Transcript: 'Nat' on ABC Adelaide Breakfast 06/04/21

[Ali Clarke] On this day one year ago, Ann Marie Smith, who lived in a beautiful house in Kensington park that was left to her by her parents died. She was suffering from septic shock, multiple organ failure, severe pressure was mounting nutrition and had issues connected with her cerebral palsy. Now, at the time of her death, police said that she had been spending her days and sleeping at night in a woven cane chair. Now, as David mentioned, the 68 year old woman who cared for Smith has been charged with her manslaughter. But what has been learned one year on, what has changed? Is it safer for people living with disabilities? You're about to hear from a woman who we'll call Nat and she has had a name change, and you'll hear her voice has been disguised as well, because she's so worried about someone identifying her and removing her care. And she'll explain why, in just a few moments. Now we meet Nat through an interview with disability advocacy group Purple Orange. So Nat can't move her arms, nor legs, and has an NDIS plan for support for workers to come to her home. But even though she's with multiple agencies, she still can't have her needs met.

[Nat in podcast tape] I'm getting workers who have very poor English, I can't say can you untwist my left sleeve, it puts me in danger. I have swallowing difficulties. If they're giving me drinks or medication at the wrong angle or the wrong speed I can choke. I'm just always having to be alert, working out how I'm going to ask for it in more than one way. My agencies all say that I'm prejudice. It's not prejudice. When you've only got verbal communication, and nothing else, you can point nothing. It doesn't work.

[Ali Clarke] She can't do anything for herself, as she says. So as part of that, and just try to imagine what you would feel and how you would feel being in this situation. But she would like a female worker to help her with her personal care. And who wouldn't want that.

[Nat in podcast tape] I prefer a female worker for all personal care because I can't do anything for myself but I sometimes get told that it's not a choice. And I don't need to feel that way. They'll say we only have male workers. So do you want it done or don't you? So, I don't know, I'm not supposed to feel anything?

[Ali Clarke] Remember when everyone also was so outraged that Ann Marie had been left in her wheelchair. And due to the nature of Nat's disability, she needs two workers to move her from her chair to her bed, but is often only sent one. Or even people who can't physically do the work, they might have a bad back or something like that.

[Nat] For over eight years, I've been sleeping most of the week in my wheelchair. And if my worker that can do it, has to go away, I don't go to bed for however many days she's on leave. I'll say to him, "ah, make sure the worker is aware that I'm going to be short and tired because it's my third day my wheelchair."

"Yes. Okay."

And I'm like, "You get thought don't you?"

"Yeah, yeah. Okay. You haven't got out of your wheelchair."

And I'm like, "For three days."

"Oh, why?"

"Because you haven't sent anybody?"

How do I get someone to do three hours of manual handling to get me out of bed? And to constantly be told a difficult high need client? They're not tears because I'm glad someone's listening and hearing. I just wish the right people would. It's all about training. A lot of workers do not have any of the skills for high need care. Why are they telling NDIS that they can look after people with high need care, and take on our contracts, if they don't have high need carers? And why aren't they doing something about it? They're getting the money. I thought it would change after Annie's tragedy. But it hasn't made a bit of difference to anyone. They leave me in this position and go to bed every night.

[Ali Clarke] So living and sleeping in her wheelchair for eight years. That's what Nat is facing. And then, the remarkable response from her was "Yes, I'm going to be short and I'm going to be tired." One of her good support workers has said that the first thing she does when she gets to Nat in the morning is to just slide her hands under her to try to relieve the pressure because Nat is in so much pain. So why don't we hear more stories like her? Well, this is where we start finding out why Nat is too afraid to speak up.

[Nat] I'm afraid two people's agencies have in the past limited what we care we get if we complain. One agency I complained about them not providing me the right staff to go to bed. And that I hadn't been to bed for three days. And they dumped me within three hours. Because I was rude. I didn't swear at them. I said, it's not right. She goes, "We can't get anyone tonight. Sorry. We'll be right" And I thought, "I won't be alright. I'll have to live through, hopefully. But this isn't acceptable, this is day fou now. I think that's unacceptable to leave me in my wheelchair for four days. And apparently, I upset the person, and they dumped me, and sent no one in the morning.

[Ali Clarke] And a lot of you are saying oh, gosh, isn't there somebody else that Nat could speak to in this? Well, she had already gone to the NDIS Safeguard Commission, but she said that they were no help, and she at least, is sharing this story with all of us now because she has a voice. But is very, very aware that so many others can't speak for themselves, like Ann Marie Smith.

[Nat in podcast tape] Really it was Ann Marie. When I heard what happened, I saw my life. NDIS gave funding for care to an agency who didn't provide and she wasn't capable of complaining, and copped the life she copped. And I don't want her to have died in vain, so I feel responsible that she does have her name mentioned, and is remembered, until it's fixed. We have to talk to people out there. Not only the agencies, not only the government, our neighbors, our friends, they need to know. I can't tell my family, because it upsets them and they cannot help, but the world needs to know that we're being neglected.

[David Bevan] Now, we've taken that audio from a podcast, which has been organised by Purple Orange. Purple Orange has its genesis in the old Julia Farr Center, which before that was the home for incurables, but then its operations its building was taken over by the state government and Purple Orange is what we have now. And it's an advocacy group for people with disabilities. And Robbi Williams is the Chief Executive Officer with Purple Orange, and he joins us now. Good morning, Robbi.

[Robbi Williams] Morning.

[David Bevan] So Purple Orange has put this podcast together with Nat. We'll get details from you later where people can go to hear all of it. How many Nat's are there?

[Robbi Williams] More than one. How many? I don't know to be sure. Nat tells us there are plenty of other people like her in a similar situation because people do build mutual support networks. But I think part of the problem is that we don't know for sure how many people are out there who are living in similarly fragile circumstances.

[David Bevan] Are we any better off today for our Nats than we were 12 months ago when Ann Marie Smith died?

[Robbi Williams] No.

[David Bevan] How can that be?

[Robbi] Well, that's a big question. The the issue I think the presenting issue for Ann Marie Smith made it possible for people to think about the actions of one particular agency or a particular worker. The issue for someone like Nat is that there are so many different contributing factors to her situation, that if something were to happen to Nat or someone like her, it would be nobody's fault. And it would be everybody's fault. So there are issues around the nature of the choices that she has around the service providers that are out there. There are issues around how their service providers recruit their staff, with what value proposition, how they're trained, how they're supported, and how they retain their staff, they are issues around how Nat is supported by the NDIA to make a plan. And then there are issues around how Nat is supported to bring that plan alive through a role called a Support Coordinator. Now for all sorts of reasons, none of those elements particularly gel together that well at the moment, despite what's came out of the taskforce following Ann Marie Smith's passing, and also following the Robinson review, which is what the quality and safeguarding commission also did after Ann Marie's passing.

[David Bevan] See I don't understand, and the people listening right now, don't understand. Surely after Ann Marie Smith, and at the circumstances of her death, somebody did an audit that said, how many people are in Annie's position? And we need to get a team of people together who will go around and regularly check on them to make sure this never, ever happens again. Why hasn't that happened? Why is it so hard? What Why don't we accept a bureaucracy that will say, I'm sorry, it's just too difficult, people are going to fall through the gaps. It's not that hard, we get an audit, we know who these people are. And then we go around and we make sure that they're cared for. It's pretty simple stuff.

[Robbi] Not rocket science. I think the what we've heard from people is with the shift from the previous arrangments before the NDIS where things sort of were within the state. Now moving to the to the, to a federal arrangement, it seems to create a little bit more distance between people and the system that supports them. I also think that because the system is going to look a lot more moving parts, it makes it more important that there is a person who is assigned to each participant who can build a longer term relationship with that person, and be their first point of contact. That's meant to be the role that they call the LAC. But it doesn't play out like that in reality. So that's a that's a key thing that's missing. And even though the Robinson review, talked about the need for greater information exchange between states and territories, and the Commonwealth Government, around a people living with disability who are on the scheme. And even though it talked about people having a named worker that doesn't seem to have come to pass.

[Ali Clarke] Where can people go? Is it and are other states and territories doing things differently to what we're doing here in South Australia that we should be learning from?

[Robbi Williams] Well, there's there's one, it doesn't give us the answer for Nat because Nat is very fearful of speaking up to anyone, including at the moment, independent advocacy agencies, but that we had, we do have good independent advocacy agencies in South Australia who do individual advocacy. But this appears to be the only state that doesn't invest in that it's just Commonwealth money that funds the South Australian independent advocacy agencies, whereas the other states and territories all tip something in as well. So may not necessarily fix things for everyone. But certainly the state government can and should invest in individual independent advocacy. So people like Nat do have a phone number they can go to without joining a waiting list and get confidential help with the issues they're concerned about.

[David Bevan] That's the voice of Robbi Williams, Chief Executive Officer with Purple Orange, which is an advocacy group working on behalf of people with disabilities. And they have organised this podcast with Nat, not her real name. And that's where the audio that you heard earlier was taken from.

[Ali Clarke] One of the things that's very confronting is how many people are saying [crying] that they know about this, that it's happening to their loved ones, on our tech line.

[David Bevan] Nat Cook is the Shadow Minister for human services. Good morning, Nat Cook.

[Nat Cook] Good morning, what a what a confronting piece of audio Ali, I know how personal you would be feeling this as well. And I, I've worked in disability services on and off since the mid 1980s and looked after people and supported people to discharge out of institutionalised care from Julia Farr services and the story of Nat hits home to me very deeply. There has been very little change, I think the opportunity to make significant inroads and investments into the change of our disability sector has been missed, at this point. There's been a lot of talk and commitment that's happened, but I just don't see the effective, person centered changes that are required. At the end of the day, there are people that live with disability that are so very strong. They are some of the strongest people I've met and spoken to. But it's the very policy makers that have been talking and doing nothing about that for the last 12 months that make these people vulnerable and it's just not good enough. We have to stand and make changes now.

[David Bevan] Irene has called from Goolwa at almost nine minutes to 9. Good morning, Irene.

[Irene] Hello. This is pretty heartbreaking. Why hasn't it stopped? Where are the advocates? Or the advocates being bought off by the industry, are they? Maybe we should send that rumor around that the advocates being bought off by different agencies?

[Ali Clarke] Well, we do have one in the room to be fair here, with Robbi Williams and Purple Orange, what I'm also seeing, understand Irene you left the industry 15 years ago, but I'm seeing a lot of people like you Irene that have said that they have been in the industry and that they have left, and they see a lot of good people leaving it because they've been so frustrated in it. Robbi, what do you say to someone like Irene, but also to people who are saying there seems to be a really high turnover of good people who want to work, but they just get frustrated by system.

[Robbi Williams] I think it's very true that people can enter Human Services, wanting to make a difference, and then find that they get frustrated either by the system or by the agency that they work with. But our experience is that if you attract people, on the basis of strong values about making a difference, and then make it possible for them to do their job, well, then they stay. It's not rocket science to attract the right people, and to keep the right people in a sector like this.

[David Bevan] Now, we did ask for Michelle lensink, who is the South Australian minister responsible for this sector disabilities and she wasn't able to join us. But we were sent a statement saying that the Marshall Liberal government has acted on all seven recommendations to improve safeguards for our most vulnerable South Australians. But that's all very well and good, she can come on and talk for herself rather than us reading out a statement. But let's just finish where we began with you, Robbi Williams, is anything better than it was a year ago for the Ann Marie Smiths and the Nats living in South Australia?

[Robbi Williams] No, nothing is better for people at the moment. But it could be and it's not hard.

[Robbi Williams] Where do people go to hear the entire podcast?

[Robbi Williams] They can go to our website, which is purpleorange.org.au. And it's also on Spotify.

[David Bevan] I think there's also going to be a vigil tonight for for Ann Marie Smith. And I think Bill Shorten was very much the architect of the NDIS, he's going to come out and take part in that as well. So this will play out throughout the rest of the day.

Now obviously, it's been fairly heavy going, but important going but if after listening, you do need to speak to someone, don't hesitate to reach out you can ring an organisation like Lifeline on 13 11 14. And in the meantime, Robbi Williams, Chief Executive Officer of Purple Orange, thank you very much for coming in here. Nat Cook Shadow Minister for human services also part of that conversation as well.