

## 'And You Think You're the Expert?'

### Episode 4: Support Coordinator

**0:00:00.1 Jane:** This podcast talks about sexual violence and domestic violence. It might make you feel upset or scared. If you need someone to talk to, there are numbers in the notes for this podcast.

[music]

**0:00:13.3 Jane:** We would like to first and foremost, acknowledge the Traditional Owners of the ceded lands on which we are gathered on for this recording, the Gubbi Gubbi people. We would like to pay our respects to their Elders, past, present, and emerging.

**0:00:27.5 Abbey:** If people believe that we can't make decisions, then they don't believe in us.

**0:00:33.0 Minnie:** If support tells you what to do all the time, you'll never learn.

**0:00:36.4 Amethyst:** Don't talk to me like I'm a child, but don't also talk to me like you're a professor.

**0:00:41.5 Luna:** Help us when we ask for help.

**0:00:44.2 Poppy:** To speak up instead of feeling scared and afraid.

**0:00:48.8 Betty:** Listen to us. We know what we need.

**0:00:51.7 Kaitie:** Hello, this is 'And You Think You're The Expert?' podcast where we talk about intellectual disability, accessibility and violence. Welcome. My name is Kaitie and I'm one of the workers from WWILD who helps out in each episode.

**0:01:04.8 Jane:** My name is Jane and I'm the other WWILD worker. Your host for each episodes are experts in the field, so they are women with an intellectual disability or ID for short. Please see our introduction episode, if you would like any more information.

**0:01:18.6 Jane:** Make sure you are making sense. This is one of the main ideas we heard in our workshops when we talked about support coordination. Our experts shared that NDIS plans and the money that goes with it can be very challenging to understand. We heard about the importance of everyone talking to each other, but keeping the person in the loop at all times. When it comes to supporting people when they are going through violence, our experts felt that their support coordinators could be doing more. Many felt that support coordinators needed more training around domestic violence and the types of things they could be doing to support their clients when they are experiencing violence. So before we get into it, I would like to introduce our experts and our peer worker today.

**0:02:04.3 Cassie:** Hi, I'm Cassie.

**0:02:05.4 Jane:** Thanks, Cass. We're also joined by Abbey, Chloe and Star. We also had our expert, Linda, contribute greatly to coming up with questions, but she can't be with us today, so we will read out some of her thoughts as we go. So I would like us also to introduce Agnes. Agnes is from Community Living Association, and has kindly given up her time to be with us today.

**0:02:28.5 Cassie:** Welcome, Agnes.

**0:02:29.8 Agnes:** Thank you, Cassie. I'm actually really happy I'm invited as well.

**0:02:33.7 Cassie:** How do you communicate with your client who has an intellectual disability, and how do you make sure you're making sense?

**0:02:44.1 Agnes:** Thank you for the question. So what we will do is we use easy English, and we will use visual aids, like we talked about with Abbey earlier. So in the visual aids sometimes we use drawing or even pictures, just

to make everything easier. And then also we will check understanding as well, like we might ask if they can repeat what we have discussed and check everyone's on the same page.

**0:03:11.9 Star:** My support coordinator writes things down for me, and that helps. She helps me go through the plan, she doesn't use difficult words and she takes her time.

**0:03:25.8 Agnes:** Yeah. That's really good. And to be honest, writing it down is easier for me to understand what I'm going to say as well.

[laughter]

**0:03:35.3 Agnes:** Yeah, so I actually prefer that, using visual aid, using some drawings and writing things down, it will help us. Me and my participant, we can be on the same page together.

**0:03:46.3 Chloe:** Workers need to communicate properly, lots of people with intellectual disabilities don't understand and they need to change how you communicate with you, they need to talk and respect, some workers don't, communicate and respect... Respectful manner. They need to talk... Hang on... They talk in a nasty manner. Use a shorter word instead of long words, or hard words, talk slower and don't talk fast.

**0:04:31.9 Agnes:** Yeah, I think that will be really important that your support worker will be able to support you in a way that everyone understands and communicates in a transparent way, and especially really being respectful to each other.

**0:04:47.2 Jane:** Linda had some reflections that she wanted to share about her support coordinator so I'll read this out for Linda. Linda says, "My support coordinator lets me work out my way, if she doesn't think that's the right way, she lets me know. It's good. She is still okay if I do it my way. It's my life and we can't be pushed around by our support coordinators." She also said that it was important for workers to talk to each other. Linda says, "I find it was really great when everyone talks to each other. When I had my rails done in my

house, they organized everything. They spoke to the OT. I didn't have to do it. They talked to my mom and dad about it. My support coordinator organized it all. If they didn't do that, my plan wouldn't work and it would be really hard to do it myself." Does anyone else wanna share what helps?

**0:05:39.2 Star:** Could they write the questions down and we sort of answer it in our own way?

**0:05:44.3 Agnes:** Yeah, sometimes it might be after discussing, I might ask, Which is the preferred communication way with the participant? Some of them, instead of using phone calls, so they can answer at their own pace, they do prefer me to text them or email them, just so they can reply whenever they want and they can think about it first, or if not, it has to be a phone call or a face-to-face conversation. I could let them know, "Why don't you think about it first? You can get back to me whenever you want."

**0:06:13.3 Chloe:** A lot of people don't feel comfortable talking on a phone where... They do feel better talking face-to-face, where with the eye contact in that. And I think the eye contact, talking face to face, is a lot better than talking on a phone, because I know myself, I'm not good at communicating or talking on a phone.

**0:06:36.4 Agnes:** Totally agree with that 'cause sometimes, face-to-face, you can read a lot of non-verbal cues as well. Even though you may say, yes, you actually look hesitant, so I could pick up on that and know that you might actually don't feel like saying yes.

**0:06:49.6 Chloe:** And you can always tell, too, whether somebody has also got communication skills too, whether they're actually listening to you, because their body language in that also gives them away, 'cause their body language in that plays a big part in whether they're listening or whether they're not listening, and that plays a big part in their communication skills as well.

**0:07:13.7 Jane:** Why do you think it's better to meet with the worker face-to-face rather than on phone?

**0:07:18.1 Cassie:** 'Cause face-to-face, you can actually build more of a relationship. Over the phone, you can get disrupted so many times, and you can't actually build that relationship with the person than what you can face-to-face, and know how to treat someone more understanding that has an intellectual disability.

**0:07:46.5 Agnes:** I really agree on that. I believe relationship is best felt with this face-to-face communication or face-to-face meeting, just so everyone... We can understand each other better. Sometimes on the phone, it can be very restricted and limited communication between on the phone. I can't see how your face... Your facial expressions. Yeah, it's very difficult on the phone sometimes.

**0:08:10.4 Kaitie:** Linda, who couldn't be here today, agreed it was easier to talk face-to-face. She said, "It helps me the way my support worker talks to me. She talks slow in that. She's understanding. She doesn't use big words. She uses words I can understand, and that if I don't understand, I'll ask her to repeat. I can trust her and all that." Like we spoke about in other episodes, um I think it's really important... Well, a lot of our experts said it's really important to feel safe enough to ask the question, to feel safe enough to say they don't understand. And it's particularly true when talking about really complex things like support plans. Next, we'll be talking about what support coordinators should be doing when their client's experiencing or has experienced violence. Chloe, would you like to ask the next question?

**0:08:56.2 Chloe:** Well, what can the NDIS do for clients with intellectual disability who are going through domestic and family violence?

**0:09:08.4 Agnes:** Thank you for the question. NDIS has made it clear that funding cannot be used for supports that are covered by mainstream services, for example, domestic and family violence and housing. It is then the support coordinator's role to support the person to research and connect them with communities and mainstream services. People may be able to use the NDIS funding for therapeutic counselling.

**0:09:37.3 Star:** Why can't they use it for family violence and all that?

**0:09:40.9 Agnes:** So NDIS have made it clear that there are government or mainstream services available for the domestic and family violence area, so they will not cover that area, but then what our support coordinator do is to connect the participant with the mainstream services.

**0:09:57.7 Star:** That should have been in the first plan, not just... Has that been recently that they added that, or is it been a while?

**0:10:06.1 Agnes:** Always been that way, unfortunately.

**0:10:08.2 Jane:** How do people feel about that because I know that we've heard that going to mainstream DV services can be really difficult if there's anyone I wanna talk to about any experiences.

**0:10:23.2 Abbey:** They really should change the policies and procedures of nearly half the NDIS, because some of it, I would like to say a few choice words, but anyway... I was going to say suck, but anyway. But I think that domestic violence too, also goes into the situation of people with disabilities. If we're not understanding... Okay, I'll briefly go back there and say, this life from when I was a child till I was about 18, I was abused. Then up to 18, I still was abused because of situations, and we won't go down all of the situations, and no one really helped. So how are we supposed to get help if youse are only gonna, as I would say, flog us off to... Maybe that's not the right word. Okay, you're gonna pass us to another department. That's the word for flogging off, sorry. And say to us, "Okay, you can ring them," and not just say, "Oh, well, sorry, we're not gonna help, and we can't do anything." So to me, this situation has changed so that you could say, "Okay, I'm in that situation, you could maybe take me over to Charlie's place and make sure that I'm okay with Charlie. Stay with me till I'm feeling calm, relaxed at Charlie's," and then ring me up the next day and go, "Oh, okay, look, we've got this place that we can take you to. Would you like to go? And if you don't wanna go, this is another place you can go," because, otherwise, you're just dumping us from here to here, and we're gonna feel, like, lost. Sorry.

**0:12:21.9 Agnes:** Yeah, that's okay. Yeah, would it help if... 'cause you can still

use NDIS funding for support worker, right? So if you have a trusted support worker, while the support coordinator will be responsible for researching, let's say, Charlie's place may be suitable for you, and then support worker can support you to get to Charlie's place, take a look at it.

**0:12:42.4 Star:** Yeah.

**0:12:43.1 Abbey:** You're on the right, that's what I was meaning...

**0:12:45.4 Star:** Oh, yeah.

**0:12:45.8 Abbey:** I'm agreeing with you because I was... If we sit there and you just go, "Okay, you're gonna go to Charlie's place," and even though I know where Charlie's place is, but I've just been in a situation and I'm gonna be frazzled Like I am the moment still, but any way. You just get really... You can't breathe, your chest goes tight, this... Now I'm gonna go... You could ring a friend and go, "Oh, look, could you come and get me?" But they might be busy.

**0:13:13.0 Agnes:** Yeah.

**0:13:14.7 Abbey:** So you gotta get there somehow, and if you can't get in the cab 'cause you're all shaking and whatever, and you've got your problems or issues as I'm gonna call them, then you need that help then and then. So somebody needs to organize right. If you've got that, ring Sally who's your support worker, she'll be there like a click as a tail. She'll get you to Charlie's, and then we're sort it out from there.

**0:13:42.5 Agnes:** Yeah. It would be good 'cause when you're in such a hectic situation, you'll be so anxious, so frustrated, you just need the Support Co-ordinator to be solution-focused. This is what I found, this is what I researched, this is who can take you there, and how you're gonna get there. It will be really good if someone can do this step by step and make... Yeah, the solution.

**0:14:04.5 Cassie:** Yeah. In our group, people were saying that when they

needed to leave a DV, they needed to go pretty well quickly, and it always took NDIS slow to get, um, moved into a more stable place. And some of the women also said, NDIS workers should be trained around DV and that, so the workers know to pick, "Okay, this person's been in a domestic violence."

**0:14:48.7 Agnes:** I totally agree on that point. I think when a support worker is more trained in domestic and family violence situation, they will be able to pick up some cues from you, that they will be identifying that, "Oh you might be under some kind of violence situation that needs to be addressed." And maybe that could be the starting point of moving you to a safe place and that could be picked up faster.

**0:15:12.2 Abbey:** Or I was going to say, with DV or domestic violence, if you wanna call it that, there's not just hitting, so how would you pick up on... Okay, maybe you're looking at me, are you gonna pick up and sit there and tell me that I'm having domestic violence? I'm just looking.

**0:15:32.2 Agnes:** I would say physical abuse is of course very easy to pick up, 'cause you can see if there's any bruises, but emotional abuse is just as horrible. So how would I normally pick up is, maybe this... Because, while I have the relationship with the participant, I will know suddenly they sound really down, or they suddenly don't want to attend activities they want to do, maybe something's going on. Then that is something that maybe I could pick up.

**0:16:00.9 Abbey:** I really don't like it when people say, they're sorry. I think they should try and find out more, ask if we want to talk about it more, ask the person what type of help they might need. I think it's important for the person to see a worker in real life, not on the phone, let the person talk about it at their pace. If you push people, this is not going to be good for their mental health, especially if it's their first time. I think the worker should always believe the person, because it's dangerous if the worker doesn't believe the person.

**0:16:44.3 Agnes:** Yes, I really agree with that point. I think it is important that you have a support worker, 'cause in a DFV situation, you might not be ready to leave yet, it might not be safe for you to leave. And so it's always important



that there's a support worker who can always physically be there with you, and just ready to go whenever you can, and just have a safety plan with you, understanding what's going on. I think that's just really important.

**0:17:12.5 Kaitie:** While support workers can have an important role, Support Coordinators are the people that organize someone's plan. While the NDIS is not funded for DV, Support Co-ordinators still work with women who experience DV. Ah, navigating DV assistance is really hard for everyone, I think, but particularly hard if you have an intellectual disability, and harder again, for women who need extra support like supported accommodation. We heard, when we spoke to our experts time and time again that the NDIS does not move quick enough, it doesn't respond to women when they need it to. While a woman who doesn't have an ID can go to refuge, a woman with an ID, who wants to leave a DV situation and needs supported accommodation may wait months to get that new supported accommodation, even moreso if she hasn't accessed it before. And we talked about how unfair this is, it's really truly very unfair. There should be equal access. So how would you help someone who's going through Domestic and Family Violence, who would like to move out of their home and needs supported accommodation?

**0:18:12.9 Agnes:** Thank you for the question. Firstly, our team did talk about, we need to check what's the definition of the supported accommodation, 'cause in NDIS language, supported accommodation might mean supported independent living, which means there will be 24/7 support in a shared housing situation. So is that the supported accommodation means the supported living, independent living? Yeah, so if that's the case, we need to check with the participant whether their disability support meets the criteria for NDIS support accommodation. Normally, they will request evidence from an occupational therapist, maybe psychologist... Yeah, to say why you would need 24/7 support. Is that to assist with daily living, or is your support needs going to be that high that you would need 24/7 support? But if that's not the case, let's say emergency shelter or other Department of Housing Support, a Support Co-ordinator can support participant to explore housing options, like connect them with Department of Housing, apply for housing transfer, emergency accommodation from Micah project, or other women's shelter.

**0:19:34.7 Cassie:** Yeah, and people with intellectual disabilities, when they go to a refuge, they don't feel like they're getting supported by the people at the refuge.

**0:19:47.1 Kaitie:** So they need more support?

**0:19:48.4 Cassie:** Yeah, they need more support with home and yeah...

**0:19:54.5 Agnes:** And I agree. And I feel really bad that the government actually didn't put enough funding for domestic and family violence services. I know that shelters sometimes are just not the ideal situation to move in, there's not enough the level of support that you would need. And sometimes, they may say you can't put in your own support workers in there. That your own support workers can only support you while outside of the shelter, 'cause the shelter needs to be in a safe environment. And there would be shared housing, where it could be quite overcrowded sometimes.

**0:20:32.1 Abbey:** Yeah, so if you're getting from a domestic violence, and you're getting probably put somewhere, you are going to go into overdrive. Well, I call it overdrive, because otherwise, you're just, you're just lost. And if you're putting me into a sheltered place, and you haven't worked with me before, I am definitely going to go into overdrive, 'cause I'm gonna feel like I'm claustrophobic. I'm gonna feel like I'm locked up. And then on my brains, there's going to do... I'm gonna be doing a stampede and wanting to get out the door, where I'm feeling already unsafe out there, I'm not gonna feel safe in there. So you need to talk to and know us. And do maybe in steps, like I said before, just say, "We're going to go to Charlie's now, this will just be for the night, you're gonna be checking tomorrow, we'll send a support worker to say, "how are you feeling, how are you coping?" You know, talk to us like a human being. And then don't make things that are triggered, because otherwise, if you don't know what triggers us, you're never gonna know, because otherwise, you're just going to put us back to where we were, a scared little rabbit in the first place.

**0:21:55.1 Cassie:** Yeah, people shouldn't have to wait because they need extra support.

**0:22:00.1 Agnes:** I agree, 'cause I think the system does makes things taking a longer time. Let's say if you want extra support workers, that will mean you might need... If it's not coming out from the same organization, you may need an extra service agreement. And for the organization to draft it up, it might already take one week, or for the organization to match you with a new worker, it might take time as well. And if you have limited funding on your NDIS plan, your support coordinator will need to ring up NDIS together with you to talk about this change of circumstances, that you experienced domestic and family violence and you need extra support. And that could take at least three months to get back a response. But what the support coordinator can do, what I do, I will call NDIS every day. [chuckle] I kinda, yeah. Just to let them know you are in such a crisis situation. We need a plan review. We need extra support. We need extra funding in there to get you out to safety.

**0:23:08. Abbey:** Why does it, not to be rude... Why does it take three months? If you're just more or less said to whoever you've said it to, that you are putting a change of circumstances or a review, why does it take so long if you're wanting... You need that help now, why are they taking a snail pace to do something?

**0:23:32.5 Agnes:** 'Cause within NDIS, there is different team working on your plan review progress. So we might call the call center, the NDIS call center to let them know your change of circumstances that we put in a plan review request. And that call center will send a plan review request to the plan review team. So until the plan review team pick that up, the request, they will see if this request is urgent or not, and to approve it or not. And that will get sent for the plan review team member to give you a call and schedule in a plan review. And that takes several steps. That's why it is time-consuming.

**0:24:14.9 Abbey:** Time consuming and very confusing.

**0:24:16.8 Agnes:** Yeah. And sometimes a support coordinator can also call back the call center, 'cause we have no access to the plan review team. We don't have the direct number at all, and we can't contact them. So we'll call the call center and escalate that request, and by sending more messages to

the plan review team and let them know "it's very urgent, please read our requests."

**0:24:43.8 Abbey:** Well, that was helpful, but I still reckon companies who, whoever they are, should be talking to one another and they're not talking to one another to get us help. It's not just for people with disabilities, it's, well, whoever it is. We all need help, and if no one's going to give us that, and we're all sitting there in that little spot waiting for that to be passed to that one and that one to be passed to that one and that one to be passed, I could be dead.

**0:25:11.2 Agnes:** Yeah, there's a lot of information.

**0:25:13.5 Star:** If you don't mind me asking, how many steps are there?

[laughter]

**0:25:17.7 Kaitie:** This is a really great question.

**0:25:20.1 Cassie:** And you got her at the right time.

[laughter]

**0:25:24.2 Agnes:** I am thinking it will be... I will think three or four steps. The first step will be you letting support coordinator know or support coordinator picking up something's going on. And to call the call center will be the second step. And for the first step will be for the call center to pass that message on to the plan review team. And the last step would be... Oh no, the fourth step... Actually, there's two more steps, sorry. [chuckle] Five Steps. The other step will be for the plan review to approve or reject your request. If they approve it, we approve it means they will give you a call and schedule in a plan review with you. Reject means we will need to appeal.

**0:26:13.2 Star:** So what do you mean by appeal?

**0:26:14.7 Agnes:** Appeal will be... Um... Asking for an internal review, I think. There's like a request or review... Of reviewable decision, 'cause a plan review

team make a decision to reject your plan review request. So we will ask an internal review to review that, to challenge that decision. And if they still reject us, we need to go to the AAT, which is the Tribunal, to challenge that decision again.

**0:26:47.4 Cassie:** Now, to myths, our favorite part.

**0:26:48.8 Jane:** So as you know, we talk about myths in every episode because they're so important. Most of the women in the groups wanted to talk about these myths, because they thought that their workers believed them. These myths can be so dangerous, because they excuse abuse and make getting good service impossible. So, let's jump into it.

**0:27:06.2 Star:** Some people think that people with intellectual disabilities mostly have higher levels of support, which means they don't get abused. What do you think about this?

**0:27:16.4 Agnes:** Thank you for the question. Abuse can happen to anyone. It comes in different forms: physical, sexual, emotional, financial, and comes in different settings: formal and informal such as homes, workplace and social settings. We need to be aware that people can be exploited by their formal and informal support networks, such as families and friends, support workers or other paid staff whom they get... Come in contact with.

**0:27:47.0 Jane:** I think there's also a bit of a myth in the myths. There's a myth that all people with disability get support.

**0:27:52.2 Star:** Some people get the support, and some people don't.

**0:27:55.3 Abbey:** Not everybody gets a high level of support. This is fact.

**0:27:58.8 Kaitie:** Yeah. And I think, going on what Agnes said before, that having a high level of support can mean that people are abused by the workers as well. So people with ID who have high levels of support experience more opportunities for abuse, like someone who needs help showering, for example, is more likely to have moments in time or opportunities where

abuses could hurt them. And then on top of all this, a lot of experts said they're less likely to be believed. So I think it makes it even worse.

**0:28:30.3 Jane:** I think that brings us to the end. Thank you so much to Agnes, for joining us today.

**0:28:34.6 Kaitie:** Yes. Thank you, Agnes.

**0:28:36.5 Agnes:** Thank you for inviting me. All the feedback are really useful.

**0:28:40.5 Cassie:** I hope you got a lot of... Out of this, Agnes. And I hope you can take it back and share it with the rest of your team.

**0:28:48.7 Agnes:** Yeah, even the whole organization will be really good.

**0:28:52.1 Cassie:** And I hope this is going to be helpful for you guys when it's finished.

**0:28:56.4 Jane:** Thank you, everyone, for this episode. This was a really tough one. This area, so that is working with the NDIS system with women who have an intellectual disability and violence, is so confusing. I think this was made really clear in this episode. There are a lot of different ways to navigate it. And a support coordinator is usually the one working out the path. Agnes was a gem in answering all of our tough questions about systems, which I'm sure she finds really hard as well. There is no one answer here. I think the big message from our experts was, once again, slow down, break it down to steps and help them, connect them with DV and sexual violence services, making sure that DV and sexual violence services work hand in hand with their support coordinators.

**0:29:42.4 Alison:** We have made a booklet with information about the Listen Up! project. This is information about a house, how we did the project and some other stuff that may help workers. You can find it on our website. See the notes for this podcast for more information. If you find some of the things we spoke about today upsetting, you can find numbers for the support if you live in Australia in the notes for this podcast.

**0:30:12.0 Jane:** This podcast was created as part of the Listen Up! project at WWILD. We were kindly funded for this project by the Department of Social Services as part of their community-led projects to prevent violence against women and their children. What we talk about in this podcast is not advice. WWILD expressly disclaims any liability howsoever caused to any persons with respect to any action taken in reliance in the contents of this publication.