, can I indicate that Mr Hodge, Senior Counsel representing the Commonwealth, is present in the hearing room today.

CHAIR: Yes. Thank you, Mr Hodge, for gracing us with your presence today.

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MR GRIFFIN: And can I indicate that before I ask Marmingee or Geoff any questions, we have a very short video to play of Tristan talking about his gardening business.

**(Video plays)**

40

**(Music plays)**

TRISTAN: My name is Tristan. I run a business called Tristan's Yard and Garden Maintenance. I do whipper snipping, I do mowing. I do raking up. I do chainsawing. I cut down the trees  
45 and put it into a bonfire.

**(Music plays)**

TRISTAN: I do lots of places around here. I do the courthouse. I mow at Bayulu School and Fitzroy School. I just make the place look tidy around here. I look outside my door and it's like, "Oh, man, the grass is so long. I just want to cut it." I mostly cut grass because it's very important because you don't know what's in it. If you are working with barefoot, there might be snakes. The secret to a good lawn is to make it even, and I cut it really low to make it really nice and so people can see what's in the grass and to make it safe. If you want your grass to be cut, I'm the guy to call.

10 We have to take good care of the equipment, and just looking after my gear, I check the blades on the mowers and the filter and the fuel and the oil. When I garden, it's - it's really good for me. It really clearing my mind and my stress goes right down. And it keeping me healthy. It's really good for our muscles. And if you don't like the sun too much, that's your bad luck. No one can ever survive in this heat, but I can.

15 I like to be my own boss because it's really good and they listen to me. I have four people who work for me. I like running my own gardening business, and I just can't get enough of it. I do take good care of this place, and people respect me a lot. So, when they come to me, I want it to be perfect. I want it to be really good. I work really hard for that. Well, the Fitzroy Crossing gardening is looking pretty good because it is me.

**(Video ends)**

CHAIR: Yes, Mr Griffin.

25 MR GRIFFIN: Marmingee, I wonder whether you might give the Royal Commission a little bit about your background, firstly your educational background and also your family background?

30 MS HAND: I guess I grew up in Fitzroy Crossing, went to school at Fitzroy at the old mission school. I completed my high school at Derby Junior High and then went down to Applecross Senior High school in Perth and completed - I went to year 11 and then decided to - to leave school and then return back to Fitzroy and got a job as a teachers aide at the Fitzroy High - Fitzroy School.

35 MR GRIFFIN: You've been involved in and continue to be involved in many community organisations within Fitzroy Valley?

40 MS HAND: Upon returning to Fitzroy, I got involved with the adult education centre here, Karrayili, was a lecturer there. Also the Fitzroy Valley Aboriginal sporting association, because I love sports. And Marninwarntikura organisation, I'm the founding member of Marnin and also was involved with Marra Worra Worra organisation in the old days when the community development program was around. And then lately got involved with - where my mum came from, I was born on the desert, Yanunijarra, which is a prescribed body corporate. And also, involved with the football here at Fitzroy.

MR DAVIS: Garnduwa.

MS HAND: And another one is Garnduwa Regional Organisation which is a sport and rec body.

5 MR DAVIS: The chairperson.

MR GRIFFIN: You have a Master's degree in Indigenous Languages?

10 MS HAND: Yeah, I just recently finished my Master's in Indigenous Languages out of Sydney Uni. And it took - I think it took me four years to complete it, but other than that, I managed to complete it in April of this year.

MR GRIFFIN: And you've had a life-long interest in language?

15 MS HAND: Beg your pardon?

MR GRIFFIN: You have had a life-long interest in language?

20 MS HAND: I have, because I'm - when I - my own language was my first language, which was my mum's language. And not knowing and understanding English, I guess, you know, my own language was my first language and really interested. Because my mum actually spoke seven different Aboriginal languages. So, my interest has always been in my own language and, currently, I am - I coordinate the Aboriginal languages program in our school.

25 MR GRIFFIN: And you mentioned you've had an involvement with sport. In fact, you are the president of the Central Kimberley Football League?

30 MS HAND: Yes, I am. I work very closely with my husband - my partner, Geoff, in relation to getting football, you know, off the ground here in the Valley. And we have been running the football now for the last 20 years. And in the last four years, the women actually came on to start playing Australian Rules Football, and it's really great to see our young women and, you know, some older women out there playing football.

35 MR GRIFFIN: 20 years suggests that you know how to keep that mob under control, Marmingee.

MS HAND: We try to --

40 MR DAVIS: She's a good teacher.

MS HAND: But I suppose, being a teacher, you try and control but sometimes, you know, it - a lot of things do happen that's beyond our control. So, we try to manage as best we can.

45 MR GRIFFIN: And you and Geoff have been together for 30 years.

MS HAND: Yes, we have.

MR GRIFFIN: Can I go to you, Geoff. Can you tell the Commissioners a little bit about your background, particularly in relation to your time in Fitzroy Valley?

5 MR DAVIS: I was born and raised in Manjimup in the south-west of the WA. From graduating teachers' college, I went to Jigalong and spent a year there and first came across working with Indigenous people there and found that it was a very enjoyable experience. In the early 80s, I went to - I was a school teacher for six years and I ended up in Kununurra, and then from there I got involved in the sport and rec industry, and that's where I first bumped into Marmingee.

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I got a job back in Broome in the early 90s, and we set the Garnduwa organisation up. And, during that time, I travelled extensively throughout the Kimberley, visiting remote communities and assisting them set up their sport and recreation activities and training and all that sort of stuff. I moved from Broome to Fitzroy in '95, to be with Marmingee and her family and, yeah, basically I've been there ever since.

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MR GRIFFIN: Does 25 years qualify you as a local?

MR DAVIS: I would say about 30 per cent.

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MR GRIFFIN: And we just saw a video of Tristan. He seems a delightful and very popular young man around Fitzroy. Is that right?

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MR DAVIS: Yes. Tristan's challenged in lots of ways. That video was most probably the pinnacle, I think, for showing how he - he deals with things. He's a delightful young man who - most probably has the best moral compass of anybody that I've met. But he's quite significantly challenged in lots of ways. And it's been an absolute pressure in actually being able to raise the kid. We've raised him since he was - basically since he was let out of hospital, because he was very premature.

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Marmingee looked after him and made sacrifices - excuse my voice - in the early days. She took time off to be with Tristan, to assist in raising him, because he had significant issues when he was very young. But I think with a fair bit of love and care and attention and stuff like, the kid's - the kid has developed into a fine young man, but he's still challenged by lots of the issues that - that his brain damage through fetal alcohol has caused.

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MR GRIFFIN: I will come back to that a little later, Geoff. But, Marmingee, do you also have Tylon and Quaden, your grandchildren, under your care?

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MS HAND: Yeah. We do. Yeah. Tylon actually came to us when he was nine months old because the relationship that my son and his partner was having was very toxic, so the - there - his grandparents of - just basically said, "Look, you need to take this child." So we just took on Tylon. And then the other young fella, Quaden, came to our care when he was 18 months old. So, you know, we had - we were looking after four children, including Tristan's older sister, who was also living with us at that time.

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So I guess for me, in taking on four children, because I had this plan that I didn't have any of my youngest - my son didn't live with us and he no longer lived with us, so I had this planned life that I was going to go and do lots of stuff but, bang, I had to look after four children.

5 MR GRIFFIN: And each of those children have quite complex needs.

MS HAND: They - yes, the - the four of them have, and they've got very complex needs. And each and - each one of them shows different behaviours. And that's what both Geoff and I had to, I guess, live with and trying to manage the best way we can to support these  
10 young - you know, these four young people who live with us. And, mind you, we only had a two-bedroom house and we tried to manage care of those four children living with us.

MR GRIFFIN: Was it your concern, Marmingee, that those children may have been removed from the community if you and Geoff didn't step in?  
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MS HAND: Well, I guess with - it came to us when Tristan actually was - when he was born, and my sister took him to Perth. That's when the Department of Community Services at that time and saw that my sister sort of neglected my - you know, Tristan and this is when they were going to remove Tristan from my sister and placed him in care.  
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MR GRIFFIN: And is it the fact that, based on your experience, when children are removed from remote communities, they often suffer complex trauma?

MS HAND: Yes, they do. You know, it depends on what institution our young people are put in, and there are all sorts of traumas that affect our children. You know, the loss of culture, the loss of connection with family, you know, the home life and trying to adjust, you know, when they do come back, it brings up all this trauma that they may have faced living in institutions or in, you know, someone - in someone else's care.  
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MR GRIFFIN: And you and Geoff, I take from your statement, have a very strong view that family and community is the best location for people with complex needs, if it's possible?  
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MS HAND: Yes. And if - if the supports mechanism is put in place, similar to what we have done for Tristan, you know, really the - the care that we placed around Tristan, I mean, we had to - you know, because we love the young - we love the little - the young man now and I guess, you know, keeping my family in place together that he was being raised in - where all his family are, you know, both from my side as well as his father's side. And that he had connection, you know, to his own country here in Fitzroy. And that's the most important things that we need to, you know, have this care for our children. And the best - the best  
35  
40 care.

MR GRIFFIN: Can I -

MR DAVIS: Just to add there, the way it works for Indigenous people - and I can only speak for around Fitzroy, but it's all around family. And there's a bit of a conundrum because with the - the trauma and stuff that's been around for a long time since colonisation, there's - there's that intergenerational trauma that exists within families. And the reaction  
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of a lot of people to deal with that trauma is to hide it or to, you know, sink it with drugs or alcohol or, you know, with those sort of things.

5 And so therefore, quite often people who are most responsible in the family to make that family work are compromised themselves, and so the kids become traumatised because of the trauma that's been passed down from previous experiences of the parents or the grandparents. And so the - there is a sort of imperative that you have to remove the kid from the dysfunction that's happening in the home, but, in actual fact, because the family is the actual core logic of how the people exist, it's so important in Indigenous culture, that  
10 family is everything.

And that - and that's how the whole system operates. If that breaks down then you take the kids away, that exacerbates the problem. So, it's the sort of a conundrum because you have got dysfunction in the family already that's causing the kids to be traumatised again, and  
15 you take them away to try to get them away from that trauma, it retraumatises by removing them from the environment that most probably could, if it was set up properly and operating well, could support that kid.

And I think Tristan is a good example of that where we as a family are able to keep him with  
20 us, which has enabled him to exist within the family structures, even though they are quite dysfunctional in some ways, because there is a - there is a sort of a modicum of love and support that is provided to him that enables him to have the base to be able to exist where, you know, his - the siblings and other people are suffering from, you know, things like mental illness or trauma or suicidal thoughts, all those sort of things. He has been able to  
25 survive in that. Whereas, I think if we took him out of that, it would then expose him even more to the issues that he already faces.

MR GRIFFIN: If I come back to that issue and particularly your concern of what happens to people like Tristan if you're no longer there and your thoughts about different models,  
30 which you maybe explored, but before I do that, can I just ask you, Marmingee, in relation to fetal alcohol spectrum disorder, that was a condition you were completely unaware of, I understand, until Tristan and his sister came?

MS HAND: Yeah, I - I mean, I've got - I say my two children. My own two children were  
35 normal. They had normal birth and you know, the normal growth of any young human being that we bring into the world. But when Tristan came into our care, I noticed that there were - I mean, at the age of 5 months old he contracted hydrocephalus where we had to - he had to get flown into Perth and got put a shunt which drains the fluid out of his brain.

40 So when I took him up to the paediatrician, Dr Adams, he told me then, he said, "Are you aware about the spectrum disorder, the alcohol spectrum disorder." I said, "No, I'm not aware of, you know, this condition at all." So I guess my first hearing about them - the whole, you know, FASD was when I went to - I went to - for a professional development in  
45 Perth and I just happened to go to a symposium where Dr - Professor Elliot was speaking, and that's when all the things that I heard sort of tweaked and I said, "Well, these are the same conditions that I saw in young Tristan and also the young - you know, Rani."

5 She was displaying the same sort of behaviours. And not only that, as being a practising teacher, I saw behaviours like that within the classroom where things that couldn't - you know, kids were attending 100 per cent, but couldn't put things in the right way, so, all of these just started to - you know, click, and then when I started becoming involved in the Lililwan Project, and went across to Canada and attended some of the conference on fetal alcohol disorder, then I started to realise that our community and our children were suffering from this particular condition or disorder.

10 MR GRIFFIN: So from early 2000s, you started to self-educate in relation to this particular disorder. And then I understand between 2009 and 2015, there was the Lililwan, L-i-l-w-a-n, Study conducted in the Crossing. Is that right?

15 MS HAND: Yes, it was a prevalence study which tested quite a number of our children at that certain age group.

MR GRIFFIN: What were the conclusions of that study as to the prevalence of this particular disorder within your community?

20 MS HAND: Sorry, I can't - I couldn't hear what the question was.

MR GRIFFIN: What were the conclusions of the Lililwan study into this disorder in your community?

25 MS HAND: Well, according to the study, when it was completed and there was a - when it came back to Fitzroy, I think 20 per cent, I'm not - I think that still was children were on the spectrum out of the cohort, and I think there was about 199 children whom went through that particular study.

30 MR GRIFFIN: That study concluded in 2015. To your knowledge, did the NDIA pick up the results of that study to incorporate it into the NDIS when it was established?

35 MS HAND: I - honestly, I can't really make a comment of that because I wasn't aware. The only one was from when Tristan was already on a plan here with the WA Disability Commission, and when - and when the rollout of NDIS came, whether his old stuff went across to NDIS, that's the only experience that I can say honestly about, you know, the rollout of that particular program and who were actually on the program. Only from our own experience I could, you know, say that - you know - what impact it had on Tristan.

40 MR GRIFFIN: Thank you.

45 MR DAVIS: If I could make a comment there. Tristan was identified by his daycare gang as somebody having significant issues and he needed extra care at daycare because of some of the things that were happening at daycare with his behaviour and stuff like that. And the ladies that were involved then were very knowledgeable and actually got him registered in the state system to get support for him at daycare. To do that, there was a number of

reports that had to be written that almost had to exaggerate his conditions to attract funding to enable them to have somebody work with him at daycare.

5 Now, they were successful in getting that care, and that rolled into then his - some care given to him at school, but, again, it was the same situation. When he was evaluated, they almost had to give the worst-case scenario for him to attract funding. He was with the state system via the fact that the school and us and daycare and everybody had sort of pushed the - we knew about how it worked and that he needed that care. But there were significant other groups of kids - and I would imagine they are part of this 20 to 30 per cent that  
10 appeared in the FASD study that were affected by - and on the spectrum that weren't able to access the same services because the people didn't have the same knowledge and experience and background that we had.

15 And then the role - as Marmingee pointed out, the transition between being on a state - being recognised at a state level with that issue and then being recognised in a national level was a problem because the - they didn't - as far as we could see from our position, there seemed to be very little communication between the two about how the information from the state system was incorporated into the national system. Now, we can only comment on that from where we sit in a place like Fitzroy Crossing.

20 We obviously don't see or hear about the swap of information and how that transitioned from one to the other. But from my personal point of view - and I had sort of the handle on - on a lot of what - how Tristan was being handled in relation to his FASD and other issues, there was very poor communication with us in relation to how it transitioned from  
25 one to the other.

MR GRIFFIN: Did that poor communication include an aspect that he would have to be reassessed as to that condition for NDIS purposes, even though there had been a diagnosis made by the - and recognised by the state?

30 MS HAND: Can I make a comment on that. Just to verify what Geoff was saying. When you go through the system in relation to the education system and as a parent of Tristan, he had to be assessed to get on - in those days, they used to call it the School Plus. And in order for him to get assessed to be able to get a special needs assistant at school, which he was  
35 allocated a point - a .9 position, where he had an EA position to help him, you know, through his schooling right till he was in year 9.

40 When he went to year 9, that's where then they wanted to reassess his whole, you know, his cognitive level, where he was and how he could be able to sit all the different testing that, you know, we tend to give to children. He - he could not sit the WALNA. He could not sit the - the west - at the time before NAPLAN came, we had Western Australian - the WALNA. He could not sit those because he was not able to be able to read and write and to be able to understand those questions.

45 So when - and he took - because of his history from the time he went to daycare right through until year 12, he took all of those stuff with him to the disability here in WA. But whether that - those information, the historical information of him as a young person,

whether that went across to when NDIS came across, the only information that I received as his nominee and his carer was in a letter saying that there was a rollout of this - of now that Tristan was getting put across to NDIS.

5 MR GRIFFIN: Thank you. Geoff, I want to raise with you your role in Tristan's business. I don't need to promote Tristan's business any further because he's done it wonderfully himself in the video, but I understand from your statement that you adopted the role of a mentor and supporter. Can you describe to the Commission what you would describe as a mentor model in that situation? What do you do?

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MR DAVIS: We didn't want Tristan to be sitting - when he graduated from school - and let me say I think he was the only kid who graduated out of -

MS HAND: That year.

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MR DAVIS: Out of Fitzroy Crossing in that year, out of school. We didn't want him sitting around doing nothing and being caught up in a lot of the issues that a lot of the kids in Fitzroy Crossing are caught up with. One of the things in school that we would encourage him to do was to leave the classroom, if things were getting too challenging, and not to overturn desks and swear at teachers and all of those sort of things.

20

And he did that and he went out to the gardener's place at the school, and he made friend with the local Indigenous gardener there who taught him to ride a ride-on mower. The - in year 12, the Clontarf Foundation encouraged us to make an application for Tristan for a sponsorship thing out of - I think it was ANZ. And they - and he got a scholarship for 10,000 and when they asked him what he would like to buy or do with his 10,000, he said he would like to purchase a ride-on mower and a trailer and stuff and continue doing some of the gardening stuff that he was doing.

25

30 So Tristan has great difficulty in reading and writing and gets anxious quite often when faced with things that are not - you know, not easy to solve. And so I was at a situation where I was sort of coming to the end of my working for other people's lives, and could see that there was an opportunity to support Tristan as sort of in the background and make him - give him a feeling of ownership of his - of what he was doing. Because I think one of the things in the previous video of Tristan when he was 12, one of the things he says, "I just want to be normal."

35

And for him to be normal, we - he needed to be doing normal things. So, basically, I sort of sat in the background and have done all of the, you know, the bookings and do the financial management and - he doesn't have a driver's licence, so I became his driver to - to drive him and his ride-on mower around. And then - so it's - it's sort of - that whole - as it evolved, it - the best role for me was not to be - to own the business and to run it and do all of those things or be seen to be doing that, but was to allow Tristan to make those decisions himself about what he wanted to do.

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45

So I sort of had to learn as I went along about how to do that, and it sort of, over the years - and one of the things I will mention that dealing with Tristan and working with

Tristan was also very good for my own mental health in this. I had suffered from quite severe anxiety for a number of years leading up to this, and then working with Tristan has made my life a whole stack better as well. So, I just like to add that in because it - and playing that sort of mentor role with him meant that I had to sort of - and with FASD kids, you have sort of got to be their external brain to a certain extent to guess when they are going to get anxious and to make sure things are in place to reduce their anxiety.

And so that sort of mentor role grew and so that's the best way, I think, to describe it. And it's been going for about five years now. That gets challenging sometimes because Tristan - over the last little period for instance, he has - he's wanted to work less and so that real work ethic and things which he displayed in that video sometimes are challenged. And so Marmingee and I have got to sort of work in the background to encourage him to keep those views that he espoused on that video going.

And I would just like to say to the rest of the panel there, that - that the - the thing that resonates most with me with the FASD stuff is every day is a new day for that kid. And sometimes - it's not every day. Sometimes every hour is a new hour for that kid. So, he can be performing at a - at a quite a substantial level and, you know, doing things you saw him and speaking like he did on that video, but if something makes him very anxious, within - you know, almost immediately, it can all turn to something not quite so good.

So the idea of being a mentor for the kid is - or for the person has grown. You know what I mean? It's more than a mentor, but that's the best way to describe it and I think it's the best way for the kid.

MR GRIFFIN: I want to explore that with you, Geoff. Because I know from your statement, you're concerned what would happen to Tristan and his business when you're gone. To put it bluntly.

MS HAND: I guess the - in relation to that, we thought really hard about that and, you know, my older daughter who is - who lives in - near Geraldton, who is actually a deputy CEO of, who is the sister of Tristan, actually is - she said she's going to become the guardian of Tristan. So, I guess we, you know - and where we live, I guess, you know, that's something that both Geoff and I thought about. Not only that, also my - my two grandchildren because we - you know, we live here in this environment and I know the - you know, the ability of my own - my own family.

Tristan's mum would not be able to look after Tristan in such a way and - and I know that, you know, living in - in this environment and the community, I think they will - you know, exploit our son because he is - he is our son. We raised him, and, yeah, it's very - very emotional for me to talk about - sorry.

MR GRIFFIN: That's okay.

MS HAND: --

CHAIR: It's all right. You take as much time as you need.

MR DAVIS: I just --

5 MR GRIFFIN: Geoff, before you go on, I particularly wanted to get you to focus on what you say in your statement about a mentor model. For example, at paragraph 32 you say that:

*"If there were 20 supervisors or mentors they could probably each reach five young people and you would have 100 people in our community that would have mentoring relationships."*

10 Can you explain your thinking behind that to the Commissioners?

MR DAVIS: Yeah. The - I guess what evolved with my working with Tristan, it became a model that was working very well for Tristan in - and, as I say, the - I had to learn a set of behaviours that - that enabled him to sort of feel that he owned where he was going. But  
15 the - also going parallel to that, there was what was going on with the other two grandchildren, our 16 and 18-year-old grandchildren we are looking after. And also Tristan's younger brother Sebastian who was - who is now 22, I think.

MS HAND: Just turned 20.

20 MR DAVIS: 20. Because we gained more work, we had to have more people do stuff, and so we asked our grandchildren, and these others if they wanted to come along and be involved in it. Now, I asked Tristan would he be happy to have these kids - it started with Sebastian, really - because Sebastian was getting into major problems with the law here in Fitzroy,  
25 whether - and they asked us if we would give him a job. This is they, being the Justice Department.

And I asked Tristan if he was happy for Sebastian to work with him to keep him out of jail, basically, because when he turned 18, he wasn't - because he was no longer a juvenile  
30 offender, he was going to go to the big house. And that would have made him very vulnerable. Anyway, Tristan said yes, so we got Sebastian working for us on different jobs. And Tylon and Quaden were not going to school. They had disengaged from school quite significantly, and they then - we said to them, "Well, you can't just sit around home doing  
35 nothing. You need to earn yourself some money or you need to do something."

And so they said, "Oh, can we join in?" And they asked Tristan, and so with one of them, he engaged quite significantly. The other engaged less significantly. But we had a team of four or five young men who were all troubled, all with issues, who were doing a really good job  
40 in - as like Tristan said on that video, and you saw some of them on that video. And he viewed them as his gang. And so I was - and the role I was playing sort of in the background in organising the - you know, the places for them to go and doing a bit of quality control.

And then, you know, if the mower broke down and Tristan wanted to turn it upside down or burn it, then I would jump in and make sure that it didn't happen. And, you know, those sort  
45 of things. And we would - I remember one day, we were all driving along in the car and they were all singing along to one of the locals, and I thought this is really good. And it was - because I was driving, and they were all just sitting in there.

And we had all the mowers on the back and the trailer, and we were coming back from a job and everybody was sort of happy and talking together, which was really quite different to a lot of the situations a lot of the other kids around the place who are the same age were experiencing. And I also chair the Men's Shed in Fitzroy, Gurama Yani U, the local Men's Shed in Fitzroy Crossing. And we'd been talking about a mentor model for these troubled kids that are - there's a lot of kids in Fitzroy have been getting in trouble over the last couple of years, that the same sort of model that was evolving with - with me and my family was something we could possibly parallel with other families or other situation - other situations.

So where you have somebody who has an understanding of the issues that these kids have and has the patience and the knowledge and the understanding and the resources to be able to live with that and to sort of mould that and have the kids engage in an effective way rather than a disaffected way.

MR GRIFFIN: And I think you raised, Geoff, if I can just interrupt because I'm very conscious that we have limited time and there are some very significant issues I want to raise with you, is you say in your statement at paragraph 40:

*"The NDIA should invest in training families and community in skilling them up."*

You go on to say:

*"No use putting funding into individual plans where there is no infrastructure or services. If there a bucket of money for Fitzroy Crossing, it should go to building infrastructure and supporting training families to care for people with disability."*

So moving outside Tristan's particular circumstances, are you suggesting to the Commission that what you and Marmingee created with Tristan could be applied to a lot of other families in your area, with sufficient training and support?

MR DAVIS: If those families - and these are identified people in those families that - that are able to provide the level of knowledge and support that's required, otherwise it can get exploited. But the - yeah, the - in Fitzroy Crossing, for instance, a good example is that there could be - we could create little work parties, if you like, to call it that, but (a) we need to create the things that the kids like doing, and (b) we need to have the skilled up people to be the mentors who understand the complexities of what they are dealing with and to be able to work with those groups to keep them together. And the challenges that we are having with Tristan right now in holding that group together and working with them is an example of that.

MR GRIFFIN: Can I summarise what I think you are saying - and tell me if this is correct: That if the funding under the scheme was more flexible and could be used by individual participants and their families in a way that best suited them, on the one hand, and, on the other hand, if there was protections to prevent exploitation of participants and misuse of their funding, that would be a model that you would urge the Commissioners to consider?

MR DAVIS: Absolutely.

MR GRIFFIN: And, Marmingee, do you have any views about that?

5

MS HAND: Yeah, I - and, you know, this is what I didn't bring up very well, is that any scheme, you know, whether it's NDIS and that, there need to be screening to be able to put in place and perspective really, you know, really look at how it can work in such a community like ours. You know, there was not enough information, not enough training of people. Because I guess both of us, when we took Tristan on, we both - you know, we're both teachers and knew the model of care.

10

And knowing and understanding, you know, about the behaviours of children like Tristan or any other children who have got a disability, those sort of screening needs to put in place in - in a community such as ours where our community is a low socioeconomic community, where money is so important to - and the value of money is important to our family, and it is really based around that. How can - you know, we can best manage a program that is rolled out to our community. And that's just - just from our experience of what we have seen of the - of that scheme being rolled out here.

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MR GRIFFIN: And your experience, Marmingee, has been - I understand from your statement, that Tristan's allocation in his plans - which, Commissioners, appears at Hearing Bundle C, tab 27 - has not been utilised because the services are simply not available. That's one of the major reasons why those funds haven't been used. Is that correct?

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MS HAND: I guess what Geoffrey was trying to allude to the fact is that because, you know, the relationship that we had with Tristan, as he's being our son, we - Geoff was his mentor and all of those stuff - he's basically like his carer to be able to look after - and Tristan. And I guess that's - that's the flexibility we're saying, you know, that the Commission really need to really look at that particular scheme and who can access that.

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Because at the moment, we could not access Tristan's funding for him to even update, you know, his licence, that he really, really wants to get, and all of the other supports that was - that in his - in his plan. So, it's all of those stuff that really - he could not access because of the community that we live in and because of, you know, there is not enough staff around here to be able to - to deal with Tristan and other people - people like him who are on the plan in our community.

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MR GRIFFIN: And do I take it from both of you that it would suit your situation much better if the plans were flexible as to how the funds could be spent?

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MR DAVIS: The answer to that is yes, but also I think - and the perspective from the Men's Shed, for instance, is that - and as Marmingee was saying, the - there needs to be - there needs to be a way to oversee how resources are allocated and spent, and so there needs to be a structure in place behind the individual families to support the bigger picture, if you get what I mean? That if you are going to have, say, four or five of these Tristan's Garden

45



Maintenance happening in for our five different groups or situations, there needs to be the infrastructure behind that to support it.

5 So, if something goes wrong, how do - how do you - how do you deal with it? Because if you leave it up to the individual, families, quite often it's too difficult. So, you almost need supporting organisations behind it to - to oversee it and monitor it, like Marmingee was saying, so it is not rorted, in one sense, but is supported and - and it goes on, because part of the issue with the families - and I see it myself. If I get sick, who takes over from me? And the answer is most probably nobody.

10 And that really worries me because there is no other invested group to say - Tristan and the people that he's working in his little group and they are all FASD-type kid, they are all kids with special needs, what happens to them once the mentor or the person who is attached to them isn't available?

15 MR GRIFFIN: So, Geoff, are we saying that we need to build infrastructure and capacity within those communities like your own?

20 MR DAVIS: Absolutely. Fitzroy, and I imagine Halls Creek and a lot of these remote places are in exactly the same boat. And if you go out to the remote, communities, they are most probably even worse. If you go to Yakanarra or Wangkatjungka or Noonkanbah, we have some serve services in Fitzroy Crossing, but those remote communities have nothing. And so, you know, the fly-in fly-out, drive-in drive-out service delivery model that's being promoted and you have service delivery coming from Perth, one of the reasons Tristan couldn't get his licence because the neurosurgeon that he had to get to sign off for him to be able to get his - to sit the test for his licence was in Perth.

25 It was going to cost us five-and-a-half thousand bucks to get him down there to see him, and then we couldn't get an appointment with him because he wasn't seen to be a priority. And the neurosurgeon never comes to the Kimberley. So, we waited two-and-a-half years to try to get Tristan his licence, which is key to his mental health and how he sees himself, because he wants to own his own business. He doesn't want his old father driving him around the whole time. He - he still has - to this day, still does not have his licence.

35 MR GRIFFIN: And so a young man running a successful business wants to have greater flexibility in his business and control by getting a licence, and it's been over two-and-a-half years to try and go through the process of the assessments necessary to give him a realistic chance of achieving that goal?

40 MR DAVIS: That's correct.

MR GRIFFIN: Marmingee and Geoff, there are many other questions I could, in an ideal world, ask you now but because of the time, I'm going to invite the Commissioners to ask you any questions they wish.

45 CHAIR: Thank you very much for your evidence. I will ask Commissioner Mason first if she has any questions she would like to put to you.

COMMISSIONER MASON: Marmingee and Geoff, I just want to say thank you for giving evidence today. It's been really incredibly important to hear about the journey your family has gone on in that remote community. But also his story is one of empowerment and - but  
5 the system sitting there, in terms of the NDIS and previous disability services, are there for the benefit of people like Tristan and others there in the community, but the gap is still there in terms of getting the benefit to the individual. So, it's been really valuable to hear your evidence today and I want to say thank you very much.

10 MS HAND: Thank you.

MR DAVIS: Can I add just something there? One of the - the - I support the whole NDIS concept in that it's adding a whole bunch of resources that were never there in the first place. But, unfortunately, it seems to me that the NDIS is actually trying to fulfil gaps that  
15 exist in the broader system and so things like lack of housing, you know, lack of mental health practitioners, lack of social workers in places like this, the NDIS is actually being seen to try and replace that. And it doesn't - it's not equipped to do that.

So the services that we would normally get from state or federal agencies that are supposed  
20 to be doing these things, the model that the - the delivery model that exists in state and Federal Governments means that places like Fitzroy Crossing are always going to miss out. And the NDIS is now being seen to be the stopgap for that and it can't be, because it just doesn't have the resources to fill in those gaps.

25 COMMISSIONER MASON: Thank you.

HIS HONOUR: I will ask now Commissioner McEwin if he has any questions.

COMMISSIONER McEWIN: Thank you, Chair. Thank you, Marmingee and Geoff. I too follow  
30 in Commissioner Mason's comments. Thank you. I have one question. You spoke to us a bit about support and the importance of keeping children with their families, and you've talked about some - the various parts of support that you have had and would have liked. What in particular would early intervention support look like? So when the children are very young. What would be early intervention, like from birth to maybe 5 to 7? What could that look  
35 like?

MS HAND: That's - I guess, just from our own experience, I mean, the early intervention that we put in place for Tristan, I think, was a good model, even though it - you know, it was a family model. And the support that we had around it. And one of the things that I - when I  
40 went across to Canada to do something that our organisation, Marulu, actually saw that particular model of care which we - in - and Australia hasn't put in place as yet. And I guess if you look around that familiar model of care and you know, the philosophy behind that would be a fantastic model to use here in our country in regards to children being taken away, placed in homes and all of those. So, that intervention stuff.

45 And I guess it's also about when, you know, the intergenerational trauma that Aboriginal people are faced throughout their lives, which is really the cause of all the stuff that is

happening now. So, I guess, just from my own experience, you know, when my younger - my younger sister, who a medical condition was diagnosed with mental retardation, got taken to - to Perth and training centre, at the age of 8 years of age.

5 My mother couldn't understand the reason why she got taken away and had to live in that. And also Tristan's mum at the age of 8 years old got - was diagnosed with Leprosaria and was placed in a Leprosarium at the age of 8. So, knowing and understanding and having, you know, the empathy of what happened to my own family and my own experience, placing, you know, my two sisters in - in the medical facilities because of that. And no doubt just like  
10 all of the other policies that we were put out, you know, for Aboriginal people and Aboriginal families, I think we need to really look at - look at all the stuff that is being placed around that and what intervention is going to look like.

MR DAVIS: Can I say the - at Gurama Yani U we have been exploring how to become better  
15 husbands, better uncles, aunties - grandfathers, better brothers, better family members and to - it seems to me that we need to have - to build capacity amongst that group of men, who quite often are damaged themselves, to become those better family members to look after these younger ones. So, if there's a kid - if there is a kid born into that situation, that the family themselves can actually be supported with these other support programs  
20 themselves.

So if they have got alcohol or drug issues or they've got domestic violence issues, or any of those - or trauma issues, that we set up mechanisms to support those people do it themselves rather than try and transport the problem somewhere else.

25 CHAIR: Thank you.

MS HAND: Just on that, we need to build the resources to be able to - and that's one of the things when the NDIS plan, it was just another - another thing of, you know - I mean, we like  
30 the idea, the concept. It was another resource being placed in our - in our community, but it wasn't done effectively the way it should have been.

MR DAVIS: And the drive-in drive-out model of service provision, or fly-in fly-out, or the last one, zoom-in zoom-out, provision of service to families in remote communities is - is totally  
35 ineffective, and it's been proven to be totally ineffective forever. There are lots of organisations who get money to do some of this stuff that don't know how to connect in Fitzroy Crossing because they are based in Perth or Geraldton or somewhere else.

And that discussion I had with the NDIS about Tristan's new scheme, which happened in  
40 March, the lady was speaking to me from Geraldton. Now, how she would have any idea of what it was like - or what Tristan's needs were, her based in Geraldton and us based here, is problematic. Now, in the discussion with her, she was very compassionate when - and she said, yes, this funding is under threat because you haven't used it. And she was understanding of that because, obviously, she was quite experienced.

45

But she had no idea as to why that money wasn't spent. And then the threat of it being taken away, is - is quite traumatic, really, in its consequences for Tristan down the track. Even though we don't -

5 COMMISSIONER McEWIN: Thank you both so much. I'm conscious of time. Thank you very much.

CHAIR: Can I just, Marmingee, ask you about this - in paragraph 45 of your statement, you say that when it came to Tylon and Quaden, you didn't bother to register them for the NDIS because you didn't want to put them through another assessment.

10

MS HAND: Yeah.

CHAIR: Ideally, what sort of supports - without going into the details - what sort of supports would you like to see Tylon and Quaden have, if the NDIS was able to deliver supports?

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MR DAVIS: I think it's what I was just saying. That the - the parents quite - the parents or carers are quite often overwhelmed by the problems that the kids display. And so, you know, the fact that Tylon and Quaden left school, basically disengaged from school and wouldn't go to school, even though we're - Marmingee and I are both - Marmingee is a school teacher and I support the school, we were unable to get the kid to go to school.

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Now, to me it gets - it's building the capacity around the service deliverers to assist - to plug these kids into. So it doesn't necessarily mean money for the kid, but it means money to support the - the issue. There is a bundle of these kids with these problems. So, how do we help the school engage better? How do we help Marnin engage better with this group of kids?

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MS HAND: Just, you know, the question that you've asked me in relation to Tylon and Quaden, the reasons why, after experiencing with the Lililwan Project, it's - they had to go through a rigorous assessment, and I did not - you know, the way my two grandsons are, where their head space is, to be able to put them through that rigorous assessment again to prove to anybody about, you know, of their own disabilities, so I guess, you know, I went out of my way to support my two grandchildren through their schooling.

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When they disengaged from the school here, I got them finally into a school in Esperance which, you know, on reports at the moment, we are getting very good report. But other than that, to get study - what they call ABSTUDY for them, to attend. It took us two years or three years for Tylon and Quaden to get on that particular scheme, so, because of -

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MR DAVIS: Complexities.

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MS HAND: - you know, our income or on based on my income. So, I guess, you know, as a family we manage, and I managed to be able to, you know, try and get, you know, our grandchildren or children that we raised to the best - the opportunities like education for them. So we had to take them out of, you know, here down to another school, somewhere where this school is coping and doing quite well for the needs of our grandchildren.

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So, I guess, it's - it's about - you know, any scheme, anything that we do, we need to really think thoroughly what it's going to look like, in any setting that is being delivered to, you know, the remotes of Western Australia.

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CHAIR: Thank you. Can I just ask a couple of questions about the plan. The plan provides for \$107,000, as you said, for Tristan over a period of two years from May 2020 to May 2022. Am I right in thinking that the only part of that plan, or the own moneys that have been spent are the moneys for support coordination?

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MR DAVIS: That's correct.

CHAIR: And that goes to the NDIA, does it?

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MR DAVIS: Yes.

MS HAND: Yes.

CHAIR: What do they do for the \$11,000?

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MR DAVIS: They ring me up two or three times a year.

CHAIR: That's it?

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MR DAVIS: That's it. We have requested - again, I think it's the system. The problem here - we registered Tristan with Far North as the provider, and the reason we chose him because it was the only provider that was local. All the rest were either in Broome or Perth or somewhere else. And, unfortunately, there's been so much pressure on Far North to deliver to the other kids with disabilities here, they - they just couldn't - they said to me straight out, "We cannot deal with this licence stuff. It's too hard."

30

Now, there is other things that Tristan most probably could benefit from if he was in Perth or Melbourne or Sydney or whatever, because there would be specialists at the doorstep, you know, therapists and whatever - or in whatever space. But in Fitzroy Crossing, there are none. And so, basically, it falls back to the capacity of the people who are looking after these kids to deliver it. Now, Tristan's quite fortunate in the fact that he's got Marmingee as a - as his mother, who has such wide experience and also was able to give up her time.

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And then there's me, I was in the situation where I was able to retire from my - what I was doing to work to spend with Tristan, but the majority of the families here don't have any of that capacity.

40

MS HAND: No income whatsoever.

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CHAIR: Yes. The plan provided for \$12,000-odd for an improved daily living funding - and that involves specialist driver training. So, there was actually money specifically in the plan

to enable Tristan to get his licence. He still hasn't got his licence. And the reasons are the matters that you have described in your evidence. Is that correct?

5 MR DAVIS: And there is no driver training in Fitzroy Crossing for him to access anyway.

5

MS HAND: And especially kids with a disability, you know, trying to find the right model for any children or anybody who's got a disability to be able to obtain their licence. That's a key factor to this in relation to Tristan obtaining his lesson - his licence. Even to get his learner's, he needs to sit in front of a computer to do his online training. So, you know, that - that, you know, is a trauma for him to obtain his licence. So, you know, that is the key factor, I think.

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CHAIR: And the plan also included \$33,000 for finding and keeping a job, and the moneys were available for the school leaver employment services to support Tristan and his move to access work. None of that money could be utilised in Fitzroy Crossing?

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MR DAVIS: No, because there is no service like that. And so I fill that role, but because I'm his father I can't access -

MS HAND: He can't access.

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CHAIR: You can't get paid. Can't get paid. I want to echo the thanks that have been given by Commissioner Mason and Commissioner McEwin for the evidence you've given. If I may say so, it's very powerful evidence. I would like to see your evidence become available and actually looked at and heard by as many Australians as possible. You have provided some accounts of matters that all Australians should be aware of and that something has to be done about. I thank you very much.

25

CHAIR: I just want to check that there's no - we have represented parties, and it's par for the course for me to ask if they have any questions. I assume nobody does, but I will just check. Unless anybody leaps to their feet, I assume there are no questions. Thank you again very much, Geoff and Marmingee, for your evidence. We really do appreciate the help that you have provided to the Commission. And Tristan was able to speak for himself but also speaking on behalf of Tristan. Thank you.

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35 MR DAVIS: Thank you very much.

**<THE WITNESSES WITHDREW**

CHAIR: Mr Griffin, what do we do now?

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MR GRIFFIN: There has been a change in the schedule. The next witness will be Mudge who was originally scheduled for after lunch.

CHAIR: And do we take a break, or do we have Mudge now?

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MR GRIFFIN: It's a matter for you, Chair.

CHAIR: You tell me. I just work here.

MR GRIFFIN: Avelina would like to continue.

5 CHAIR: Sorry?

MR GRIFFIN: We would like to continue, if we could, because we are a little behind.

CHAIR: Yes. All right.

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MS TARRAGO: Commissioners, our next witness is Mudge Eric Bedford. He wanted to give evidence live today but due to family commitments and Sorry Business, he is no longer available to give evidence. We will instead play a video statement that I recorded with Mudge on 3 June 2022, where Mudge spoke about his experiences and those of his family. Operator, could you please play the recording, doc ID IND.0172.0003.0001.

15

CHAIR: Yes, thank you.

**(Video plays)**

20

MS TARRAGO: Thank you for joining me this morning. Your name is Eric Bedford.

MR BEDFORD: Yes.

25 MS TARRAGO: And you also go by the nickname Mudge.

MR BEDFORD: It's not a nickname. That's my - a black fella name that got given to me when I was a child and over the years, over 30 years, it got cut down shorter and shorter. It's originally Majibiydi. So, yeah, down to Mudge now.

30

MS TARRAGO: And has that got special meaning for you, that name?

MR BEDFORD: Yeah, it does. Like, just - you got to carry your own people's name, you know, like the song-lines and everything else that we got to carry through Australia, all us blackfellas.

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MS TARRAGO: And today, we are going to have a talk about the experiences that you and your family have had with the NDIS.

40 MR BEDFORD: Yes.

MS TARRAGO: And the things that we are going to talk about today, are they going to be true and correct?

45 MR BEDFORD: Yes.

MS TARRAGO: Yes. And you're living in Fitzroy Crossing; is that right?

MR BEDFORD: Yes.

MS TARRAGO: And you are a Bunuba man.

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MR BEDFORD: Bunuba, yes.

MS TARRAGO: Bunuba man, sorry. And how far does Bunuba country go?

10 MR BEDFORD: Well, it sort of expands, I would say, over two, three hundred kilometres, you know, square kilometres and all that sort of thing. But I couldn't tell you exactly but, yeah, I would say about that.

MS TARRAGO: And are there different language groups within that Country?

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MR BEDFORD: Well, in Fitzroy Crossing, there is five different language groups, but then there's - over the years also picked up all the other languages along the way, but five mainly in Fitzroy Crossing.

20 MS TARRAGO: Can you tell me what those five different ones are?

MR BEDFORD: You got Bunuba, Walmajarri, Nykina, Wangkatjunka, Gooniyandi. Yeah, that's five.

25 MS TARRAGO: And your family - you've got family ties through the Valley?

MR BEDFORD: Yeah, my grandmother's Fitzroy Crossing. Grandfather Halls Creek. So, that's sort of through the Valley, and then my mum's side of the family are from Broome. So, I'm sort of not only in the Valley but through the Kimberley, I think.

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MS TARRAGO: So from one end to the other?

MR BEDFORD: Yeah, half of my kids - my kids, they are, like, from half of WA, I think from the Kimberley down to the Pilbara, so.

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MS TARRAGO: And you're a dad of seven kids?

MR BEDFORD: Yeah.

40 MS TARRAGO: And at the moment you have four in your care?

MR BEDFORD: Yeah, four in my care. One is in boarding school at the moment. She - it's her first year down there. So -

45 MS TARRAGO: And are you able to tell us, for those four that are living with you at the moment, what are their ages?



MR BEDFORD: The oldest is 13, 10, 8 and 6.

MS TARRAGO: And you've also got other family that are living with you as well?

5 MR BEDFORD: Yeah, I also have family that comes in and breezes in and out, and they're always welcome at my house. You know what it's like with family. So, yeah, they come in there occasionally, and then sometimes they overstay their stay, but I don't mind. You know, it's good to have family around.

10 MS TARRAGO: Yeah. And it's really important to have those family ties for everybody. Isn't that right?

15 MR BEDFORD: Yeah. My kids have to know who their family are and, like, we always got taught, you know, you've got to know who your family are and connections and values and all that sort of stuff.

MS TARRAGO: And so, of the four kids that are at home now, at the moment, two of your children have a diagnosed disability?

20 MR BEDFORD: Yes.

MS TARRAGO: And you've got big responsibility for your family as well, and part of culture, and that includes other family members who might have a disability?

25 MR BEDFORD: Yeah, it's - well, I think they all - I'm the sort of one who has taken it in and trying to help people. So, all the other family then sort of navigate or gravitated towards me because I'm sort of getting the idea and stuff of how everything works with it, and, you know. Just trying my hardest to understand my son but then also help other family members as well with whatever I can.

30 MS TARRAGO: And that's because, in community, Aboriginal people don't see disability the same way that the western community does?

35 MR BEDFORD: Yeah, that's exactly right. We just - we see the strengths that they have. We don't see the - they just, you know, I don't know how to explain it because we just see another kid, you know. And then nothing different to us. That kid might be a little bit different, but then we just work around the kid's specialist tries. You know, like, see they specialise in something. We just let them, you know. Encourage them along to keep going with it and - or support them in a way, the stuff that they like and, yeah, make them feel like  
40 a normal child, you know.

MS TARRAGO: Because you just see the person?

45 MR BEDFORD: Yeah, we don't see the disability. We just see a person - another person.

MS TARRAGO: And today I wanted to talk to you about your son Bubbaboy and - he lives with you. Can you tell me a little bit about him, the sort of things that he likes to do and how old he is?

5 MR BEDFORD: He's a 10-year-old now, but he's a pretty big boy. And the things he loves to do is he loves the iPad, which is unfortunate, but I guess it's something to keep him calm. But then he also loves being outdoors and being in the river, especially in that water. He don't - he loves that water. I don't know if that water - him and the water have their own special connection. He won't leave the water. The water won't leave him.

10 Yeah, he loves to be out on Country, and most of the time that's the only way I can get him off his iPad, because it's going to go flat out there and eventually he will wander off and start doing some other stuff.

15 MS TARRAGO: And you take the kids and family and other community members out bush with you?

MR BEDFORD: Yeah, all the time. Every - nearly every day I'll take the kids down the river, and 10 other kids will jump on while I'm making my way to the river, you know. Or then  
20 someone else, you're always bumping into family members down at the river anyway. So - yeah, I try and tire them out down there. And Bubbaboy loves it. He loves going to the river every day.

MS TARRAGO: So the Martuwarra has a very important role for Bunuba people and other  
25 people in the Valley?

MR BEDFORD: Yeah, yeah. That plays a big role, I think, in our - you know, that's our - that's our food source, you know. That's our - we drink out of the water - the river, and, you know, that's like our supermarket. We got everything in there. You know. Like our mental health  
30 stop, mental health service, you know. We got - yeah, you know, if we are going out on Country, you just - all the worries off you. No - no more stress thinking about stuff, you know.

MS TARRAGO: So that river is really a way for people connected to it to be healthy and have  
35 wellbeing?

MR BEDFORD: Yeah. Healthy wellbeing is - I think there's a whole lot of benefits of having to live alongside of that wonderful river of ours.

40 MS TARRAGO: Now, I just want to talk about Bubbaboy and how you came to learn about the NDIS. So, when were you told that Bubbaboy had a disability or he got a diagnosis?

MR BEDFORD: When he was about three years old. Yeah, he got diagnosed at three.

45 MS TARRAGO: And do you remember who told you?

MR BEDFORD: It was a kid doctor. Quite a while ago now.

MS TARRAGO: And did they come into Community, or did you have to go out to get that information?

5 MR BEDFORD: Well, they sort of let us know over the phone, I think, because we had to go for an appointment and they had to do all these assessments and stuff. And then we had to go home and then learnt over a phone call.

10 MS TARRAGO: And you explained a bit before about some of the things Bubbaboy likes. But could you tell me what are the best things about Bubbaboy?

15 MR BEDFORD: There's a lot of - a lot of good things about that boy. But I think the best thing is he's my son. And, yeah, he get - I got him, you know, and he keeps me going. I think that some of the best things about him, you get cuddles and stuff off him now and then. You rarely get them, so when they do come, you - probably one of the best moments you get with him.

MS TARRAGO: Yeah. So make you feel real proud, hey?

20 MR BEDFORD: Yeah, yeah. I feel, you know, like, that's like another booster for me to keep going again, you know, with him.

MS TARRAGO: Yeah.

25 MR BEDFORD: Keep trying.

MS TARRAGO: And how did you come to know about the NDIS?

30 MR BEDFORD: I think, working at a women's resource centre, Marninwarntikura, I - well, they sort of seen me as a - I could be a good worker to work with this disability stuff, and I sort of took the opportunity to learn more for Bubbaboy and then along the way NDIS, I found out about NDIS, and about my colleagues here, Lauren and Sue, everybody advocating for me. I think, yeah, I think it's just - I think NDIS found me because I was a single lad and didn't know where to go to look, you know, where to get help, but then that  
35 job come up and I thought that was I good opportunity and then, I think the word got out there and everyone wanted to help. So, yeah. Just taking all the help I can get now.

40 MS TARRAGO: Yeah. And so you learnt through your job and through people also helping you at Marnin. When did you actually sit down and put an application in there for Bubbaboy?

MR BEDFORD: 2020. So, only two years now.

45 MS TARRAGO: And was that in person or on the phone or on the internet? How did that happen?

MR BEDFORD: I think that happened over the - I think in person, seeing, I think, one of their little [REDACTED] come down, the first one I seen one them, the NDIS mob.

MS TARRAGO: Okay.

5

MR BEDFORD: Yeah.

MS TARRAGO: And was it good to have someone there in person to talk to?

10 MR BEDFORD: Well, yeah, because then they don't just hang up or don't try to put you on mute or whatever, you know. So that's WHY I prefer always to talk in person and - yeah.

MS TARRAGO: And that's not just something that you would prefer, but a lot of people in community, it's easier for them to sit down face-to-face to talk to someone, isn't it?

15

MR BEDFORD: Yeah, I think that's - in any sort of conversation, I think, with us Aboriginal people you got to go and talk to the person. You know, like, you don't know you who are talking to on the other end of that phone, especially with the old people and stuff, you know. Who are they talking to.

20

MS TARRAGO: And for yourself, did you think that you needed any interpreter or do you think community might need interpreters to sit down and have those yarns?

25 MR BEDFORD: Yeah, I think that there's a - there's a whole misunderstanding with the - for me I can sort of understand both ways, but for my people, you know, it's - it will be really, really hard for them because I can - I can understand most of the western ways, but, NDIS, I don't know.

30 MS TARRAGO: Yeah. And so that person come, and were they from Fitzroy Crossing? Were they from Broome? Do you know where that person came from?

MR BEDFORD: Derby. They just come from Derby.

MS TARRAGO: Okay.

35

MR BEDFORD: I think they was the head of the Kimberleys, I think, but their office was based in Derby.

MS TARRAGO: And how far is Derby from Fitzroy Crossing?

40

MR BEDFORD: 288 kilometres to be exact.

MS TARRAGO: So if you was driving, how long would that take you?

45 MR BEDFORD: Probably two-and-a-half hours, three?

MS TARRAGO: So that's a long way to go, especially if someone doesn't have a car.

MR BEDFORD: Well, even if I did have a car, it would probably still take, like, at least more than three hours, with Bubbaboy and his siblings in the car. I would have to pull over, kick the footy around with them - my son with ADHD, burn him out a bit and then also got  
5 Bubbaboy wanting to get to the next wi-fi destination. So, yeah it's not a usual - it's not just a trip down the road for me. It's bit of a hands-on vacation sort of thing.

MS TARRAGO: Yeah. So, even more important for there to be someone in person there in Fitzroy Crossing from the NDIS to talk about those things?  
10

MR BEDFORD: Yes.

MS TARRAGO: And now, after initially signing Bubbaboy up for the NDIS, how do you keep in touch with the NDIS?  
15

MR BEDFORD: Well, I'm - because I'm so busy with work and all that other sort of stuff, I - one of my work colleagues just dedicates her personal time for just to help me with all that sort of stuff, because I'm not a very bright person with the phone or computer or anything like that. So, yeah, I got a very - very good work colleague that helps me with all  
20 that stuff.

MS TARRAGO: Yeah. And - and so if you didn't have that help, would you have to email and phone someone?

MR BEDFORD: If I didn't have her help, I would probably - to tell you the truth, I would probably give up because I - you know, like, I wouldn't know where to go, what to do, you know. And I've just been living with Bubbaboy just day by day, you know. And I just thought that - when I heard something about, you've got to try something - you want something new, you've got to try something new. And I wanted something new for Bubbaboy and  
30 thought I would try this NDIS at that point. I think I'm still working - trying.

MS TARRAGO: Yeah. Yeah. And do you think many other people in the Valley might feel the same way if they didn't have that help that you get from your colleagues?

MR BEDFORD: I think most of the people that are on NDIS in the Valley are already gived - given up on them, because I would have, I reckon.  
35

MS TARRAGO: And do you think the NDIS understands what - the way of life for people in the Kimberley?  
40

MR BEDFORD: No.

MS TARRAGO: What sort of things do you think they don't understand?

MR BEDFORD: Well, for a start, they never even been to Fitzroy. They never spent a day there. And I heard something again, if you don't wake up there, you know, if you don't go to sleep there and don't wake up there, well, you don't know.  
45

MS TARRAGO: And so is that - is that difficult for someone who doesn't live in community to be able to connect from a long way away if they have never been there and don't know the way of life?

5

MR BEDFORD: Yes. That's just like you take me down to Perth and drop me off and tell me to go to Centrelink when I already know where the Centrelink is in Fitzroy, you know. Take someone out and just get them lost.

10 MS TARRAGO: Yeah. And do you think that that's another reason why people might not want to work with the NDIS or ask for help when they might need it?

15 MR BEDFORD: Well, when you ask for help, you want the person to be standing there in front of you, and you don't - what, you got to wait two weeks when you - after you ask for help, you're going to give up after two weeks. They still not there. NDIS still never came. You know what I mean.

MS TARRAGO: So before you said that Bubbaboy has a package for - and has been signed up on the NDIS two years. You know how much is in his package?

20

MR BEDFORD: I think about 60,000.

MS TARRAGO: And did someone explain to you how to use the package or access that information, like on a portal or anything?

25

MR BEDFORD: No.

MS TARRAGO: So you had to learn those things through yourself and asking other people for help?

30

MR BEDFORD: Well, through myself, my work colleague and me, like she's a - she's a really good person. She will dig into stuff and she will actually find it, you know.

MS TARRAGO: So I just want to ask some questions around the support services. So, before you were just saying, you know, they have got to come into Fitzroy Crossing from different places. And how much time do they generally spend with him?

35

MR BEDFORD: Like one hour or something, I'd say. Drive eight hours to do one hour a month. I think that's - I think the trip costs more than the session, I think, therapy session.

40

MS TARRAGO: How do you feel about that?

MR BEDFORD: Well, it's not fair that my son lives in Fitzroy and you've got another kid in Perth that, you know, can just go around the corner and - well, it's a bit unfair, I reckon.

45

MS TARRAGO: So if you had to leave Fitzroy Crossing to go and get those services just around the corner, like you say in Perth, that's it's easy access, what would it mean to be off Country?

5 MR BEDFORD: Well, I think it would be - it would be hard. Unfamiliar country, unfamiliar surroundings. And, you know, got to adapt, unfamiliar weather; all that sort of stuff, you know. It will be like - I don't know. You can't just walk into the neighbour's yard and stuff like that. It won't be the same.

10 MS TARRAGO: And would you have family if you had to move to somewhere like Perth just to access services?

MR BEDFORD: Well, the only time I have family is probably when they do come down for services anyway to Perth. So - yeah. I probably would but then it would be, like, they stay at  
15 my house for - they come down for - looking for services, probably too, you know, or some of them. Something that we don't have in the Kimberley, you know.

MS TARRAGO: But it's not like what you have now, where family is around you all the time, you can go bush whenever you want to.

20

MR BEDFORD: Well, yeah, you know, like family member, now, the family member they drive past the front of my house, the kids jump on, they going to the river, you know. I just get a message on my phone, "I got the kids in the river," you know. And Perth - what if someone - what if someone do that down in Perth? My kids are used to just seeing a car  
25 drive past with people they know, they usually jump on. What if that happens in Perth? That's a kidnap. I lose my kids.

MS TARRAGO: And -

30 MR BEDFORD: You know.

MS TARRAGO: - is that also - when you are living there in Fitzroy, being on Country, everyone looks after everybody?

35 MR BEDFORD: Well, even the Country looks after us, you know that. You know. Even the old people. They might be gone but they still looking after us, you know, they still got an eye on the kids. And - yeah.

MS TARRAGO: So you don't have that feeling if you have to move off Country? You don't  
40 have that support and that community that everyone look after everyone and the old people and Country looks after everybody as well?

MR BEDFORD: Yeah. Well, then like going to another country, that - that country probably don't know, you know, how we feel. It probably won't look after me, you know, and stuff  
45 like that. And - well, back up here, you know, people can - you can see the people looking at the kids. You go to the city, people looking through windows looking at it, you know, looking at you and stuff like that. You don't what you need in the city.

MS TARRAGO: And that's a long way - Fitzroy Crossing is a long way from Perth, isn't it?

MR BEDFORD: Yes.

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MS TARRAGO: So, it's not like it's down the road.

MR BEDFORD: Well, I am going to feel totally unsafe because I only got two hands and I've got four kids. How am I going to hold on to them in Perth? Bubbaboy is not going to hang onto my legs walking down the street.

10

MS TARRAGO: And because we were talking earlier about, you know, family breeze in now and again into your home or just into community, they might be travelling through, so you have responsibility in community as well, which is why you - it's - you have to really be connected to that and it's - it would be hard, if you had to move off Country, for family?

15

MR BEDFORD: Well, yeah, I - it is - it would be hard and then it would also be hard on my younger brothers and - you know, like all - I'm one of the oldest grandsons on my grandmother and she's a Stolen Generation, but she - we are trying to keep all - whatever she still has, the knowledge that she still has, we're trying to keep it going. And that's one - one of my - I think she put me in charge of all that stuff. I've got to teach my other brothers and, you know, I think it's like if my little brother steps out of line, you know, in culture, you know, if your little sister steps out of line, well, as a big sister you feel like you're not doing something right, you know, we didn't teach them right.

25

So, I also got that. I'm trying to teach my younger brother's kids also, you know, teach them what I know about the western world and all that sort of stuff too. And it's like a big - it's a - yeah, really big thing on me. And, yeah, so I'm sort of - yeah, I'm sort of - that's why I'm a busy man, I think.

30

MS TARRAGO: And so you wouldn't be able to do that if you had to move out of community and, like I was saying, to Perth, for example.

MR BEDFORD: Well, for example, if I say that - if I got to move to Perth and one of my little brothers get into trouble or something, if I phone them up on the phone booth, they can just hang that phone up on me. If I'm in person, you can't just hang your phone up on me then, you know.

35

MS TARRAGO: Yeah.

40

MR BEDFORD: And it's my job as an older brother to keep them in line and if they do step out of line with their parents, that's when I've got to - you know, that's part of my job as in the kin - in the kinship system and cultural system, you know. Everybody got a role, you know. And if I reckon - it's like the ecosystem. You move the crocodile, you know, the ecosystem will start going out of whack. You move the person that everyone listens to and stuff like that.

45



5 You know, like my younger brothers, they all listen to me and come to me for advice. You remove me, and what's going to happen to my little brothers. You know? And now I want - for me, I really think that I've got a good - I think that I'm a good person, and I'm hopeful that some of my little brothers will turn out like me, too. So, then we do have more people out there, like, you know.

MS TARRAGO: Yeah.

10 MR BEDFORD: Start the ripple effect then.

MS TARRAGO: And make that community strong.

15 MR BEDFORD: Yeah, well 10 men, you know, are worth more than one. So, I would rather empower 10 men than empower myself, because, you know, I would rather share my knowledge with 10 people than keep it all to myself. Then I know that I got - you know, I taught 10 good people and there is 10 more good people out there, you know.

20 MS TARRAGO: In the meantime, you've had some help from your colleagues and Marnin, and how important is it for you to have that in your life?

25 MR BEDFORD: Well, that's really important because my son's getting help, you know. And the main thing I want is for him to be independent, and I think the more help that we can get for him is another step forward for him, you know. Not about me; it's about him, I think. Not only him. It's about all our people that - many have been getting help from NDIS.

MS TARRAGO: And Marnin, they understand culture and family?

30 MR BEDFORD: Yes. That's - culture and family is, I think, part of the Marnin. And you know, it's a Woman's Resource Centre and what starts a family? Culture. Women. The holders of the - you know, yeah.

MS TARRAGO: And Marnin understands how you need support, how Bubbaboy might need support, so that you have the best life for you and your family?

35 MR BEDFORD: Yeah. I think - yeah, they - Marnin is all about family and, yeah, I think they all about helping the whole Valley and trying to - yeah, they teach everyone to look after their family and all that sort of stuff. I think Marnin is doing a really good job.

40 MS TARRAGO: And it's a community organisation, so it's run by people from the Fitzroy for people in the Fitzroy?

45 MR BEDFORD: Yeah. Well, Marnin is run by - CEO is the woman who grew up in Fitzroy. Grew up in, you know, seeing all this stuff. She - she had seen me grow up and, you know. And that's why I - that's one of the reasons why I trusted Marnin because they had people there that I knew and I'm familiar with, you know. It's like - yeah, it's like you - when you try to move me down to Perth and get me working for someone else, you know. It will take that time again for me to earn that trust and, you know, like whether I can trust this person or

not, you know, it's like a - but because I know the bosses and everyone that works at Marnin, I - I just felt, you know, I slipped straight there and I felt at home on the first day.

5 MS TARRAGO: And that's important for you and community to - to have that?

MR BEDFORD: Well, I think it is - yeah, that's the most important thing to have, connection with the community and your country, family ties and all that sort of stuff, you know. Cultural ties and you've got to have connections. You know.

10 MS TARRAGO: Now, I wanted to talk about respite. Have you been able to access respite for Bubbaboy?

15 MR BEDFORD: That's another thing. I would rather the money go towards his therapy and stuff than, you know, like - like I said earlier, it's about him and - like, if I got - if I don't have respite and he gets another therapy session, then that will be it. You know. Because I'm not going to go - like, use his money up for myself when he could have used that to, you know, have another therapy session. And, plus, there's - I don't think there's even enough money for that. So - yeah, it's complicated.

20 MS TARRAGO: Yeah. But if you had to access respite, is there respite in Fitzroy Crossing?

MR BEDFORD: No, you got to come out to Broome. And that's another. That's - I don't know why - I wouldn't trust that. Leaving him with someone I don't even know, you know. That's - I wouldn't - I wouldn't have respite if that's - that wouldn't even be respite. That will be a holiday for Bubbaboy but more stress on his dad because I don't trust that person that he's going to. I don't even know that person, you know, and my heart's higher than when he - you know.

25 As respite meant to be to - I don't know, meant to give the parents a break or something. But that don't - that's not a break for me. I wouldn't call that respite. I would call that admitting there --

30 MS TARRAGO: So, do you think the western understanding of respite is very different to what Aboriginal people might need for respite?

35 MR BEDFORD: I don't think they - I don't think they understand respite for us compared to respite for them. You know.

40 MS TARRAGO: So - for you, what would it look like? Would it be going bush and being able to be supported to do things like that, or what would it look like for you?

45 MR BEDFORD: Yeah, like, you know, something that I could probably just go spend a few - like a day - at least a night out on the river on, you know, like, just me and my girlfriend, and you know, just going out fishing. Be out on Country. That's - every time I get a break, that's what I'm doing. I'm hooking the boat up and I'm going out bush, you know. You won't see me for the - until - until I say I got to get the kids back or they say they are going to bring the kids back, you know.

5 So, I will - people like - like all the people that I know help me look after Bubbaboy, like my sisters and that's - you know, like - and that's another thing. I will only let them - I will only let Bubbaboy go to certain people that I know I feel comfortable with. I have to - like something inside me has to calm to let Bubbaboy go, you know. Like, I have to get that - earn that trust from that person, that - pass my knowledge on to know that that person knows what Bubbaboy is on about, you know. Like - yeah.

10 It's - I don't know. I got a - I have to feel good inside to have respite. Like, with people I trust and I know that will look after my son. If I'm going to send him to Broome that's not - yeah, I wouldn't - that's not respite. I probably just go and check in around the corner and just keep an eye out, you know. That's how - that's how bad I'd be. Like, if he was with my sisters I can, you know - like, I can go out fishing and switch my phone off, sort of thing.

15 Whereas if I've got to send him to Broome, I'm not going to switch my phone off. I'm going to go somewhere where I'm going to have reception so if something does happen. But then whereas if he's with my sister, if something does happen he's still in good hands, you know. So, yeah, respite - I don't know. I don't know what they call respite.

20 MS TARRAGO: And do you think that - sorry.

MR BEDFORD: They should call it wrist bite, bite me in the wrist every time.

25 MS TARRAGO: And do you think that the NDIS needs to understand the - the role of family and - and of that connected community in looking after one another? We were talking about it just before. But in - in the context of respite and support, the difference of having people from outside come in, do you think they understand that difference?

30 MR BEDFORD: No. They don't understand it. Because, yeah, I don't know. I - if you ask an NDIS person if he get that feeling that I just explained to you, but, you know, then they might understand, but I don't know if they do understand that. Respite is meant to be to give the parent a break. A break is more, you know.

35 MS TARRAGO: So, do you think the NDIS actually understands Aboriginal people, whether it's --

40 MR BEDFORD: They don't understand us at all. Like, they don't understand the kinship, culture, you know. Everything. They don't - they just - I don't know. They don't - yeah. No, they don't - they don't - yeah, they don't understand the life we live and - you know. If we switched lives, I think they might. But, yeah, I don't think anyone would want to look after Bubbaboy and Tooty.

45 MS TARRAGO: And from your experience, have you worked with any NDIS people that are Aboriginal?

MR BEDFORD: Every other race but not Aboriginal. Sorry to say that. But, you know, it's true.

MS TARRAGO: Do you think it would make a difference if they had Aboriginal people there working?

5 MR BEDFORD: Well, if they hired me and you, it would change everything; right?

MS TARRAGO: Yeah. I reckon so.

MR BEDFORD: It would change the whole structure of everything.

10

MS TARRAGO: Do you think they understand that in Aboriginal culture we also have men's and women's business and why that's important to our people?

15 MR BEDFORD: No, they don't understand that. They - they think we all under the same thing as them, you know. Yeah, that's - they wonder why us Aboriginal people most incarcerated people in the world because we got a - to look after our - you know, we got to live with the western cultures and ways, rules and then our rules, you know. So, yeah. They don't understand it, you know.

20 MS TARRAGO: What do you think they need to do to be right way for Aboriginal people and your family?

25 MR BEDFORD: Well, like I said before, you know, never too late to start listening, hey. Sit down, come - come sit down here with us, live with us in the community, you know. Come - and, you know, like, come and sit on the grass and have a cup of tea with us, you know. Instead of me going to your office and getting lost 10 times before I find the door and, you know. Come and - yeah, actually come and sit down and listen to us. You know.

30 MS TARRAGO: So, what message do you have for other Aboriginal people who might be experiencing the same things that you and your family have had to deal with? What message would you have for them?

35 MR BEDFORD: Well, my people, keep fighting. You know. Don't stop - don't - like, they - you know, never give up. Don't give up this. We got to keep fighting for our kids next generation, and hopefully we will be the people to change it for our next generation then. You know. I just keep - you've got to keep fighting until I get somewhere. Maybe keep talking - keep - keep talking too, so they then - they hearing us but we got to make them start listening. You know.

40 They can hear that noise in the background but then until they hear what that noise is, you know. I reckon us as Aboriginal people, yeah, we will keep - should keep fighting and trying to make it better for our people and - yeah.

45 MS TARRAGO: And what message would you have for government?

MR BEDFORD: Never too late to start listening. You know. Yeah. Never too late to start listening.

MS TARRAGO: Mudge, is there anything else that you wanted to say?

5 MR BEDFORD: I think there's a lot of things I would like to say but - I reckon that NDIS should - how they say, the National Disability Insurance Scheme, well, we all national, you know. How come we get treated different than someone down in the city? But it's a National Disability Scheme. You know. Should they change it to "city"? Because that's - yeah. I got to - I got to pay for my own flight to go down to Perth to get therapy for Bubbaboy, you know, but a person down in Perth, would you know. So, yeah.

10 MS TARRAGO: So, they treat remote and very remote communities differently from the city communities?

15 MR BEDFORD: Yeah but then they say they are national, you know. They say they cover all of Australia, but then you go under the rules of the city, you know. In the city, you got public transport and stuff. What we got up here? So, yeah.

20 MS TARRAGO: Thank you, Mudge. Really appreciate you sharing your experience and your life, and Bubbaboy's experience and his life.

**(Video ends)**

25 MS TARRAGO: Commissioners, Mudge also partook in a short interview about the Martuwarra Fitzroy River. Before we play that video, I would like to acknowledge the Martuwarra Fitzroy River Council and Stephanie King for their efforts in producing the short film, allowing the Commissioners to show it today. Operator, could you play doc ID MFRC.9999.0001.0001.

**(Video plays)**

30 MR BEDFORD: You just feel free at the river. Nothing to worry about. I try to get down as much as I can. Me and the cousins will go out nearly every day after work on the boat and just even have dinner down at the river. Just to be at the river, I think. It just takes all the worries off your shoulders, you know, and is a place to, I think, healing and you know, just bring you back down-to-earth and not worrying about anything else in town. And you just feel free at the river.

40 The old people used to teach us a lot, like you can cook fish in the paperbark trees. And some of the trees along the river, they're like medicine. When a certain tree is flowering, yeah, we know that the crocodiles are laying eggs and about to hatch and that. We are in a pretty bad drought now. I never seen this river quite - you know, this low before in my life. Usually the water a bit back up there. It used to be good all year round, you know.

45 You do farming around here, I think, yeah, most of the chemicals end up in the river. If you going to get the big pumps and, well, that's just taking more water. Well, for my kids, like, I want to see them see this river how I used to see it. You know. And not polluted and all that with all the farming and stuff. I reckon just leave our river alone, you know. It's home to

most of us. And we used to walk this river up and down, but I think with the farming they will stop all that, you know. Stop our kids from going hunting along the river and fishing.

One thing the old people used to tell us, you look after the river, the river look after you.

5 And, yeah, it will always - so we always had that thing about looking after the river, you know. Got to look after the Country, you know.

**Video ends)**

10 MS TARRAGO: Thank you, Commissioners. It takes us to the morning tea break. If we might adjourn until 12.20.

CHAIR: Yes, all right. Thank you. On behalf of the Commissioners, I too would like to express our appreciation to Mudge for speaking to Ms Tarrago and giving us the benefit of his  
15 experiences and his views about the operation of the NDIS in Fitzroy. We will take an adjournment now until 12.20 central time.

**<ADJOURNED 12:06 PM**

20 **<RESUMED 12:22 PM**

CHAIR: Yes, Ms Tarrago.

MS TARRAGO: Commissioners, we will now hear from Ronita Jackamarra and Topsy  
25 Jackamarra, who will be appearing, again, from Fitzroy Crossing. And they have both been administered the oath prior. And I understand that our connection has just been joined.

**<RONITA JACKAMARRA, CALLED**

30 **<TOPSY JACKAMARRA, CALLED**

MS TARRAGO: I will just check, is Ronita able to hear us?

35 RONITA JACKAMARRA: Yes.

MS TARRAGO: So, Ronita will be appearing off camera, and we will speak with - speak with Ronita first before we hear from Topsy, and her partner is there supporting her today.

CHAIR: Thank you. So, we will hear first from Ronita, but both for Ronita and Topsy, thank  
40 you for being prepared to come to the Royal Commission and to give evidence, and we have had the benefit of the statement from Topsy. Ms Tarrago, do we have a statement -

MS TARRAGO: So, in terms of Ronita - and I will get to that momentarily - there's a  
45 pre-recorded audio and there's some other aids.

CHAIR: Okay. Thank you.

MS TARRAGO: And there is a statement that Topsy has -

CHAIR: Yes. We have the statement from Topsy. So, thank you, Topsy, for your statement and thank you both very much for coming to the Royal Commission to give evidence. Just to explain where everybody is, in case you're not aware, we are, of course, in the hearing room in Alice Springs, and on my left is Commissioner Mason, and on my right is Commissioner McEwin. We are the three Commissioners who are responsible for the conduct of this particular hearing. And, of course, Ms Tarrago is in the Alice Springs hearing room with us. So, Ms Tarrago.

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**<EXAMINATION BY MS TARRAGO**

MS TARRAGO: Ronita, you are a Yawuru woman?

15 RONITA JACKAMARRA: Yes.

MS TARRAGO: And you live in Fitzroy Crossing?

20 RONITA JACKAMARRA: Yes.

MS TARRAGO: And you work on radio as an announcer?

RONITA JACKAMARRA: Yes.

25 MS TARRAGO: And you have been doing that role as a radio announcer for a long time now.

RONITA JACKAMARRA: Yes.

MS TARRAGO: And you're the longest serving staff member for Wangki radio.

30

RONITA JACKAMARRA: Yes.

MS TARRAGO: We've got a recording of some of the work that you've done, and it's an interview that you conducted with a community member about her grandson who lived with a disability. Operator, can we hear the recording doc ID IND.0168.0001.0013.

35

**(Audio plays)**

RONITA JACKAMARRA: What would you see change in Fitzroy?

40

SELENA: Good question.

SPEAKER: For your grandson?

45 SELENA: For my grandson?

RONITA JACKAMARRA: Yeah.

SELENA: More support for him with his hearing problem and maybe better teacher in the school that understand Auslan. And we need support in learning how to learn Auslan. And we haven't got that here. So, people who - with, like, NDIS, wherever the support comes  
5 from, they need to have a really good look at kids because it's not just my grandson. There's heaps of young kids that has disability with being deaf.

RONITA JACKAMARRA: Okay. Is hard for to you find - to use that NDIS?

10 SELENA: Sort of, because we don't really know what the programs and what - how it helps Aboriginal people. But I'm sure there is an office in Marra Worra that deals - or wherever, maybe Marnin or Marra Worra or whoever is running NDIS in this Valley, they need to come and sit with families and really explain what is NDIS and what does it mean to the families and how it helps - how it helps the families to get services and to help our young people in  
15 this town who has a disability.

SPEAKER: -- plan?

SELENA: I don't think so.

20 RONITA JACKAMARRA: Do - do you think we need to get another bus or another car support to take - to pick up clients?

SELENA: Well, we we've got a hack here. I don't know, Far North, so all those services are  
25 there but how do people get to them? How do they know what's the thing about - how do you work with families from remote communities, Aboriginal communities and how do you - and how do they let people know what do they do in this town?

RONITA JACKAMARRA: Okay. Well thank you Selena.

30 **(Audio ends)**

MS TARRAGO: Ronita, on 29 April this year, I came to see you in Fitzroy Crossing and we had  
35 a yarn about what's been happening for you. Do you remember that?

RONITA JACKAMARRA: Yes.

MS TARRAGO: I will ask the operator to play the recording of our conversation. And that's  
40 doc ID IND.0168.0002.0001.

**(Audio plays)**

MS TARRAGO: Hey, Ronita, we're here today. You're here with Avelina and we have been  
45 having a yarn about a hoist that would help you for the house. Can you tell me about what troubles you have been having for it?



RONITA JACKAMARRA: I'm waiting for things to come over the border. And - and there's one part just came last week, and they opened it up and they tried to put it together, but they found out there was a part missing.

5 MS TARRAGO: So, does that mean now that there's a delay?

RONITA JACKAMARRA: Yeah.

MS TARRAGO: And you - how are you feeling about having to wait?

10

RONITA JACKAMARRA: I can't wait too long. It's stressful. Yeah.

MS TARRAGO: And what about your wheelchair? Have you been waiting for a new wheelchair too?

15

RONITA JACKAMARRA: Yeah. So long.

MS TARRAGO: Do you know how long? Years? Months?

20 RONITA JACKAMARRA: Years, I think years. I don't know, I think it was years.

MS TARRAGO: And the wheelchair that you have at the moment, I think you were just saying before, like, it's nearly ready to go.

25 RONITA JACKAMARRA: Yeah. It's - yeah, can't last long.

MS TARRAGO: Because what would that mean if you didn't have a wheelchair? Would it be really difficult for to you get around?

30 RONITA JACKAMARRA: Yeah, I can't - yeah, that is really - yeah, it is true.

MS TARRAGO: And is there another hoist as well that you've been waiting for? To maybe help you in and out of the car?

35 RONITA JACKAMARRA: Yeah.

MS TARRAGO: And you're waiting on that one too, hey?

RONITA JACKAMARRA: Yeah, still coming over from overseas. But I don't know.

40

MS TARRAGO: You've been waiting months, years for that one?

RONITA JACKAMARRA: Two years?

45 MS TARRAGO: Two years. So, there's a couple of -

RONITA JACKAMARRA: Three years.

MS TARRAGO: Three? Yeah. So, it's a long time that you've been waiting for a few things that's going to make your life a lot easier, hey?

5 RONITA JACKAMARRA: Yeah. So, what other one?

MS TARRAGO: So, Ronita, we were just having a yarn about what transportation that there is, and you've been a couple of different places - in Broome and other places that have a lot of services, but not so much here in the Valley. What sort of things do they have in Broome, for example, for transport?

RONITA JACKAMARRA: Like, they have, like, more wheelchair buses and more - more things in and around that place, like, for supports in that place. Yeah.

15 MS TARRAGO: To get around and access your supports and get around different places?

RONITA JACKAMARRA: Yeah. Yeah.

MS TARRAGO: What about respite, to go access respite?

20

RONITA JACKAMARRA: It's pretty hard. Well, for me, I had to find my own respite.

MS TARRAGO: Did you?

25 RONITA JACKAMARRA: And place - respite place.

MS TARRAGO: Where did you end up having to go for respite?

RONITA JACKAMARRA: Out - Broome.

30

MS TARRAGO: So that's a long way from the Valley, hey?

RONITA JACKAMARRA: Yeah.

35 MS TARRAGO: How long is that drive between here and Broome?

RONITA JACKAMARRA: 400.

MS TARRAGO: Kilometres?

40

RONITA JACKAMARRA: Yeah.

MS TARRAGO: So, four hours. A long time, hey.

45 RONITA JACKAMARRA: Yeah.

MS TARRAGO: Yeah. So, if - if you've got no transport in Fitzroy Crossing, you have to wait for someone to maybe come down from Broome to pick you up?

5 RONITA JACKAMARRA: My mum drives me over.

MS TARRAGO: Yeah.

10 RONITA JACKAMARRA: But - she took me in a lower bit of a car, where I can, like, put a little bit of support on my legs. Yeah.

MS TARRAGO: But, normally, is her car a bit bigger and that's why you need the hoist to help you in and out of it?

15 RONITA JACKAMARRA: Yeah, now it's high.

MS TARRAGO: Yeah. So, it makes it hard, hey, without the hoist?

RONITA JACKAMARRA: Yeah.

20 MS TARRAGO: When was the last time you had respite?

RONITA JACKAMARRA: Just, say, about a month ago.

**(Audio ends)**

25 MS TARRAGO: Ronita, since we spoke in April, are you still waiting on both the car and home hoist and a new wheelchair?

30 RONITA JACKAMARRA: Yes.

MS TARRAGO: And last week did you have some problems with your wheelchair?

RONITA JACKAMARRA: Yes.

35 MS TARRAGO: Would you be able to tell the Commissioners what happened?

RONITA JACKAMARRA: My tyre came off. The big one.

40 MS TARRAGO: And did it take a little while for you to find - somehow find a solution to that?

RONITA JACKAMARRA: Yes. An hour.

MS TARRAGO: And did that affect you getting to work?

45 RONITA JACKAMARRA: Oh, I was there.

MS TARRAGO: Okay, so - sorry.

RONITA JACKAMARRA: I was there already when it happened. It came off at the workplace.

MS TARRAGO: Okay. Now, the NDIS bosses will be listening today.

5

RONITA JACKAMARRA: Yes.

MS TARRAGO: Is there anything that you would like to tell them about what's been troubling you?

10

RONITA JACKAMARRA: Yes.

MS TARRAGO: And what would you like to say?

15

RONITA JACKAMARRA: Waiting for this tyre so long and having to get a tyre off my son's bike to put on here to help me get into the studio and toilet. Yeah. I was in there one hour stuck in the toilet.

MS TARRAGO: And so you really need to have your wheelchair replaced.

20

RONITA JACKAMARRA: Yes. The seat is about to rip on the one I'm using.

MS TARRAGO: And is there anything else at the moment that's troubling you?

25

RONITA JACKAMARRA: Getting around - around this town and got - this tyre is about to break. I'm trying to get to places.

MS TARRAGO: Thank you, Ronita. Commissioners, did you have any questions for Ronita?

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CHAIR: Commissioner Mason?

COMMISSIONER MASON: No, thank you, Chair.

CHAIR: Commissioner McEwin?

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COMMISSIONER McEWIN: No, thank you.

CHAIR: No. Well, thank you very much indeed, Ronita, for your evidence. We very much appreciate that you were prepared to talk with Ms Tarrago and to provide the information that you have today, to which we have listened very carefully. Thank you so much. Yes, Ms Tarrago.

40

MS TARRAGO: Thank you. We will now have an opportunity to speak with Topsy, who you can see on screen. Topsy is Ronita's mum, and she's supported by her partner Marty today. I will just check in if Ronita needed any opportunity to have support or whether she would like to stay in the room as well?

45

RONITA JACKAMARRA: Yeah.

MS TARRAGO: Okay. Yes. Good. And, Topsy, you have already taken an oath prior to this?

5 TOPSY JACKAMARRA: Yes, I have.

MS TARRAGO: And you're Ronita's mum?

10 TOPSY JACKAMARRA: Yes, I'm Ronita's mum and carer. So Ronita is my oldest daughter. Her biological father is deceased, and my partner and I have six other adult children and 14 grand children as well.

MS TARRAGO: And three of those grandchildren are also Ronita's children?

15 TOPSY JACKAMARRA: They are. I support Ronita with caring for them as well. Three of them - they're all boys. Their ages are 8, 9 and 10. They have a range of medical and mental health issues, and they're all on medication as well. So a part of my daily routine is administrating medication to the boys and caring for Ronita.

20 MS TARRAGO: And you also work as well?

TOPSY JACKAMARRA: And I also work full-time. Yes.

25 MS TARRAGO: Yes. Topsy, prior to the NDIS, Ronita had been receiving some supports through the State Disability Services. Can you share with the Commissioners what it was like in terms of supports back then?

30 TOPSY JACKAMARRA: Before the NDIS, I found it much easier to get supports for Ronita on the basis that they were based locally in Fitzroy, central in town. They were based out of the IGA where communities and people all come to do shopping. It was like a meeting place. So, it was easy for people to just pop into the Disability Service Commission Office and seek support from there. So, in the days that they were supporting us, they used to do face-to-face home visits, just to check on - check in on us and used to arrange meetings with other families with disabilities, family members, to get together and discuss issues.

35 And also they used to provide activities for people with the disabilities to keep them occupied. And one other thing that they did was advertise locally for support workers, and that was just by putting notices up around notice boards around town, where anyone could see that this family or certain families need support. So, that was some of the things that I have sort of - could say about disabilities. They have also supported us with extending our - our home.

40 So they have supported with building a bedroom with a toilet and shower specifically for Ronita and ramps out the front and back doors so she can get outside and get around - out and around the house. We didn't have much trees then, so they were also extended our veranda so she had a bit of a place to go outside and sit when she was quite young.

MS TARRAGO: So there was a lot more accessibility back then in terms of a community presence and more sense of community in terms of people being able to come together to discuss issues in the disability community.

5 TOPSY JACKAMARRA: Yeah, that's right. I think being based on the ground, locally in town, in Fitzroy, where people can see the service, access the service, was a big benefit for us, having their presence.

MS TARRAGO: And what has been the most beneficial from that previous scheme? What  
10 was the most beneficial thing for Ronita?

TOPSY JACKAMARRA: That was being on the ground, faster service, having that regular contact, face-to-face contact, just checking in, was really supportive when they were - yeah, when they were around at that time.

15 MS TARRAGO: So just touching on the face-to-face contact, is it important to members of the Fitzroy Valley community to know who they're working with and establish a relationship with that person?

20 TOPSY JACKAMARRA: I think it is important to maintain contact because – because Aboriginal people, they like to know that that person is always going to be there for them. Not just a one - one-time visit and they're gone. They like to know who that person is so if any issues come up, they can go back to that person or that place and seek support for their issues.

25 MS TARRAGO: Is that connected to maybe experiences where there's issues of trust or accountability?

TOPSY JACKAMARRA: I think both, yeah.

30 MS TARRAGO: And when was it that Ronita first applied for the NDIS?

TOPSY JACKAMARRA: I believe that she applied in 2018.

35 MS TARRAGO: And how did Ronita or both of you come to learn about the scheme?

TOPSY JACKAMARRA: I don't recall - remember a lot about how Ronita became an NDIS participant. All I knew at the time was maybe she was transferred over from Disability Services when that closed down. I was - I had a lot of concerns at the start because I didn't  
40 know anything about the service and how they were going support Ronita and myself in regards to services and supports. So, yeah, I was a bit concerned how that was going to work.

MS TARRAGO: And do you remember if the NDIS, they had physically come into Fitzroy  
45 Crossing?

TOPSY JACKAMARRA: I can honestly say that I have only had one face-to-face contact with them. This was in 2020 at Karrayili at a review meeting for Ronita, and I'm not aware of them - even if they have come here, I wasn't aware that they have come into town because of no notifications.

5

MS TARRAGO: Is there any presence in Fitzroy Crossing of the NDIA?

TOPSY JACKAMARRA: In the past, there wasn't any but now just recently Marra Worra has developed a position which has a project coordinator - NDIS project coordinator based there, so it's a new service. So, yeah, that's on the ground as now. It's a bit too early to comment on how that's working because it's only quite new.

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MS TARRAGO: And Marra Worra is one of the community organisations that's in Fitzroy Crossing?

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TOPSY JACKAMARRA: That's correct.

MS TARRAGO: And what do they generally do as far as the work that they deliver?

TOPSY JACKAMARRA: So, they've got a range of different types of work that they do. My partner works for them, so he's a supervisor for the CDP program. They look after the community housing, and they've got the new service, the NDIS project happening there as well.

20

MS TARRAGO: So you've got this community organisation, but do you think that the NDIA should have its own physical presence in Fitzroy Crossing?

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TOPSY JACKAMARRA: I feel that it should be a separate identity from where it is, because it needs to be visual. It needs to be there where people can see it, not in an organisation that, you know, certain people don't actually go to that organisation. So, therefore, I believe that it should be central, visual, people can see what it is. You know, if they don't know, they will ask, "What's this place? What's it for?" That sort of thing. Yeah.

30

MS TARRAGO: And is there - from a practical sense, is there a place in Fitzroy Crossing where that could happen?

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TOPSY JACKAMARRA: Well, at the time that I've provided my statement, there was a vacant - vacant building office at the IGA complex, so, yeah, that would have been the ideal place, being there where people come to meet - come to town to do their shopping. There's the post office there. There's the Centrelink there. There's the Department of Community office there and the - yeah small takeaway shop. So, that would be the ideal place.

40

MS TARRAGO: So back when you first became involved in the NDIS in terms of Ronita signing up and being allocated a plan, did you understand back then what the NDIS was about?

45

TOPSY JACKAMARRA: Not at the start. The first time I found out about the NDIS was when Ronita came home one day with a copy of one of her plans and that's - I looked at it and I didn't understand it at that time. Yeah.

5 MS TARRAGO: Did Ronita understand it at that time?

TOPSY JACKAMARRA: No. I don't - I don't think she - she did. She was just given it and she brought it to me and wanted me to help her understand it. But I couldn't understand it myself.

10

MS TARRAGO: And did anyone sit down and explain it?

TOPSY JACKAMARRA: No, not that I can recall. Nobody explained it to us. I know that Fitzroy did have a information session. NDIS came to town and provided an NDIS information session, but at the time, we had missed that because we weren't aware that it was happening and we found out after it was finished that it occurred. So, we missed out, that opportunity.

15

MS TARRAGO: And do you think that the NDIS is easy for people in the Fitzroy Valley to understand?

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TOPSY JACKAMARRA: I think it's quite difficult. Just being a community member, it's - and I'm getting, like, people coming up and going - they don't understand their plan. For one. They don't understand who to contact, or who is responsible. It's not really clear, and they get confused because there's - you know, you got a support coordinator, then you got the plan manager, then you've got the NDIA. You know, there's three different lots of people here. That's the confusing bit. Who do they contact, who is responsible for what. In one of my review meetings, I bought that up and I go, "We need to discuss whose responsible because when we ask one service, they say, 'Go to the other service'". So we've been getting

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MS TARRAGO: And have you experienced any other difficulties or, you know, observe difficulties by other community members accessing the NDIS? So are there community members that don't have access to phone or internet or interpreters?

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TOPSY JACKAMARRA: Yeah, there's - there's a lot of - so I've - I can recall a community that's about 120km out of town, with the NDIS client on it. So, the family member had come up to me and said, that he - he didn't understand his plan and that they needed support to support the family member that they were caring for out there. They didn't know who to contact and - and any of this. So, yeah, just - a lot of difficulties from other family - individuals in the community as well. Not just for me.

40

Recently, I've - just through my work, I've just picked up a new - an Aboriginal male who was caring for his 21-year-old son who has a disability, and I just asked him, "Is there any services supporting you with your son?" And he said, "No, I've been doing it all by myself." And his son doesn't have a voice, and I think there might be some hearing problems as well. So therefore I referred him over to Marra Worra to be assessed for some supports. So

45



there's people out there still not even being provided a service with because they're still - yeah - needing to be picked up and assessed.

5 MS TARRAGO: And what about now? Has your understanding of the NDIS improved or even just in relation to Ronita's plan in particular?

10 TOPSY JACKAMARRA: Well, I can understand that - now looking at it, that there is some goals and them goals need to be reviewed - reviewed. But according to all the wordings, I - I struggle to understand a lot of the wordings on the plan. I'm - you know, I'm pretty well educated, but I struggle. What more other Aboriginal people in community and English being their second or third language, you know, and - so, yes.

15 MS TARRAGO: And do you know, in terms of Ronita's plan and looking at it, do you know how the money can be used and what the purpose of each of the supports are?

20 TOPSY JACKAMARRA: Well, I can see that there's - in her plan there's some transport money, which doesn't go very far, because when she goes on respite to Broome, Broome is 400km away. So, a lot of that funding is used up, you know, just about in one trip. And then, therefore - I think this happened last year, where she went on respite and then we were told by Far North that there was no funds left for her to get to work. So, she - therefore she had to find her own way to work because she took that respite.

25 MS TARRAGO: And so do you think the NDIA needs to understand those distances and build that into a plan for participants in those remote areas?

30 TOPSY JACKAMARRA: I think so, because Fitzroy Crossing, we have 30-plus Aboriginal communities in the Fitzroy Valley and the outlying communities, and the distance from town - the furthest community is about two hours' drive. Noonkanbah Community. So, you know, they got to take into consideration the distance when we're talking about transporting - you know, bring participants into town to access services or treatments or whatever they need to come in for.

35 MS TARRAGO: And so, just talking about those distances, so what services does Ronita have to access and how far do they come from?

40 TOPSY JACKAMARRA: So the services Ronita accesses, she gets transport. There is one service in town. That's the Far North Community Services. So, they provide transport for her to and from work to Wangki radio station. They provide occupational therapist, and they also provide a physiotherapy service. And she used to get to see them once a month, but at the moment it's gotten a bit better, so we are having regular contact with them through fortnightly visits or contact through emails and phone calls.

45 MS TARRAGO: We heard just earlier that Ronita's been having trouble accessing a hoist for the house and the car and also a replacement wheelchair. Have you had any dealings with the - that process and do you know how long those have been delayed?

TOPSY JACKAMARRA: Yes. So, back in 2020 when we had the review meeting at Karrayili, I - I've found some information about a car hoist that could help us. So, I took that to the review meeting, and we actually thought that was put in the plan back then. And we kept waiting and waiting on the hoist to - to arrive. Because it was getting quite difficult for me to lift Ronita in and out of our car. I was starting to get unwell due to having an issue with myopathy, which is a muscle weakness.

And I kind of - I see my doctor to provide a support letter to try to hurry up the hoist and hoping that was going to work for us. But obviously it didn't. The hoist did come, but then we found out there was a delay because one of the parts were missing. So we had to wait further for that to arrive back. This is the car hoist I'm talking about. And then it arrived in - I think June 21st, we got the car hoist.

The OT came into town, trained us how to use it, so me and Marty was both trained, and then we returned to work, and they took Ronita for a ride in the - in the car and while they were getting her out of the car, the hoist broke. So they could not leave the hoist with us. They had to take it back to Broome because it was unsafe to use. So, that was the hoist - the car hoist.

In regards to the home hoist, the - we got that a while ago. So that was sitting in Far North office from April. So no one knew how to put it - put it together because the OT at the time - they were getting a new OT, so they didn't have any OT at the time, Far North. And then when the new OT started, she came to town, put it together, brought it around to my home and we realised that the home hoist couldn't fit down the passage because the legs on the hoist was too long to turn.

So - and we also tried to fit it under Ronita's bed, and it couldn't fit under the bed as well. So, that hoist is sitting at my place not being used at this stage. The OT said that she needed to order a commode so we can lift - use the hoist to lift Ronita into the commode and then wheel her down to the passage. That commode turned up last week with no seat.

MS TARRAGO: So constant delays and -

TOPSY JACKAMARRA: Constant.

MS TARRAGO: And issues.

TOPSY JACKAMARRA: Yeah.

MS TARRAGO: What happened about the wheelchair?

TOPSY JACKAMARRA: The wheelchair, that's one of the biggest issues we - which is ongoing. We always got trouble with Ronita's wheelchair. The bearings pop out. The wheels fall off. We struggle to fix them. We do have a - with the work that we can't do, we usually take it to the mechanics but, you know, that's a four hour or longer - sometimes longer waiting for them to have time to fix it between fixing up cars. So, Ronita has to sit on a bed and wait.

And sometimes we go out of our way to try and fix it ourselves, and some of the things that we did was I've seen one - one week I was driving to work, and I seen an old wheelchair on the side of the road, and - and I drove past it and then the week later Ronita's wheelchair stuffed up. So, I went back there to look for this chair, and it was gone. So, I drive around the community to look for it, and then the last point was to go to the rubbish tip.

So, I went out to the tip, and I found it on top of the rubbish, this chair that we - was exactly like Ronita's that we could have used the parts. So we got that wheelchair down off the pile of rubbish. I took it back home. I have given it to Far North to get them to fix up the chair. So, they took it. They came back with Ronita's chair fixed and they also kept the other parts to fix other people's chairs up in the community.

MS TARRAGO: But is that the solution that you would expect under the scheme?

TOPSY JACKAMARRA: No. Not at all.

MS TARRAGO: What difference would it make to have these things in Ronita's life? To have a car hoist, a home hoist, a commode and a wheelchair.

TOPSY JACKAMARRA: It will make a big difference to her life and our lives. Ronita hasn't been on holiday for quite a while now. Or the whole family hasn't because of - you know, we can't get her in and out of our car. She doesn't attend any family funerals, which is not good, and she doesn't go to visit family in other towns. She's always remains in Fitzroy. So, yeah, it will make a big difference, and it also make a difference, you know, in regards to my health as well. So - and it will - you know, be less stressful on us.

MS TARRAGO: So, I'm going to ask the operator to bring up a video or two videos. The first, operator, if you could display doc ID IND.0164.0002.0002.

**(Video plays)**

**(Video stopped)**

MS TARRAGO: And, operator, if you could also display doc ID IND.0164.0002.0003.

**(Video plays)**

**(Video stopped)**

MS TARRAGO: So just for the benefit of the transcript, we just viewed a video of - Topsy, of you transferring Ronita from her wheelchair into your vehicle, which is a four-wheel drive-style vehicle which is higher off the ground, and you also having to load the wheelchair into the back of your vehicle. So, in terms of our discussion earlier of the car hoist, will that remove you having to physically transfer Ronita into your car?

TOPSY JACKAMARRA: Yes, certainly.

MS TARRAGO: And so that would also impact on your health as well?

TOPSY JACKAMARRA: Yes. Yes.

5 MS TARRAGO: Would it make a difference if you had been living a larger city or town, as opposed to in Fitzroy Crossing? Do you think that other communities in larger towns are treated differently?

10 TOPSY JACKAMARRA: I think so. Because there's more opportunity for them to, you know, access other services, more services. Can, you know, get parts, get parts and access buses as well. So, yeah, living in a remote place, we just got limited services. We only have a - a hardware shop that we could go to buy bike tyres, but they're not always there when we need them.

15 MS TARRAGO: And should you have to leave your community to access those things?

TOPSY JACKAMARRA: No. I don't believe we should. We should be - we should be able to have the same things that other places have. Just because we are a remote place doesn't mean we need to be left behind.

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MS TARRAGO: And do you feel that the NDIS is flexible for Ronita or for other people in the Fitzroy Valley?

25 TOPSY JACKAMARRA: No, I don't think so, in regards to families supporting. So, family's always there for their loved ones, and they do all the caring. They do all the supports for them. So, I don't think NDIS is flexible around having family get paid for the work that they do and yet they can pay strangers to come - come out and do the same work and get paid.

30 MS TARRAGO: Do you feel like the NDIA understands Ronita or First Nations people?

TOPSY JACKAMARRA: No, I don't. I don't think people understands our environment we live in and how hard it is, living in remote places with limited services and limited supports. We always struggle. And I can just imagine the outlying communities, how hard it is for them as well, not having anything out there. The Far North services only cater for 30K radius around Fitzroy, but, like I said, we got communities further out that's missing out on a service.

35 MS TARRAGO: And there's also other barriers that exist in the Valley as well in terms of housing and accessibility. Are they things that trouble you as well?

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TOPSY JACKAMARRA: Yeah, I think also overcrowding issues as well. So there's not enough housing. There's, yeah, just wait lists for housing everywhere.

45 MS TARRAGO: So in terms of housing and Ronita's experience, what happens when it floods in Fitzroy Crossing and she's staying at her house?

TOPSY JACKAMARRA: So one year the floodwaters came right up to her front door. So, she had to have sandbags around her front door. She couldn't get out. We had to go there in a four-wheel drive because the waters was halfway up our tyres. So if she had to get out of there, she would have been under the - basically sitting in water up to her waist in the wheelchair. And for her to get from her place to my place, she needs to go all the way around town on the higher ground to get there because the shortcut is bit of a ditch, a bit of a ditch area where floodwaters flood and come right up to her property.

MS TARRAGO: And how often does it flood in Fitzroy Crossing?

TOPSY JACKAMARRA: Once - once a year, it would flood. Sometime it's - we'll get a really big flood

MS TARRAGO: And are there crocs - crocodiles?

TOPSY JACKAMARRA: Yes, we've got a lot of freshwater crocs in the Fitzroy River.

MS TARRAGO: So, it's not really a safe environment to be stuck in a flood in a wheelchair that doesn't work?

TOPSY JACKAMARRA: No. No.

MS TARRAGO: If you could tell the big bosses of the NDIA your thoughts, what would you tell them?

TOPSY JACKAMARRA: I would tell them that NDIS needs to make some changes to make it more culturally and more appropriate for Aboriginal people and, you know, just - it's not working for us. Look what - look what I'm going through. And I'm just one individual. One family here. What about everyone else in this community? You know, I'm struggling with all this, so, yeah, changes need to be made. Better changes. And community need to be more consulted with in regards to what they - what might work for them in regards to having family support and being paid and things like that.

We need to also, you know, think about the distance - like I said, the distance that people need to travel to access services. That all needs to change. Yeah, a lot of our mob is not even getting a service, like I said before.

MS TARRAGO: And do you think that people in the Fitzroy Valley, local people, have local solutions?

TOPSY JACKAMARRA: I think so. My partner knew the issue with Ronita, so in regards to getting to work. So, one - one day Ronita said, "I need to get myself to work." And I said, "well what's happening with the bus?" And she said, "Well, the bus has gone to Broome to take people for respite." So, when that happens, the whole town comes to a standstill. So, my partner said, "Well, you know, I'm happy to put my hand up and I want to try and support NDIS with transport."

5 So he was thinking about going into a business to provide a service. He approached Far North to be subcontracting with them, but they didn't appear to be interested. So, he went to Perth, and he attended an office in Perth. And he went to speak to the person at the front desk and he said - he asked what does he need to do to be a registered service provider. And the person at the desk said, "I don't know. It's my first day on the job."

10 And he said, "Well, can I speak to your manager?" And he said, "Well, I am the manager." He didn't get anywhere that day. But he has - he went to the extent of getting himself an ABN number, but the barriers for him is just too hard to get over. So, there is people in our community who want to help, but struggle.

MS TARRAGO: And so, there there's also a large administrative burden on those people as well?

15 TOPSY JACKAMARRA: Yes, it is. Yes.

MS TARRAGO: Topsy, if you had a message for other Aboriginal people who might be listening or Torres Strait Islander people who might be listening, would you like to share any message for them?

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TOPSY JACKAMARRA: I would just like to say that we all have our own stories, and we all need to stand together to be strong, to support each other for change in this area, which is a big need, because it's not working. Not working for us. Not working for our mob.

25 MS TARRAGO: Is there anything else that you would like to tell the Commissioners?

TOPSY JACKAMARRA: Yeah, I just - I feel proud that I could stand here and speak up for my people. And hopefully my story can have a bit of an impact on - on change.

30 MS TARRAGO: Thank you. Commissioners.

CHAIR: Thank you, Topsy. You have been there and speaking up for your people, and that's one of the functions of the Royal Commission, and it's a privilege for us to give people that opportunity and to see it taken advantage of. Thank you. If you don't mind, I will ask my colleagues as to whether they have any questions for you, and I will start with Commissioner Mason?

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COMMISSIONER MASON: Thank you, Topsy, for your evidence today. And thank you, Marty, for being there as well and for your daughter to be there. You are a family and so we appreciate the work that you've done to prepare for today to give your evidence. We've heard a lot about family and the importance of family in communities, in Aboriginal and Torres Strait Islander communities, and that sometimes that's not understood.

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We have also heard how things need to be understood at a local level and at a family level, and that family is really integral in supporting our family members who have a disability. And in your statement, to me, paragraph 71 and 72 really emphasise the ripple effect of people letting down a person with disabilities as well as their family, because you talk about

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something that you were suffering with last year around muscle weakness, and you had to spend time in hospital, very stressed.

5 It really was debilitating even to the point of not being able to keep your own car and having to get a different car. Not being able to take Ronita to funerals because you didn't have the equipment to lift her. Trips to Darwin, interstate, not able to take your family and see your family because you weren't able to have the hoist. And there's this ripple effect that happens and it accumulates, and it accumulates when those solutions that are promised don't get delivered.

10 And I just want to say a really big thank you for laying it all out for myself and also my colleagues because it's really given a very clear example of the - a simple process of ordering equipment through an OT, and yet, in a remote area, the golden rule in delivering equipment into a remote area is that it must be robust and it must be durable over a much longer period than being in the city, because the services to maintain and repair are often not there in the community.

20 So, the equipment got to be really durable. So, these are, like, the number one rules working and living in remote areas. So, yeah, you get a hoist that's broken on its first go, wheelchairs not being maintained, commode, parts missing. It's like you are ordering from an overseas business and you are waiting in the post for something that, you know, you are just hoping it works. And we're talking about a system that is supposed to be operating in Australia and in a remote community.

25 These - these are small but very important decisions for wellbeing and for proper help within a remote community. So, I'm sure people across Australia listening to your evidence today are in no way now under any misconception around how things work at a family level, at a community level from your evidence today. So, I just want to say thank you. Thank you very much. It's been a privilege. And as a grandmother - grandmothers are - they are the glue in community.

30 Grandfathers are the glue in the community. And, you know, listening to you and others today, it's like listening to expert panels. You know, you've got so much lived experience but, you know, Aboriginal and Torres Strait Islander people are always problem solvers. Always looking for the way to make the way through, and that's what, you know, you've told us today around the problem solving. Going to the tip to find a - a wheelchair so that it can be used as a toolkit for your daughter's wheelchair. I mean, this is what happens. So, thank you very much.

40 TOPSY JACKAMARRA: Yes. Thank you.

CHAIR: Thank you, Commissioner Mason. But don't write-off the grandfathers, please. Commissioner McEwin?

45 COMMISSIONER McEWIN: No questions. I too want to add my thanks and appreciation to all of you for your very compelling story and experiences. Thank you.

CHAIR: Topsy, I just had a couple of questions about the plan. We have in the documents that have been put together for the purposes of the hearing the plan for 2020 to 2021. Actually, May 2020 to May 2021. The total provided was \$101,000. That appears in tab 41 of the bundle volume C. And then if we go to tabs 54 and 55 - you don't need to worry about the tab numbers - we see that, of that amount, only 57,000 was spent. Do you know why only 57,000 out of the 101,000 was spent in 2021?

TOPSY JACKAMARRA: Yes. At the time, COVID was one issue. So, we were a bit scared on Ronita leaving the community, leaving Fitzroy, because COVID was around at that time. And also the other issue was that my family was on sorry side, so there was a death in my family. My brother had passed away in Broome and that was the other issue.

MS TARRAGO: Thank you for that. The plan that is currently in force appears behind tab 52. And it's in operation from October 2021 to October 2023. And it provides for a total during that period of \$248,000. When we look at the amount that has been expended between October 2021 and the end of February 2022, there is only \$18,000 that's been spent out of that \$248,000. So, that's only a - that's a - only a proportion of the amount that one might have expected to be spent. I'm just wondering if you know the reason why the expenditure is below what you would expect?

TOPSY JACKAMARRA: Yeah, Ronita has been requesting respite for quite a while and through Far North, but their bus hasn't been able to take her. So, they haven't been able to support in that area. We have a lack of services in town as well. And just at the moment - Ronita used to have a cleaner who used to help clean her home. When COVID started, they left cleaning for Ronita to go to the schools to do the cleaning. So, that sort of took that service away from her getting that service from them as well.

CHAIR: The plan provided some money for assistive technology. Has that arrived for Ronita, do you know?

TOPSY JACKAMARRA: Well, I don't really know what that word means.

CHAIR: I see.

TOPSY JACKAMARRA: So, this is one of the issues that I spoke about in the plan, that these big words is really hard for us to understand.

CHAIR: Okay. I understand that. And just one more question. There is provision for a support coordinator. Do you know who the support coordinator is?

TOPSY JACKAMARRA: Yeah. I - we know the support coordinator, he's - he sits in Perth, which is over 2,500km away, I believe. Something like that. We - we haven't seen him for about, what, approximately two years now. But he does ring up on - on the phone and - and contact us through phone.

CHAIR: Does he help with the delays that you've referred to concerning the wheelchair and so on?



TOPSY JACKAMARRA: Well, Ronita contacts him as well and so do I in regards to this. He tries to support but we're still not getting anywhere. Even with that support.

5 CHAIR: All right. Thank you very much. Again, I repeat what Commissioner Mason and Commissioner McEwin have said. We very much appreciate the very clear and straightforward and frank way in which you have explained the experiences that you have had and that Ronita has had. Thank you very much.

10 TOPSY JACKAMARRA: Thank you.

**<THE WITNESSES WITHDREW**

CHAIR: Ms Tarrago, do we now adjourn for a well-earned lunch?

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MS TARRAGO: Yes, Chair, to 2.25 pm central time.

CHAIR: You're being very tough. All right. We will adjourn until 2.25.

20 **<ADJOURNED 1:26 PM**

**<RESUMED 2:25 PM**

CHAIR: Yes, Ms Tarrago.

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MS TARRAGO: Commissioners, our next witness is Jazsukah, who appears on screen. Jazsukah's two sons have pseudonyms: Big Fella for her elder son and Little Fella for her younger son. That's pseudonym direct, CTH-DNP-00136. Jazsukah has already been administered the oath.

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**<JAZSIKAH, CALLED**

CHAIR: Thank you very much. Jazsukah, thank you for being prepared to come and give evidence to the Royal Commission, and I know that you have had a previous engagement with the Royal Commission through a video recording. So thank you very much for the contribution you have made, and we look forward to hearing your evidence today. I would just like to make sure you know where everybody is. I'm in the Alice Springs hearing room. On my left is Commissioner Mason. On my right is Commissioner McEwin. And Ms Tarrago, who I will ask you some questions, is also in the Alice Springs hearing room. So, I will now ask Ms Tarrago to ask you some questions.

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**<EXAMINATION BY MS TARRAGO**

MS TARRAGO: Jazsukah, today you are appearing from Broome?

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JAZSIKAH: Yes.

MS TARRAGO: On 8 June this year, do you remember speaking with me about the experiences of you and your family?

JAZSIKAH: Yes, I do.

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MS TARRAGO: And during those conversations, are the things that you told me true and correct?

JAZSIKAH: Yes, they are.

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MS TARRAGO: Thank you. Operator, can you please play the pre-recorded video statement, Doc ID IND.0173.0004.0001.

**(Video plays)**

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MS TARRAGO: Thanks for joining me today, Jazsika. We are going to talk about the experiences that you have had and that your sons have had with the NDIS. And the things that you're going to speak about today, are they your experiences?

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JAZSIKAH: Yes.

MS TARRAGO: And what you say is the truth, to the best of your knowledge and belief?

JAZSIKAH: Yes.

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MS TARRAGO: Jazsika, who are your mob?

JAZSIKAH: I'm from Broome originally, so my mob is all the Yaruwu and Nyamba Buru people.

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MS TARRAGO: And you're currently living on your partner's homelands?

JAZSIKAH: Yes.

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MS TARRAGO: And you have two children together?

JAZSIKAH: Yes, we do.

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MS TARRAGO: And who are his mob, if you don't mind me asking?

JAZSIKAH: His mob are Gooniyandi, Walmajarri and Bunuba.

MS TARRAGO: And with your two sons, how old are they?

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JAZSIKAH: My oldest is 5 in October, and my baby is 4 in December.

MS TARRAGO: And your boys have got a disability?

JAZSIKAH: Yes. [REDACTED] has been diagnosed with autism and [REDACTED] has been diagnosed with GDD and is showing traits - signs of autism and ADHD.

5 MS TARRAGO: And when did you find out about their diagnosis?

JAZSIKAH: I would say [REDACTED], I found out roughly two years ago when I noticed he wasn't like the other kids his age. He wasn't talking or communicating with me and my partner. And then [REDACTED], we noticed his - yeah, same time, around two years ago.

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MS TARRAGO: Okay. And can you tell me a little bit about your sons and what they like to do?

JAZSIKAH: Yeah, well, my oldest son, he is - he likes to play by himself, but he does - he's very independent. He's very smart. If he can't do something or something is stuck or tangled, he knows how to untangle it and how to unstuck it, and he finds another way around the obvious. So, yeah, he's - he's his own little - little person.

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MS TARRAGO: Thank you for sharing that. And what about your Little Fella?

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JAZSIKAH: [REDACTED], he's always on the go. He's always running. He's always jumping. He's always climbing. But he's very loving and he's always kissing and hugging me and his father. So - yeah, he's - yeah, they are both their own little persons. You wouldn't put them any other way.

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MS TARRAGO: So, Jazsika, can you tell me a little bit about the boys' relationship with their siblings?

JAZSIKAH: Yes. So, my two sons, they have two older brothers and an older sister. So, my oldest son has a very good bond with the two oldest brothers, which, you know, shows him and teaches him all of the, you know, Indigenous and cultural ways that things need to be done. You know, fishing or hunting. And then, you know, my baby, he has a connection with his older sister, you know, where she loves swimming and fishing. So he follows her fishing and swimming and, you know, collecting all the -- we call them freshwater mussels here. It's a teaching and learning process for them.

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MS TARRAGO: And so it would be really hard if they had to move for services and couldn't be near their siblings?

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JAZSIKAH: Yes. They actually get physically sick. So when they went to spend time with their mother, the older ones, yeah, [REDACTED], they weren't feeling very well. So.

MS TARRAGO: So, really important to keep family together?

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JAZSIKAH: Yes.

MS TARRAGO: And so, living on Country, that's something that's important for you, for --

JAZSIKAH: For me, my partner and my kids. They - they can understand and communicate with their grandparents in their language and Kriol. So every time we go fishing - so they call the water Ngaba. So they say that, Ngaba. And, you know, for turkey when we go shooting, they say Galamura. So they are making the turkey signs and the language itself. So even when we are fishing [REDACTED] knows to get - my oldest knows to get the fishing bag and the bucket.

And even when we go shooting and we've got something, he knows that - he jumps out and he helps me drag it over to where the fire is and helps me prepare, plucking or skinning of whatever we catch. So it's important to us to show them that, instead of just putting them in front of a TV or giving them a phone just so that they can just go sit in a corner and kind of just not irritate anybody.

MS TARRAGO: And so you're really highlighting their abilities and what they can do and what they enjoy doing, which is being with family and out on Country?

JAZSIKAH: Yes.

MS TARRAGO: And so they speak language. How do they communicate ordinarily? Is it in language and a mix with other things?

JAZSIKAH: Well, with my oldest, he - we've been implementing a lot of sign languages at home, and he's been learning them at school as well. So, you know, he does a lot for the bush animals, and he does a sign for turkey, kangaroo. And, yeah, "thank you" and "more". So he's - he's got that. And then when we're kind of out in his element, you know, he's talking his language, you know, he's - his mind is like always going, going, going, going. It's just - yeah. You have to see it to kind of understand it, the difference, yeah.

MS TARRAGO: Yeah. And if you wouldn't mind telling me about yourself. So you are currently working and studying?

JAZSIKAH: Yes. I - my studies are on hold at the moment, until I find a suitable kind of moment where I can put the baby in daycare, because at the moment, it's - yeah, it's kind of expensive with only one income because my partner's not working at the moment.

MS TARRAGO: And, in the future, you hope to be a financial counsellor?

JAZSIKAH: Yes. That is one of my aspects to get through to doing.

MS TARRAGO: And you've got a really strong passion for helping community work through some financial literacy and things like that?

JAZSIKAH: Yes. I do.

MS TARRAGO: So, Jazsika, I just want to talk a little bit about the NDIS and how you came to know about them. Do you remember when you first heard about the NDIS?

JAZSIKAH: Yes. I first heard about it from my mother saying - you know, because I had told her my concerns about my oldest child and she said, you know, get him assessed and then, you know, get them to refer you to NDIS and all of that. And then I kind of didn't want to believe he had - there was something wrong with him. So until NDIS actually came to Fitzroy Crossing and kind of more or less promoted NDIS or kind of make a presence that they are in the Kimberleys, and that they are there for help. And so -

MS TARRAGO: And so they then came into community?

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JAZSIKAH: Yes.

MS TARRAGO: And did you have a sit-down with anyone at that time?

JAZSIKAH: Yes, I actually made contact with one of the mob that came over. And so they kind of linked up with the girls at Marninwarntikura here. And so, yeah, Cheyenne gave me a call and said, you know, they want to meet up and - because I think that's when we actually got a diagnosis from the paediatrician that he had GDD, and then, yeah, from there we had the interview and, yeah.

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MS TARRAGO: And do you remember whether it was a man or a woman that you sat down with and how that fit in culturally for you?

JAZSIKAH: Well, it was - at first, it was two ladies and - and a man that came promoting NDIS, and then when I went and done the plan, the planning was with a man itself.

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MS TARRAGO: And how did you feel about that, sitting down with a man talking?

JAZSIKAH: I didn't feel comfortable. That's why I invited my partner with me to come - to do the plan.

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MS TARRAGO: And would you have needed any interpreters, or your partner needed any interpreters to come with you? Or is it on the first time when they first came in or that plan that you were just talking about?

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JAZSIKAH: Not in the first instance, because I'm pretty good with mainstream English and mainstream society itself. But if it was for someone that doesn't have the schooling or the literacy and numeracy skills that I have, they would not have understood any of the words that they were talking about.

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MS TARRAGO: So do you think interpreters would have been needed for other community members who might have struggled to understand?

JAZSIKAH: Yes, and - and probably a presence of an Indigenous worker.

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MS TARRAGO: And what difference does it make to have an Indigenous worker there?

5 JAZSIKAH: It's - it's more of a connection. When you are sitting down with a non-Indigenous person, you know, you really feel threatened. You know, you have to kind of - that's why a lot of people just say, "Yes, yes, yes." While, you know, if it was an Indigenous person, like a liaison officer that was there, you would have felt more comfortable, and it would have been less daunting on you.

MS TARRAGO: So it - you know, you would be able to get a bit more engagement between community and the NDIS if you had an Indigenous worker there?

10 JAZSIKAH: Yes.

MS TARRAGO: And from that first time that there was a physical presence of NDIS in Fitzroy, do you remember where that was? Like, where did they have that sit down?

15 JAZSIKAH: So they came and sat with me here at the early child learning centre, and I think they went out to other communities, and they also went to the adult learning centre here in the town.

MS TARRAGO: And are they places that are easily accessible in community?

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JAZSIKAH: It depends on, because there's 39 little communities around Fitzroy Crossing. So, you know, not really knowing that someone's here to help you with your child that may have these disabilities, like, if you live 120ks out on a dirt road, you wouldn't have any idea that they were here.

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MS TARRAGO: Yeah. Can I ask about the plan that you were talking about. Did you understand the plan when you were given it?

30 JAZSIKAH: Not at first. And I still don't know. I just kind of understand that they are there for those certain supports. But kind of I don't understand what can come under those supports and what can be considered as, you know, therapy or things to help my children be where they need to be.

MS TARRAGO: Yeah. And so do you access a portal?

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JAZSIKAH: Yes, I do.

MS TARRAGO: And is that easy to understand?

40 JAZSIKAH: The portal is very easy for me. The plan managers are very good with sending me statements and invoices. So I look at the invoices before they get paid. So I approve them before they get paid. So it's a good system like that for me to understand, but for other people, I don't, yeah, probably think that they would understand.

45 MS TARRAGO: Yeah. And do all people in Fitzroy Crossing have access to the internet for example?

JAZSIKAH: No, not a lot of people. Not a lot of people do.

MS TARRAGO: And just looking at those invoices that you said you've been approving, is there a lot of information for you to understand how things are calculated?

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JAZSIKAH: Yeah, I - I understand that side of it, and I understand - because it's very detailed on the plan managers that I use. It's, like, really cut down and broken down to where all the money is going. So it's good.

10 MS TARRAGO: That's good. And what about when you need to contact the NDIS? How do you normally do that?

JAZSIKAH: I normally just ring the office.

15 MS TARRAGO: And do you speak with any Aboriginal staff at all, or you don't -

JAZSIKAH: Every time I've called - I've probably called like three times and, yeah, it's not a lot of Indigenous people.

20 MS TARRAGO: And so do you think they understand you or what it's like in community?

JAZSIKAH: They would probably understand a person like me, but, yeah, like I said before, someone that doesn't have the schooling that I've had, they probably wouldn't have understood them, and they wouldn't have understood the NDIS.

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MS TARRAGO: Yeah. And do you think it would be important to have a physical office in Fitzroy Crossing?

JAZSIKAH: Yes. A physical anything, actually, in Fitzroy Crossing.

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MS TARRAGO: And why is that? Is face-to-face better for community?

JAZSIKAH: Well, I can speak for myself. I relate to people more physically, because then I can read their body language. I can see what they're feeling. You know, if they respond negative or positive to what I'm saying then I know, you know, them as a character.

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MS TARRAGO: And do you think that's a similar experience for other people in community?

JAZSIKAH: Yes, I do. Because all Indigenous people - well, most Indigenous people I know are visual people. You know, you put a piece of paper in front of them with words on it, they wouldn't understand what is being - what they're talking about. And if you come in - if someone was to come in with a big graph and a big board and came in person, to break down and answer the questions that people may have, then, you know, a lot of Indigenous people would understand.

45

MS TARRAGO: Jazsukah, I want to ask you some questions about services. Are there any local support services in Fitzroy Crossing?

JAZSIKAH: None whatsoever. There is a presence of Far North Community Services. It's pretty much just two support workers now. There used to be a beautiful lady that used to work there. She no longer works here now. Yeah, she would always keep me updated with  
5 whatever is coming up, or, you know, things like that. Even the community itself, you know, doesn't really have, you know, a presence in the community for kids with disabilities or, you know, it's - yeah, there is no services whatsoever.

MS TARRAGO: Have you turned to any other local services like Marnin, that you mentioned  
10 before, who might provide different types of supports?

JAZSIKAH: So, I do. I see Marnin here for the support workers that they have on the ground. So, they let me know when there - the therapists are coming. So, they came out every three weeks for, like, an hour and a half. So, you know, both my sons do therapy an hour and a  
15 half that day. And then they kind of drop off for three weeks and then they're back again. So, it's like - it makes a difference, but then it doesn't really, because it's not a consistent, you know, week-by-week or every fortnight. It's every three weeks.

MS TARRAGO: And did COVID sort of interrupt that for a while?  
20

JAZSIKAH: It has, actually. We - we didn't receive any services for over a month, maybe two months because of COVID.

MS TARRAGO: And what effect did that have on your boys?  
25

JAZSIKAH: Probably therapeutically because of the - what they were doing. The - because I do everything repetitive anyway, so whatever the therapists do with them in that session, I kind of implement that at home for those three weeks. So, for myself, I can say my - my kids don't really drop off as much as other kids probably would.  
30

MS TARRAGO: Yeah. And would it be important for you to have local services as opposed to people coming from outside community?

JAZSIKAH: It would be better for local services, yes. Because they would have an  
35 understanding on how we live and, you know, what we face day to day or, you know, monthly or seasonally. You know, it's just - yeah, just NDIS just doesn't understand what it's like to live remotely or on a dirt road that can be blocked off by water or by flood. You know, or even the shopping prices here that can affect the way our children eat.

MS TARRAGO: And just talking about floods, it happens quite often during wet season that the whole town is even cut off. Is that right?  
40

JAZSIKAH: Yeah, well, I live 30 Ks out, so when it floods, we - I don't - we don't have access to anything for two weeks.  
45

MS TARRAGO: And at the moment, where are services coming in from to support you and your boys?



JAZSIKAH: So, we've got our services coming from Broome. So we've got Far North and Patches coming in from Broome every three weeks.

5 MS TARRAGO: And how long does it take to drive from Broome to - to you?

JAZSIKAH: Well, if I'm in town, that's 397 Ks. If I was out at home, that would be four hundred and probably thirty.

10 MS TARRAGO: So it's quite a distance and time for someone to come into community, and I would imagine going into Broome, for example, it would probably take a little bit longer if you had to have breaks.

JAZSIKAH: Yes.

15 MS TARRAGO: I want to talk a little bit about respite. What does respite look to you? Like, if you could have it in a perfect situation for you and your boys, what would it look like?

20 JAZSIKAH: Some rest for me, yeah. I've inquired about respite. There isn't anything that's in the vicinity of Fitzroy Crossing or in Broome. And just - even here in Fitzroy, you know, even when I'm at work, the respite, it would be nice just to have someone to take the kids for two hours so I can clean, you know, the house properly or, you know, do the whole load of washing that's sitting in the laundry. You know, it doesn't have to be about me all the time but -

25 MS TARRAGO: And what about local respite for the boys? What kind of activities do you think they would like to do?

30 JAZSIKAH: Well, anything to do with being outdoors. They hate being indoors. They - yeah, we couldn't - we could never, ever close them up inside. We have always got them outside. So, you know, we have always - we've bought the swing set, we've bought the jungle gym and, you know, the see saws. That all came out of our pocket so they can keep - stay in their yard. But, yeah, they still tend to go to the neighbour's house or --

35 MS TARRAGO: And so if you had to leave your home now to move closer to services or closer to more regular respite, what effect would that have on you and the kids, to be away from Country?

40 JAZSIKAH: It - it will have a big impact because even when we go to Broome to see my family, they hate it. They hate being in the car for the four hours of travelling just to go see my family. And it's just - they don't like change. They don't like new. So, it's just - it's very hard for them to be away from something they've always known, or people they've always known. So -

45 MS TARRAGO: And what about if, for example, you had to go to somewhere like Perth? Would that be even more different for them?

JAZSIKAH: Yes.

MS TARRAGO: And how do you think they would go in the city?

5 JAZSIKAH: Well, they have - both of my boys have sensory issues. So, you know, some of  
them - both of them don't like very bright lights or very loud noises. So, being in the city  
that's always busy, so always bright, always loud, I don't know how they would go for  
themselves. Or even the plane ride there. Wouldn't - I wouldn't know how they would  
10 respond, you know, to the cabin pressure on the plane or the turbulence. So, yeah, not  
going to drive down there. That was 26 hours.

MS TARRAGO: And so living and being out bush and on Country is - do you see that as part  
of their health and wellbeing?

15 JAZSIKAH: Yes. Because they were raised here, okay. So, they've had that automatic  
connection anyway. They - they know when it's cold weather, they know the plants, the  
water, you know. The dirt, you know. It's like an unseen connection that you just can't really  
explain unless you actually sit and you pay attention to how they respond to the changes,  
20 you know, the seasonal changes or to the changes in anything. That's just so norm to them.

MS TARRAGO: And the Martuwurra has got a really significant meaning for people in the  
Fitzroy region?

25 JAZSIKAH: Yeah, it does.

MS TARRAGO: And is that some of the connection that you are talking about, it's to places  
and ceremony and all of those things being interconnected?

30 JAZSIKAH: Yes.

MS TARRAGO: Do you think that the NDIS is flexible?

35 JAZSIKAH: Myself, I've asked for certain things and they've responded to me saying that  
does not cover - or that does not come under this - you know, what - the funding. So I've  
had to go out and purchase a wi-fi so that I can, you know, receive emails or liaise with the  
therapists or the support coordinators when I'm locked off or even when I'm not reachable,  
when I don't go to work. So, where I live it's not a lot of reception out there.

40 MS TARRAGO: So, those sorts of things are really important for you to be able to  
communicate properly for your boys. And do you think the NDIS is culturally appropriate for  
you and your sons?

45 JAZSIKAH: Not really, because I don't think they understand much about culture or how a  
child with autism connects to culture and tradition. Because I don't think it's really seen  
much or heard of much for someone with, you know, a disability to be on Country, to be in  
that element where they feel normal.

MS TARRAGO: And is that cultural learning, that's really important not only for Aboriginal people but for non-Indigenous people to learn?

5 JAZSIKAH: Yes. I would say so. Being, you know, the oldest, you know, people in the world at the moment, you know, you kind of have to learn about it to understand it. So, you have to educate yourself first before you can, you know, understand another person's culture.

**(Video ends)**

10 MS TARRAGO: Jazsukah, if you could tell the NDIA your views today, what would you tell them?

15 JAZSIKAH: Well, I would tell them to come out and see for yourself, the struggle that we have with having no services for children with my - that has disabilities like my kids. Or, you know, the understanding of what it's like to live in a remote community with the limited services.

20 MS TARRAGO: And if you could design what the NDIS looked like, would you have any ideas that you would be happy to share?

25 JAZSIKAH: I would get some Indigenous people in there. Get them out along with your mob when they come. You know, it's like - it's more better to connect and understand the - what NDIA is coming to a community for if, you know, if you have an Indigenous person to - you know, not advise but mediate

MS TARRAGO: And if they were to come out to community, how long should that be for?

30 JAZSIKAH: Instead of coming for like two or three days, maybe come for a week. You know, like, have more of a welcoming thing, you know. Have a barbecue and put more flyers out and, you know, encourage outside communities to come into the town. Or if they go to the communities, you know, like have a barbecue at the hall. You know, and put things up around and kind of make - like, promote themselves and why they are there.

35 MS TARRAGO: And would you expect them to create a base there or would they be fly-in fly-out?

JAZSIKAH: It would be good, because of Fitzroy because of the surrounding communities, if they did have an office there.

40 MS TARRAGO: And does that go back to what you were saying about being able to read someone's body language and knowing them?

JAZSIKAH: Yes.

45 MS TARRAGO: And for the First Nations people who might be listening, do you have any message for them, if they've had the same experience as you and your family?

JAZSIKAH: Just don't be ashamed. Because when it comes to your kids, they are your next generation. They're the ones that have to follow in your footsteps, and then they lead the next generation.

5 MS TARRAGO: Is there anything else that you wish to tell the Commissioners today?

JAZSIKAH: I don't know. It's just - yeah, it's difficult to say the things that I want to say. Yeah, it's just -

10 MS TARRAGO: Thank you, Chair.

CHAIR: Jazsika, I know it's difficult to say the things you want to say, but you have told us a lot.

15 JAZSIKAH: Thank you.

CHAIR: I will ask the other Commissioners if they have any questions for you, and I will ask Commissioner Mason first.

20 COMMISSIONER MASON: Yeah, thank you, Chair. Thank you, Jazsika, for your evidence today. Are your boys - your oldest is 5 in October, and your baby is 4 in December. So these important learning years are happening now, as well as school and what happens inside the school gate. What's your preparation in supporting your children in your local community in their learning and ensuring that they have an inclusive education there in your local school?  
25 What are you doing now or what are you thinking about?

JAZSIKAH: Well, with the school, I've given them the reports of my oldest son's autism. So I have actually also got in touch with the therapist to see if they can come into his classroom and offer his teacher their teaching techniques or their therapy techniques to help with my  
30 oldest son's education.

COMMISSIONER MASON: And has the school been open to these ideas or you are still to talk to them about it?

35 JAZSIKAH: Yes, they have. They're just actually searching for funding and searching for a special needs teacher to actually come in and work at the school with my son.

COMMISSIONER MASON: And do you talk to other parents in the community who have children with disability and who will be going to that school, or have you spoken to parents  
40 who are already there and what their experiences are, if they have children with disability?

JAZSIKAH: Yeah. Well, a lot of families or a lot - it's mainly all the mothers that come up to me and ask me to help them understand what the NDIS means for their child. And, you know, where services that they can go to or who they can get in contact with and, yeah, it's  
45 kind of - I've kind of been the go-to person about -

COMMISSIONER MASON: So, the other parents want to maximise the time their children are in school, and they're asking you about what supports are available to make that a really rich experience?

5 JAZSIKAH: Yes.

COMMISSIONER MASON: Fantastic. Thank you very much.

CHAIR: Thank you. Commissioner McEwin?

10

COMMISSIONER McEWIN: Thank you. Jazsika, thank you for your evidence. I have one question. When your boys were diagnosed with, in particular, autism, what information or what kind of information or support were you referred to or were you given contacts about where you might get information?

15

JAZSIKAH: The NDIS fella that did the interview for my oldest son, he gave me a link to click on to and to read through. Because I've never - I have only heard of autism from my mother. And, culturally, we don't really pick up on disabilities in our children unless it's physical, where we can see, you know, face-on, but when it comes to behavioural or neurological stuff, that all lying underneath stuff, we - I had no idea. I read about it, and you know, asked

20

COMMISSIONER McEWIN: Thank you.

25 CHAIR: Jazsika, in 2021-2022, that is, from July to July this year, just now, was - how much of the - what proportion of the NDIS plan was actually spent? Was there any money left over or was it all spent?

JAZSIKAH: It's - not even half of it was spent. Not even a quarter of it was spent.

30

CHAIR: And why was there so much unspent?

JAZSIKAH: Because the lack of services. And -

35 CHAIR: Sorry, what would you have liked to be able to spend money on for the boys?

JAZSIKAH: Consistent services. Consistent therapies. Instead of coming out every three weeks just for an hour or an hour and a half, and then you come and bill me over \$2,000, just for an hour, an hour and a half - like, why, when you didn't really do much.

40

CHAIR: And the plan provided, did it, for much more intensive therapy for the boys than, in fact, they received?

JAZSIKAH: Yes. Because of their disabilities, they took that into consideration on early intervention to help them get ready for school. So I think that's why they gave them such a large amount.

45

CHAIR: And there had not been the services available that allow you and the boys to undertake that preparation for school?

5 JAZSIKAH: Yeah. They didn't take into consideration of what services were firstly in Fitzroy, to designate that such amount.

CHAIR: Do you have any ideas as to why the NDIA would be unaware of these difficulties at the time they approved the plan? They are fairly obvious, aren't they?

10 JAZSIKAH: Yeah, they are obvious if they were - if they did their research. If they actually had a presence in the community first and to understand - you know, like go out and see the networks in the community, you know, what is there first.

CHAIR: And what happens to the unspent money? Do you know?

15

JAZSIKAH: Well, I just did a rollover of both of my children's NDIS plans. They extended it for two years. And I did make it very clear - of the person that did the reviews, like, what is he going to spend it on? There's no services here for three weeks.

20 CHAIR: So, in effect, you have been able to carry over the unspent money for the next period?

25 JAZSIKAH: Yes. I have even inquired - I've even asked them for a support worker in that three weeks gap to, you know - to take them and, you know, teach them things and they said that I wasn't - they weren't equipped for it. There's no money in the funding for a support worker.

30 CHAIR: Yes. I see. Thank you very much, Jazsukah. That's been very, very helpful. Thank you for giving evidence today, and thank you also for participating in the session with Ms Tarrago in June. Thank you so much.

JAZSIKAH: Thank you.

**<THE WITNESS WITHDREW**

35

CHAIR: Shall we adjourn now for a short period, or shall we go straight on?

MS TARRAGO: We can move straight on, Chair.

40 CHAIR: That's fine. Let us move straight on.

45 MS TARRAGO: Thank you, Chair. Commissioner, we will next hear from Marninwarntikura Women's Resource Centre, and we will be hearing from the Chief Executive Officer, Emily Carter, and Lauren Rice, who is the research fellow and works at the Marulu team at Marninwarntikura. Both will be giving evidence at the Marninwarntikura office in Fitzroy Crossing. Emily and Lauren have prepared a joint statement that's dated 20 June this year, and the statement can be found at Hearing Bundle A, tab 63. Annexures to the statement

can be found at Hearing Bundle A, tabs 64 to 76. And both witnesses will take an affirmation.

5 CHAIR: Yes, thank you very much. Ms Carter, Dr Rice, thank you very much for the statement that you have jointly prepared, which we have read with care. It's a very detailed statement. Thank you. And thank you for being prepared to give evidence today to the Royal Commission. I would just like to explain where - you probably know, but where everybody is, just to be clear. We are in the Alice Springs hearing room where Ms Tarrago has just introduced you. On my left is Commissioner Mason. On my right is Commissioner  
10 McEwin. We are the three Commissioners who are responsible for the conduct of this hearing, which happens to be designated as Public hearing 24.

15 I will be grateful, then, if you would follow the instructions of my associate, who will administer - I think it's the affirmations in each case? The affirmations. Thank you.

**<LAUREN RICE, AFFIRMED**

**<EMILY CARTER, AFFIRMED**

20 CHAIR: Thank you very much. Now Ms Tarrago will ask you some questions.

**<EXAMINATION BY MS TARRAGO**

25 MS TARRAGO: Thank you, Chair. Emily, you are a proud Gooniyandi-Kija woman from the Central Kimberley region in Western Australia. Could you tell the Commissioners about your background and experience?

30 MS CARTER: Okay. Yes. Firstly, I want to acknowledge the Bunuba people on which land that we live and work here in Fitzroy Crossing. Yes, I am a Kija-Gooniyandi woman from the Central Kimberley. I come from Stolen Generation parents. My mother was taken from the Fitzroy Valley, and my father was taken from the East Kimberley from a community called Violet Valley, which is part of Wuggubun community. So, I haven't - I wasn't brought up in a very cultural environment but certainly I do - coming back to work and live in Fitzroy Crossing in '94 has immersed me back into my mother's language group.  
35

40 My life has been one of working - when I started working as a 16-year-old for the Department Community Welfare in 1975 in which, at that time was - we were just almost at the end of the White Australia policy, when Indigenous people was able to go back on Country and start to be excited about living on their traditional lands, which here in the Kimberley was known as the Homeland Movement. And government believed that Aboriginal people could make a future for themselves, and we as Aboriginal people certainly thought that we could make a future as well.

45 So here in the Fitzroy Valley, we have about 36 indigenous community communities. They range from very big communities to very small communities. And I worked in welfare for a very, very long time. I grew up in the Department of Community Welfare from 16 to 33 until I moved here to Fitzroy Crossing. So what I've seen over the years, amongst our Indigenous

people, has been one of optimism around building their futures and then having all of those things taken away from them. So where we are today is around our people having to wait for services to be delivered to them when they can get those services. Which is a far cry from self-determination, by the way. When that was the whole point of Homeland Movements.

MS TARRAGO: And you're the Chief Executive Officer of Marninwarntikura Women's Resource Centre?

MS CARTER: Yes, I am. I became the Chief Executive Officer of Marninwarntikura Women's Resource Centre in April 2017. Prior to that, it was June Oscar and, as we all know, June went on to become the Social Justice Commissioner.

MS TARRAGO: And, Lauren, if I could also get you to explain to the Commissioners what your role and also your education and experience at Marninwarntikura.

DR RICE: Yes. So, I am a research fellow and -- through the University of Sydney. I have been working in the disability sector for 19 years this year. The past 11 have been in the academic area. So I did my PhD in mental health in people with developmental disabilities, and then I joined Emily and the team at Marnin in late 2018 to work on The Bigiswun Kid Project and then started living up here in 2019. I have been here more or less ever since.

Because the NDIS rollout began late 2019/2020 and I had experience in the disability sector, Emily asked me to be involved in some of the consultation. So I've been around pretty much since they began consultation, just listening and watching and explaining to Emily how it differs in some ways to what I've seen in Sydney and other parts of Australia.

MS TARRAGO: And you're continuing that work now? Yes. Emily, could you, for the benefit of those who haven't read your statement, explain to the Royal Commission what Marninwarntikura Women's Resource Centre does?

MS CARTER: Okay. The Women's Resource Centre provides a range of services for women and children of the Fitzroy Valley, so - but physical infrastructure, we run a women's refuge. We have a legal unit, so we have a lawyer that represents women in court for VROs or Family Court matters. And we have a social worker and a counsellor, and we also run our early learning centre and our child and parents centre.

And we also have another unit called the Maralu. Maralu in Gija means "precious, worth nurturing" and that's also a Bunuba word as well. So they're the - the Maralu is part - was set up after we - we did the first prevalence into fetal alcohol spectrum disorder to explain to families about what came out of that research and how do we support the families who's got children with complex needs in the Fitzroy Valley. So we have - I think we have about 55 full-time staff and about 35 part time.

MS TARRAGO: Earlier, we heard evidence from Mudge, and he explained the difference language groups. I'm going to ask the operators to display doc ID MWRC.9999.0001.0117. Is that appearing for you on your screen?



MS CARTER: Yes. Yes.

MS TARRAGO: If you could just take us through what that map represents?

5

MS CARTER: That map represents all the - the language groups in the Fitzroy Valley, and they are all colour coded for the different language groups. One of the things about the language groups also is the fact that the Fitzroy River is shared by all of the - the language groups. The language groups that are closer to the river are also known as the River People, which is Gooniyandi and Bunuba. And the outer language groups are the Desert Communities, which is the Walmajarri and the Nyikina and the Wangkatjungka people.

10

They - they are those - when I talked earlier about the Homeland Movement, that's the homelands that we are talking about here that have now - where people have set up their communities.

15

MS TARRAGO: And the township itself of Fitzroy Crossing is a central place for all of those languages?

20

MS CARTER: It's the central place - it's the central place for all of these language groups, where they come in to do their food shopping and to go to the hospital or to - to catch the bus out of here, where the services is - Fitzroy is the main service area for these languages.

25

MS TARRAGO: And there are also other groups that are outside of what we see in the map that may travel through to Fitzroy Crossing to access services they wouldn't otherwise have.

30

MS CARTER: Yes, of course. And if you think about Aboriginal language groups, it's also the - how you're connected to the next language. So through that - through the songlines and that, people also come and they access services or they come to see relatives or - and friends as well. So - and we are on the highway. We're on the Great Northern Highway, so we do have a lot of traffic through here as well.

35

MS TARRAGO: I will also ask the operator to display a photo. Doc ID MWRC.9999.0001.0115. Is that displayed for you?

MS CARTER: Yes, yes.

MS TARRAGO: And what's that a photo of?

40  
45

MS CARTER: That's the photo of our main river in full flood. And that - you know, when the - when it's in full flood, the amount of water that goes under that bridge can fill up the Sydney Harbour every 12 hours. So a lot of water goes under there, and, unfortunately, we also have pastoralists that are looking to extract water from our rivers. And the river is our life. It gives us - every time the floods come, it's like - it's renewing everything for us.

MS TARRAGO: And earlier we watched a video of Mudge talking about his connection to the Martuwarra, and during that video, the river was quite bare during that particular

season. So is it a famine and fast in terms of - feast, sorry, a famine or feast in terms of the flood waters that might travel through that country through the seasons?

5 MS CARTER: Yeah, very much so. And you can't guarantee, because of climate change, whether you are going to have a good wet season. And - so we do - earlier this year, we had a reasonable enough wet season, but the - the river isn't full all the time. There are pockets of parts of the river where there's water all year around. But most times it's - it's not running at all. But it is a precious system for us. It's - this is where we go to get relief from the - from what's going on in your day.

10 It brings families together. We use the river to - it's to - it's like medicine for us, to help us with our mental health and to be able to destress, but it's also that gives us food as well. So we get fish from the river and our freshwater prawns, which we call cherabins over this way. But we get those things always in season. And when the water flows out of the Fitzroy River and on to the Fitzroy Plains, well, then they are filling up our billabongs.

15 And so that water isn't just seen as going out to sea, that it is rejuvenating and filling up our aquifers all on the Fitzroy river and it's filling up our billabongs and that. So it's the cycle of life. And it's the only - it's seen as the second wildest flowing river in the world beside the Amazon. So it's in everybody's interest to care for this river.

20 MS TARRAGO: Thank you. Thank you, operator. Lauren, could you tell the Commissioners about I will firstly start - both of you co-authored the NDIS Commission report "*People Don't Know What Good Looks Like*." Can you tell the Commissioners about how and why Marninwarntikura was approached to prepare that report for the valley.

25 DR RICE: Yes. So, there was a range of NDIA representatives coming up to the Valley to meet with people - with Emily and other CEOs and other Aboriginal community-controlled organisation. And they were sort of all coming to listen, and the CEOs were saying the same thing, but they didn't feel heard. And we were fortunate enough that during one of those consultations, an Aboriginal woman who worked for the NDIA, Simone Kenmore, was there, and she could see the frustration in the CEOs feeling unheard and told us that she had done a similar consultation with Palm Island and asked us if we wanted to do one ourselves to help raise the voice of the community.

30 And so they had some - the NDIA proposed some questions that they wanted asked about what a good life look likes and what kind of disability supports people want, and then Emily met with the board and other people to find out what else the community wanted to ask. And they were particularly interested in knowing how the NDIS is rolling out, what's working, what's not and how it could work better. So we incorporated those questions.

35 We formally interviewed 15 people with a disability, ranging - mostly adults, as well as 20 parents of some of those adults, but also parents of children. And we formally interviewed 13 disability service staff, so drive-in drive-out service. But we also informally consulted with many, many more. Pretty much anyone who came around the NDIS, we invited them to come to Marnin and chat with us. And then we walked along side at least 20 people to help

them access the NDIS and attended any consultation or information sessions that the NDIA ran.

5 And then, from that, we had a look at some of the policies around how the NDIS started and put that together with all the work that Marnin has already been doing around disability into this report. So it was something I did on the side of my full-time Sydney Uni job on Sundays for about a year, but Marnin also invested a lot of their time. We had community navigators for every single person we interviewed so that it was done the right way.

10 MS TARRAGO: And, Emily, was there anything else you wanted to add to that or speak to in particular about that experience of the consultation and preparation of the report?

15 MS CARTER: Other than to say that we was actually forced into doing this. We had no alternative but to really highlight what was going on for people, because there wasn't anything for them.

DR RICE: For any avenue for public consultation, yes.

20 MS CARTER: Yes.

MS TARRAGO: So things were falling on deaf ears, for want of a better phrase, prior to that opportunity?

25 MS CARTER: Mmm.

MS TARRAGO: And in the report you - it talks about what an ordinary - what the ordinary life looks like for a person with disability in Fitzroy Valley. Emily, are you able to share with the Commissioners what that looks like?

30 MS CARTER: What that looks like? At the moment?

MS TARRAGO: Yeah, for a person with disability in Fitzroy Crossing or the Valley.

35 MS CARTER: Well, earlier, you would have heard, you know, we had a lady that talked about her disability. But, look, life is very hard for anyone living in such a remote place who has a disability. And just to actually exist on a day-to-day basis, being able to try and navigate the world for the day is very hard for most people, whether you are in a wheelchair or you have some cognitive disability. It is really hard. And we rely on family members to be able to do that work for our - for our family who has a disability.

40 Because we live so remote, one of the things I did talk about - whilst I talk about, "People don't know what good looks like", why should we in such small remote towns miss out on services for the community when our town is 98 per cent Indigenous population? That's the town and the surrounding communities. So we are predominantly an Indigenous town. We  
45 need - and this is a human rights issue I'm talking about here.

5 People with disability should be able to be afforded the same level of service and to be able to live a good life as somebody that's living in a regional town or in cities. But it's not happening here in small places like the Fitzroy Crossings of the world and our remote communities. And that's - and people shouldn't have to decide to move to be able to get that, and leave their family and leave their connection to Country and culture and all the support systems around them just to get a service.

10 I would have - and we're on the highway. We're on the highway. And that's brought us to this, to do this report, because we needed to raise the voices of the families that are in desperate situations around their families with disability.

15 MS TARRAGO: Thank you. Lauren, was there anything that you wanted to add or in particular highlight in terms of barriers that prevent those lifestyles for people in community?

20 DR RICE: Yeah, I mean, when I first came here, I could not believe how different it was to Sydney and how little access to services there were. Particularly because I was familiar with the Lililwan Project and I knew that it got a lot of awareness, both nationally and internationally. Everybody knew the rate of disability here. So to come here and find that I, who have a PhD in disability, couldn't find anyone to help diagnose children with disabilities or to find disability services or to get speech or OT and, yeah, it was just shocking.

25 I think, going back to your question about an ordinary life, one thing that I really liked that was highlighted in everybody's comments today and I think is so vital is every single person we interviewed not only for this report but for the Bigiswun Kid Project, which was 194 other people, said that they love living here and they want to live here. So there are lots of great things, and there is so many protective factors.

30 The kinship system, just blows me away in how protective people feel. I have had the fortune of walking alongside people with disability who live here and then who have to go to Perth for services, and to see how comfortable they feel and having a - like, an undergraduate degree in psychology, it makes so much sense, if you have a cognitive impairment, but your place is predictable, you know how life works and you feel safe and you know who everybody is, you have so much more freedom.

35 And as soon as they go to Perth, their world becomes so small, and they are scared to leave because there is all these language and cultural barriers and not understanding how to navigate the world, but then throw a cognitive impairment on top of it and it's just impossible. So, yeah, I think there are lots and lots of barriers. But, at the same time, there is also lots and lots that could be happening that just isn't. And I was shocked to see that.

40 MS TARRAGO: What sort of things do you think should be happening?

45 DR RICE: When - well, I think the NDIS is a huge scheme. Like, it's the biggest health reforms since Medicare. So we knew it wasn't going to be rolled out perfectly straightaway. But it was disappointing to see how little consultation there was. I think they just had to get it out,

and now that it's out, it would be great if there was proper consultation to ensure its place-based and designed for each community or each region.

5 One thing I've noticed is that Fitzroy is very different to Halls Creek, to Derby, and to Broome. So I think there needs to be consultation. And one thing somebody very smart said to me when I first came here, and to the NDIA when we were in one of the meetings, and which Mudge reiterated, is if you do not go to sleep here and you don't wake up here, you don't understand here. I have done all interviews. I have read all this work. I've spoken to these people. But it's walking alongside people and living here that's taught me everything.

10 So I think having an NDIA representative in Services Australia who can actually see the barriers but also the solutions, I think is vital. The introduction of the Remote Community Connectors at Marra Worra is great, but it's only half the puzzle. All of the other region - towns that have AMSes, they have the Remote Community Connector, but they also have evidence, access and plan coordination. We don't have that because we don't have an AMS.

20 And it means that knowledge around the NDIA and the complexity of the NDIA isn't understood. And so you've got people who are trying to help community understand the NDIS, but they don't understand it and they don't have that support. And I think having that component based here as well - the plans are so confusing. I still do not understand the language. They are designed to be - I assume they're designed that every section, everyone with a disability has, but some 50-year-old man in Tasmania versus a 7-year-old here is completely different. And so it becomes - the headings for the sections of the plan are so vague they mean nothing. And I'm constantly having to write next to them to remind myself what they are so I can explain them to someone. So, I think -

25 CHAIR: I wonder if you just might consider slowing down just a little because we have to translate into Auslan and have the real-time transcript. I reassure you, you are not the first person that has received that.

30 DR RICE: Sorry. I apologise. You are definitely not the first person to tell me that I talk too fast. So, yeah, I think that there - having somebody in Services Australia, having a locally-based evidence and access person to help create the plans, but then also, once people have plans, the support coordinator and specialised support coordinator roles in - like, the concept is fantastic and exactly what's needed to help navigate the complexity of the scheme, but they're not based here.

40 And at the moment, I am constantly having to advocate for them to do what they are supposed to be doing, and I - the pattern we have noticed is that their support coordinators are part of a disability service that also provides allied health therapy. And they are very good at making sure that allied health therapy goals are achieved, but not the other goals like getting a wheelchair fixed and other resources. And I think if they were based here, they would be much more accountable, but they would also be able to work with the community to break down barriers.

And then, lastly, the specialised support coordinator. So many of the plans that have been written that I've sat in on, the planner is like, "Yeah, this person needs a specialised support coordinator. They are homeless. They have a mental illness. They are experiencing DV." All of these things need to be broken down before they can access disability services. We have funding and a pathway to do it, but there's no specialised support coordinators here, and it's beyond the NDIS to have to provide that, because disability services are private. So they are just some of the solutions that we have in our report, and I guess a lot of it comes down to making more place-based services.

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10 MS TARRAGO: Emily, was there anything else that you would like to talk about in terms of the solutions for your community?

MS CARTER: Look - no, not really. I just wanted to reinforce what Lauren has said, that we need to have someone here on the ground. I listened earlier on today to - to Topsy talking, and the old Disability Commission was a better service for our people because there was a physical presence on the ground that was - that was very user-friendly, and people were able to go in and talk about what was going on for them, how they could access services and that. That's where it's all fallen down.

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20 When - in this new service, people don't know where to go and what to do. And we have gone into this as an organisation - really, we have fallen into this because of the - because of our Bigiswun research, that we had to get into this to understand what was going on for people here on the ground.

25 MS TARRAGO: Today, we've heard evidence from a number of people who have been living in the Valley talking about the lack of cultural foundation that exists in the NDIS. What have been your observations on the ground in terms of cultural capacity for the scheme?

MS CARTER: Well, look, one of the things that I've spoken about is the fact that families, Indigenous families, really aren't recognised by NDIS at all. The way the - I'm not a full bottle on, you know, the whole of NDIS. It's - it's really big and that. But what I see on the ground is families looking after their own family member who has a disability. But in the current system, those families cannot be paid to do the work for them.

30  
35 And when we are talking about a cultural system, in the Aboriginal culture, it is our responsibility to care for our family members, and especially the vulnerable in our - in our families. But there - no one recognises the caregiving that goes on within that family, that we do, or families do this day in day out. They are saving governments a lot of money, but because they are family, they are not being paid for the work that they are doing in giving care to their loved ones. That's a flaw, I think.

40  
45 And the family will always do that, regardless. When you're talking about respite and that, no one's going to really access respite, because it means going out of Fitzroy Crossing. But they will probably give an extended family their family member to care for so they can get respite. But they can't access money because they are related. I think the other thing is that NDIS has been set up more like a business, and Aboriginal people are really scared to go into that part as well.

5 "Why should I have to get an ABN and register as a lone provider for my family or for - or for a - a vulnerable person just down the road there?" So it's become a business, and that makes people scared as well. So - and there's got to be flexibility in this system. And can I just say, NDIS has been set up looking at everything in a very western lens. There's been no consideration given to Indigenous peoples of this country or people of minority where English isn't their first language. And we're supposed to navigate the system.

10 MS TARRAGO: So, there's a need for interpreters, as a starting point?

MS CARTER: Interpreters. Everything is online. We want to be able to see these people. We want face-to-face contact with the people that's supposed to be from - that can give you clear - clear information. We want to be able to have people in there that understands that we are a diverse group of people and that how do we make sure that our culture and customs is recognised and respected so that our families can get a good service?

15 Understanding that cultural and practices and that for our mob, because, for us, it all - it's the obligation or if things go wrong, there are stuff that happens in the cultural sense. They're the things that got to be taken into consideration. And the only way that's going to happen is if we have somebody that comes and lives and understands and build the relationships with our communities.

20 MS TARRAGO: Now, in terms of trying to get some more capacity-building within Fitzroy, was Marninwarntikura approached to start delivering services at some stage?

25 MS CARTER: Initially, yes. Initially, we were approached and, of course, at that time, I - I felt that the responsibility was being pushed on to NGOs, you know, to ACCOs, especially Marninwarntikura and Marra Worra. The Aboriginal resource centre down the road here. And we knocked that back and we continued to knock it back because this is the government service. They have a responsibility in providing this service. We as ACCOs have so much - we do our own work, but we have so much expectations on us that we are just overwhelmed sometimes. And I did say no.

30 MS TARRAGO: Are there also other complexities that exist such as a lack of housing for a staff member to deliver on those services?

35 MS CARTER: Exactly. We don't have - we are an ACCO. We get funded for programs, to deliver programs and to employ staff, but we don't get funded to provide housing at all. It's at our expense that we have to find housing in the community for our staff. But we do a lot of government work.

40 MS TARRAGO: Lauren, I wanted to get your views about how NDIS service managers, coordinators and support services coming to the Valley to deliver services, are there concerns held by participants about how money is being spent for transportation costs?

45 DR RICE: As in for the drive in and out?

MS TARRAGO: Yes.

5 DR RICE: Yeah, yeah. Yeah. So I think because it's so complex, people just get given this - this piece of paper with however much money on it, \$40,000, and it's not explained to them how it's supposed to be used. And often with the first plan, it's hard to know what things are going to cost. I know there with were five or six people I sat with and in the first planning meeting they said, "So, we will give you this much but then you will get connected to a support coordinator and to services."

10 And, you know, "If your service is based here then the price might be lower, but if your service is based in Broome or Darwin, then you will get more money to cover the extra costs." And then there were no services based here. Even the locally based service here still has a drive-in drive-out allied health therapy, and the staff turnover for those services is incredibly high because they get inundated with way too many people and it's not feasible.

15 And so there are a lot of costs coming out and people don't really understand why. And those non-Aboriginal services don't have community navigators. You mentioned - and you were talking to Emily about the importance of interpreters but it's so much more than an interpreter. Having an interpreter from even Broome speaking Kriol on the phone to  
20 someone isn't going to make them feel comfortable to speak about their child's disability, and that's one thing that I've learnt, is it has to be somebody who lives here, who says to the family, "This non-Aboriginal person is okay, you can trust them." And straightaway the whole conversation is different.

25 So these drive-in drive-out services don't have that. So sometimes people, particularly people with cognitive disabilities, they won't open the door. So someone has driven all the way from Broome and then left again, and they have no idea who they are. They are just like another white Prado; it could be anyone. It could be the Department of Communities. And so they are like, "Why is money coming out of my plan when - when I haven't received the  
30 service?"

So there's a lot of communication issues, a lost confusion around the way the money is spent and it's largely because you don't have the knowledge of the disability service, working alongside community navigators to explain that to the community.

35 MS TARRAGO: Emily, was there anything else that you would like to add to that?

MS CARTER: Yeah, other than to say that I was just thinking - I know it's not in my statement, but when Lauren was talking, I was thinking about a young family some years  
40 ago who had a plan for their little boy. And she didn't know what it all meant. And she was entitled to kimbies for her little boy for a year, and she never ever accessed that, because no one explained that plan to her. And from, what I understand, if you're not accessing something in your plan, say, this year, the money is less next year.

45 So - and these are people that are already living in poverty, and had she known that she could have accessed the stuff, that would have made life a lot easier for her.



MS TARRAGO: So, as simple as knowing that you could buy nappies under the plan?

MS CARTER: Yes.

5 DR RICE: Well, as simple as keeping receipts. She bought the nappies. But when we finally were introduced to her and explained this to her and advocated for her, they said if you don't have the receipts you can't get the money back.

10 MS TARRAGO: Emily, you know, we've earlier spoken about solutions, but do you think the NDIS is fit for purpose?

15 MS CARTER: No, I don't. I really don't. I think we are seeing even more suffering now than when it was in the old Disability Commission. Honestly. And people have to come and have a look to see what I'm talking about. There is - there is no services for these people. And if there was services - or there are few service, but one of the things I want to also say, who gives an oversight to all of these providers to make sure that they're doing the right thing? Because we're talking about money, and I - I don't see that there's any governance in that part of being a service provider and whether they're being accountable.

20 MS TARRAGO: And, Lauren, do you have any views about whether the scheme is fit for purpose in particular for the Valley?

25 DR RICE: Yeah. I have seen it work so well in Sydney, and every time I go back to Sydney and talk to parents of kids with disabilities, I just get so frustrated at what people aren't getting here. And I honestly think - because I started interviewing people before the NDIS rolled out, and that - life is just, "Yeah, that's my child and that's just the way it is." And then someone comes along, the NDIA come along to say, "You can have respite. Your child can talk with speech therapy. You can have a wheelchair. You can have all these things. Here is \$60,000." And then they disappear. It's like they have created this hope and this  
30 expectation and then let them down. They would have been better off just not - not knowing about it.

MS TARRAGO: So is there a sense in the community of empty promises?

35 DR RICE: Yes. And the frustrating thing for me is the NDIA were warned about that. I sat in the room where Emily and others said, "Please don't promise services that don't exist. Build up the services then tell people about the scheme." And they said, "Sign people up, and the services will come." We have signed up, there's - well, there was at least 80 people connected to one service, and they only have two staff. The services have not come.

40 MS TARRAGO: And has that been the experience of Mudge in respect of his other children that might also live with disability?

45 DR RICE: Yeah. Poor Mudge. I don't - I have walked alongside him throughout the whole process, and I hate how many forms I have to ask him to complete and how many meetings I have to ask him to sit in just to get a couple of speech therapy sessions. He only does it because we encourage him to persist. He definitely would have given up otherwise. And

he's trying to do it because he wants to try to break down the barriers and improve the services for all his other family who have disabilities. But it - yeah, hasn't happened yet.

5 MS TARRAGO: Emily, is there a sense in your community of fatigue when it comes to inquiries and Royal Commissions?

MS CARTER: Yeah. I think - well, I know that I - there's a sense of fatigue with me when we sit here and we watch, and, you know, we've seen the Royal Commission into Aboriginal Deaths in Custody. We have seen the Bringing Them Home report, the Stolen Generation.  
10 We have seen, you know, the Aged Care Royal Commission, the Banking Royal Commission, and you get - you wonder when things will change for the better for people on the ground.

And certainly, I always advocate for women and children here in the Fitzroy Valley as long as I'm able to stand and talk and breathe. But you wonder when things will change for the better. And I would like to say to our Commissioners - and Commissioner Mason, I know personally - and that when all this is done there's going to be recommendations made to the government, but somewhere I have hope in this new government that things will change for the better, that this government is going to listen.  
15

20 Because we're sick of telling our story. We're sick of it. And bringing up the pain that we have and to see our people struggle and how we fit into a very western system. There's got to be flexibility in this system so our people benefit. And I really, really hope that the Commission does this, because we are very - we have a lot of vulnerable children out there that needs to have - to be able to live a good life, and things are hard. That's all I've got to say.  
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MS TARRAGO: Lauren, was there anything else that you wish to tell the Commissioners?

DR RICE: No. Thank you. I think Emily said it all.  
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CHAIR: Thank you very much, both Ms Carter and Dr Rice. I will ask Commissioner Mason first whether she has any questions that she would like to put to you.

COMMISSIONER MASON: Thank you, both of you, for your evidence this afternoon. I am just going to go back in history and talk about the advocacy and the work that has happened in the Fitzroy Valley to challenge and to find another way to support families and around the trauma that comes through alcohol and then the consequence we're talking about through the Disability Royal Commission, fetal alcohol spectrum disorder.  
35

40 Living in Central Australia and our challenges in this region around petrol sniffing, I look at your region and I think of this region that the understanding of - of trauma but also of disabilities coming through because of that - the social breaking down of family structures and that history, Emily, you talked about, the Stolen Generation, we've heard a lot about that in this hearing today. So I've got a question about that.  
45

Looking at those years and where we are today, why - what's your thinking around why services were not built up when the understanding of the extent of fetal alcohol spectrum

disorder particularly was known about in the Fitzroy Valley? Why the delay - and there is still a delay, from your evidence today. Why didn't that happen once the truth was starting to really be understood by researchers and governments in the Fitzroy Valley starting way back there in the mid-2000s?

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MS CARTER: Well, I don't think our Western Australian government took our - took the research very serious - took it seriously enough. From the evidence that came out of the first prevalence, where you are, Commissioner Mason, in Alice Springs, there is a centre there that will - that supports children with FASD and, you know, the diagnostic teams there. There is one in -

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DR RICE: Every city in Australia has got one. Yeah.

MS CARTER: - every city in Australia but there isn't anything here on the ground. So a lot of people - a lot of the services right across the country benefitted from the research here in Fitzroy, except for Fitzroy.

15

DR RICE: Or the Kimberley.

MS CARTER: Or the Kimberley area itself. So - and that's the truth.

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COMMISSIONER MASON: Yes. I can - I understand that. And the realisation of that is very sobering, because you're still in that situation now. My second question is about the Stolen Generation and the impact of that. And I just had a question. It's not in your statement, but should the NDIS be giving particular considerations to families with disability - family members with disability, particularly where there has been that impact of the Stolen Generation and even today with children in the child protection system coming out and being channelled towards the NDIS, being institutionalised?

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So we have got, you know, multi-generations of First Nations people and the impact of the Stolen Generation and removal. Do you think the NDIS should be paying particular attention to those families because of that history?

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MS CARTER: Yes, I think so. I really do. As we all know, trauma is a big one for all of our families, and the Stolen Generation had a huge impact right across the Kimberley area. And that is passed on. When we talk about intergenerational trauma, that is passed on. That is true. That is our lived reality on the ground here. And it stops you from being able to - being able to function properly in this world. I'm - I'm a descendant of Stolen Generation parents, but, for me, what happened to them is what drives me to do the work that I do.

35

40

But there are other families who have never ever recovered because of what's happened to their families. And that when you think about people with a disability, it's not always a physical disability. But it's that - it's hard to explain the - the inside - there's a disability for you because of what's happened. It takes - it's more than just your parents being removed. It's you as the person needing to know how you're connected to people and country and, you know, all your heritage stuff.

45

That creates really bad mental illness for families, if you don't know who you are as a person. We all need to know who we are and how we're - where we come from and how we're connected. And there's Stolen Generation that hasn't found that yet and that causes serious illnesses for them, where you - where we say you get sick from the inside out and can never function through this world.

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COMMISSIONER MASON: Thank you. My last question, you know, words matter for First Nations people because we have the oral tradition. So explaining - and also the concrete experiences our education system, "Don't tell me about it. Show me how to do it." And so this word "insurance" seems to be a block to - it's a block in the understanding of how this system works, because the Disability Services Commission in WA, the former Commission, because of that word "service" had attached to disability, our countrymen and women understood what that organisation was meant to be doing.

15 MS CARTER: Yes.

COMMISSIONER MASON: And it did it. It was providing services, as you've both explained today. So is the word - the insurance, is "insurance" a sophisticated word that has not actually really found its place within First Nations literacy? I'm talking across the board. Not just people that have gone to university, First Nations, but the mums and dads, do they understand even that concept of insurance?

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25 MS CARTER: Yeah. Exactly. Like, you know, I - I - that is a very, very foreign word for all of us, including myself. But whether we think about the five language groups here in the Fitzroy Valley, not always English is their first language. So it is foreign to us. And who came up National Disability Insurance, God knows. I wouldn't have put people with a disability under an insurance scheme. It doesn't - it is foreign.

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35 COMMISSIONER MASON: You've used - you talked about the Homelands Movement. And there's something in that, as you were giving your evidence today, around the language of how First Nations people can understand, really, what this benefit of the NDIS could bring. Because there was also that similar hope about the Homelands Movement. I'm just - I'm probably going over time now, but I was going to say thank you. You have really stimulated and awakened some really interesting thinking for me.

And I also want to thank your organisation for its heavy lifting in the area of social policy but also of healing and of finding ways to solve these really difficult problems that we've experienced in remote communities. So thank you very much.

40 CHAIR: Thank you, Commissioner Mason. Commissioner McEwin, do you have any questions?

COMMISSIONER McEWIN: No, questions from me, other than to say thank you both not only for your evidence today, but also for the work that your organisation does in supporting your local community. Thank you.

CHAIR: Dr Rice, I would just like to know a little bit more about the report *'People don't know what good looks like' - Creating Equity for People with Disability in the Fitzroy Valley'*. Was the funding for that exclusively through the NDIA?

5 DR RICE: So the NDIA provided us with funding to do it, but we - Marnin provided additional funding. And then I'm employed through the University of Sydney through a fellowship for other research. So it cost more than what the NDIA provided but, yes, they did provide funding. And then there was in-kind support from Marnin and the University of Sydney.

10 CHAIR: What was the object of the exercise, from the point of view of the NDIA as you understood it?

DR RICE: So, the NDIA's objectives or aims are outlined in the report. They were really interested in understanding what a good life looks like and what type of supports people  
15 might want. It was - but when I spoke to senior people in the community about whether we would do this and what they wanted, they obviously wanted a lot more, because it's not just telling the NDIA what a good life looks like. It's - there's a lot more than that: Telling the NDIA or the barriers to trying to implement such a big thing, telling the NDIA what life is like here, how different disability is perceived in Aboriginal communities. So we went, I guess,  
20 above and beyond their objective but they were quite supportive for us to do that.

CHAIR: In your statement at paragraph 71 and following, you address the situation since the report was written. I understand from what you have said in the statement, including at paragraph 26, that there was no response from the Minister. Has there been a response  
25 from the NDIA?

DR RICE: No. So, the people from the NDIA in the Connectors branch who were working with us on this, there were three people and they all left over the time that we did it. And a new person was appointed as the lead for that. And the summary of the report was sent to them  
30 just after Minister Linda Reynolds came and received our report and we didn't hear anything back from them. I was informed more recently that the report was - they had two meetings about it.

They reviewed it and discussed it, but they never reached out to us. I think when we did  
35 have the full report ready to go, it was right before the election, so I think everything was on standstill. So we are excited the new government is in to start working with Minister Bill Shorten and the NDIA in discussing how some of these recommendations could be implemented.

40 CHAIR: Yes, I was going to ask you, the report was completed in - by at least September 2021. And it's now up on a website, as I understand it. Is that right?

DR RICE: Yes, that's right.

45 CHAIR: The University of Sydney is going to formally launch the report. Has it - in June 2022. Well, June, of course, has passed has the report been officially launched?

DR RICE: Yes. Just this week.

MS CARTER: Just this week.

5 DR RICE: It's been available, and we have been sending it out to anyone we think might be interested, but we decided to do a media statement to help raise awareness to try to get some traction.

10 CHAIR: I see from your very impressive curriculum vitae that you have been extremely successful in getting grants for research studies that include studies in remote Indigenous communities. Are any of the studies that are referred to in your CV - other than the one, in effect, commissioned by the NDIA - any of those relate Fitzroy?

15 DR RICE: All of them.

MS CARTER: All of them.

20 DR RICE: All of the Indigenous ones relate to Fitzroy. So I was invited by Emily and Professor Elizabeth Elliot, who Emily has worked with for 12 years, to come up into the community and work with them on the Bigiswun Kid Project, following up the children from the Lililwan project 10 years later. So most of those grants relate to that work. We've recently just completed following up -- people and 100 parents. All of the young people who were diagnosed with FASD in the original study 10 years ago, we were able to interview them and find out how they're doing now, and we're currently working on analysing and writing that up.

25 CHAIR: And have - have the results of those research projects been made available amongst other - among other government entities to the NDIA?

30 DR RICE: Yes. So Marnin being such an impressive organisation, one of the things that surprised me is how many Ministers and DGs come through, and so we use that opportunity - and Commissioners. So, the Mental Health Commissioner, the State Child and Young People Commissioner, Minister Simone McGurk. Who was here last week? The Minister of Mental Health. Yeah, so anyone who comes through, we let them know about the findings, and any findings that come up, like when the suicide rates - when we started to notice how high they were, we actively informed government to make sure they are aware.

CHAIR: Sometimes it's a little like dealing with a revolving door.

40 DR RICE: It is.

CHAIR: I suspect.

45 MS CARTER: Yes.

CHAIR: All right. Okay. Well, thank you both very much, both for the work that you do - again I echo what Commissioner Mason has said, and I know she's very familiar with the

5 work that you do, and what Commissioner McEwin has said - and thank you for the contributions you have made in the written statement and in the evidence that you have given today and, of course, in the research work that you have both carried out. Thank you very much. And thank you for the - we very much appreciate the contributions to the Royal Commission.

MS CARTER: Thank you. Thank you.

10 <THE WITNESSES WITHDREW

CHAIR: Ms Tarrago, I think that Mr Griffin is approaching again.

MS TARRAGO: Yes.

15 MR GRIFFIN: Can I indicate, Chair and Commissioners, that we anticipate starting at 10 am tomorrow morning with the written statement being read of Paulette. The schedule is in accordance with the schedule that's been provided to you previously. And can I indicate to my colleagues who have leave to appear that I would expect that we will get to the Commonwealth evidence at around 3 tomorrow.

20

CHAIR: Thank you. In that case, we shall adjourn until 10 am tomorrow, Central Time.

<ADJOURNED AT 4:13 pm UNTIL THURSDAY, 14 JULY 2022 AT 10 AM

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