

'And You Think You're the Expert?'

Episode 5: Mental Health Worker

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.

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0:00:13.7 Alison: We would like to first and foremost, acknowledge the Traditional Owners of the unceded lands on which we are gathered on for this recording, the Yugambah people. We would like to pay our respects to their Elders past, present and emerging.

0:00:31.6 Abbey: If people believe that we can't make decisions, then they don't believe in us.

0:00:37.1 Minnie: If support tells you what to do all the time, you'll never learn.

0:00:40.5 Amethyst: Don't talk to me like I'm a child, but don't also talk to me like you're a professor.

0:00:45.5 Luna: Help us when we ask for help.

0:00:48.2 Poppy: To speak up instead of feeling scared and afraid.

0:00:52.8 Betty: Listen to us. We know what we need.

0:00:56.5 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.

0:01:09.6 Jane: My name is Jane, and I'm the other WWILD worker. Your host for each episode 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.

Kaitie: "We stand alone. We get treated like average people. Mental Health Services have no idea how to work with people who have an intellectual." This is a quote from one of our experts from one of the workshops we did. Throughout the workshops, we continued to hear experiences of women who have an intellectual disability and have experienced violence, being made to feel as though they were too difficult to work with, could not be helped, or felt further abused by the mental health system. Today, we will hear how mental health workers can better support women who have a dual disability and have experienced violence like sexual violence and domestic violence. Dual disability means a person has an intellectual disability and a mental illness. I would like to introduce you to our experts for the discussion, Skittles and Zarafa.

0:02:12.5 Skittles: Hi, I'm Skittles.

0:02:14.0 Zarafa: Hi, I'm Zarafa.

0:02:16.7 Kaitie: Both our experts are very passionate about this topic and have been the driving force behind this episode. They insisted we talk to a mental health worker. As usual, they are joined by our peer worker.

0:02:27.7 Alison: Hey, I'm Alison.

0:02:28.8 Kaitie: Thank you, Alison. And as usual, myself and Jane will also read out advice from other experts who could not come today. Today we will be interviewing Diana Bennett. Diana is an area manager with Richmond Fellowship Queensland, and has kindly given up her time today to answer our experts questions and listen to some of the ideas they have about what they think mental health workers could be doing better when working with women who have an intellectual disability. A big thank you to Diana for joining us today.

0:03:00.8 Diana: Thanks for having me here today.

0:03:01.8 Kaitie: So without further ado, let's jump into our interview.

0:03:04.6 Zarafa: How do you work with people with intellectual disability?

0:03:11.7 Diana: Well, we like to work with everyone in a way that best suits their needs individually. So asking how people wanna communicate, what they identify themselves as being their most important needs and wants, involve anyone that they wish to have involved so that they have people around them that they feel comfortable with, and just meeting people where they're at and going at the pace they want.

0:03:36.7 Kaitie: What do we think about that, guys? Is that a good way to work with people who have an intellectual disability?

0:03:42.7 Skittles: Yes, especially when we're speaking to a new person, we're not ready to talk about it, our problems. We need a bit more time, and we don't like to be forced to say it or getting asked the same questions every time to make us say it.

0:04:02.1 Alison: Zarafa, what are your thoughts?

0:04:05.7 Zarafa: Well, you definitely need a lot of practice, make sure you are listening, that you are really hearing what they are saying, to make sure you don't push them too far, move at their pace, don't be judgemental. Maybe if they don't understand you, you could use drawing or write it down. And then they shouldn't think we should be treated like children.

0:04:34.7 Kaitie: In our next set of questions, we'll focus on how workers can support someone with an intellectual disability who is, as one of our expert calls it, "really going off" Our experts feel that workers are often not equipped to support people emotionally when they feel really heightened or really overwhelmed. They said that the response was often to call an ambulance or the police. Although our experts understand that this response may be needed

to keep people safe, they believe it should not be the first point of call. Our experts felt that listening deeply, really getting to know the person, and giving them as much control over their decisions as possible was really important when it comes to working with people who have a dual disability and have been through violence. So who would like to ask the first question?

0:05:20.9 Skittles: How would you help a client who is really angry and going off?

0:05:29.7 Diana: Well, I think if someone's really angry, there's generally a really good reason why they're feeling that way, so I think it's important to validate how someone's feeling and give them the opportunity to talk through what's happening. When we first meet with someone, we talk about their preferences in a whole range of different things about, if they're feeling a certain way, how they would like us to respond, what they would like us to do. So as an example, for some people it might be good to just kind of give them some space and let them take some time to just have a breather. It's important, I think, for us to stay calm as well in that moment. Yeah, and just follow, follow the person's lead.

0:06:14.3 Skittles: That sounds good. That's another idea I came up with. Like you said, give them space and calm down.

0:06:20.5 Diana: Nice.

0:06:22.5 Skittles: Another thing is talk to them, like come up with different things like, "What do you like doing?" Or anything like that. Or "Do you like to go for a walk?" Or like that. Or they're not thinking straight and it gets worse, then you have to do it, ring someone. But then things should come in first before just ring up the ambulance or coppers and send us to the hospital. 'Cause I felt like you guys are pushing us away.

0:06:57.8 Dian: Yeah, that's really good advice. I think sometimes you're going for a walk on the beach or something like that can be really helpful. Yeah.

0:07:05.4 Kaitie: Yeah, and you talked about a little bit about when you had

workers who've done that really well, who've kind of helped you when you're feeling really angry, what kind of helped?

0:07:15.1 Skittles: It kinda helped me 'cause I learned how to control it now. It took me a while but, I got it in my purse, I got it on a piece of paper, I like to listen to music or go for a walk, or having a sleep.

0:07:31.8 Kaitie: Zarafa, what do you think a worker should do if someone's really angry?

0:07:37.0 Zarafa: Workers should safely keep their distance from them so they don't get injured, then sit down and try and figure out what will help them calm down. Drawing, writing, talking to someone, music, so help the person find out what will make them calm. Check and make sure they won't hurt themselves. Their safety is a high priority. Make sure their safety plan is in place. It's good to have a safety plan before that happens. Sometimes it's not that people are trying to be violent, it's that they can't communicate, and get out what they are trying to say. So learning to help them communicate is good, so asking what they like can help. My caseworker did grounding with sensory things like, you have to work with what's around you and then you calm down, it gets out of your mind. I love animals, I look outside for animals, or butterflies or whatever.

0:08:57.1 Diana: Thanks Zarafa, I think that's a really important advice.

0:09:01.2 Skittles: Like I don't like going to hospital, 'cause everything's just being taken away from me, and there's a lot of reasons for it. And I think one of the reasons is, it's good for mental health people who take us there or meet us at the hospital, explains to the doctors our history and everything, and every details, because we don't like going there 'cause this is not right, and it's not right for males search females.

0:09:38.3 Diana: Absolutely, the hospital can be a really scary place, so yeah, I think it's really important to support people if that's where they are going to have to go and help you to feel like you can advocate for yourself and say what you wanna say. Yeah.

0:09:53.9 Kaitie: Skittles, could you tell us a little bit more about why it's important for a mental health worker to share some of the person's history to hospital staff?

0:10:02.0 Skittles: Yeah, so is very important, if these guys tell the hospital our history and that, because especially when they get males search us, especially when we're been in the above situation, or sexual assault, it plays in their mind, it's gonna happen again.

0:10:23.4 Diana: That's really scary.

0:10:26.2 Jane: Yeah, Skittles. This was a really important one, this was one of the main points that you talked about, and you felt that the people at the hospital didn't really know how to support you at that time.

0:10:40.3 Skittles: No, they don't, and especially when we go to the hospital, go to the hospital and all that, so all we want is the nurses to talk to us, not medicate us 24/7, this push us away because we're not pill poppers. We just want someone to talk to.

0:11:00.5 Diana: Yeah, absolutely. And that's normal.

0:11:03.4 Jane: Does anyone have any other thoughts around why it's important for people to be in charge and make their own decisions around their health?

0:11:11.9 Alison: It can be a lot harder to make decisions when you have an intellectual disability, and you've been through violence, and you have a mental illness.

0:11:20.6 Jane: It can be. What do you think a worker could do to help, Alison, what could they do to help you to make decisions for yourself?

0:11:29.4 Alison: They can help me understand the good and the bad choices and help me make the right decisions in the end.

0:11:36.2 Jane: That's really good... So help you understand consequences and things of different decisions

Alison: And actions that come out of the consequences.

Jane: What do you think, Zarafa?

0:11:44.7 Zarafa: The workers, so the person has to say, they should explain what the medication is for, what the side effects are, let them know about natural options, work with them and say, "What do you think will be best for you?" Give people lots of information so they can make up their own minds.

0:12:10.1 Diana: Yeah, I think it's really important to find someone that you feel comfortable with and that makes you feel heard and valued. Yeah.

0:12:16.2 Zarafa: Thank you.

0:12:17.0 Jane: Getting through the mental health system is tough for most people, however, and is even more difficult for those who don't understand the system, the language used, or their rights within it. Our experts will now focus on the accessibility of the mental health system for those who have an intellectual disability and have experienced violence. Accessibility means that people who have a disability are able to receive the same type of support as those who don't. For example, it means understanding your diagnosis and being at the center of discussions around recovery and options, but let's hear more from our experts.

0:12:50.4 Skittles: How do you help explain the steps in a mental health system to clients?

0:12:57.6 Diana: We always try to do it in a way that each person is most likely to understand. So we might offer to attend appointments with some people to assist them to feel safe when they're meeting with, you know, clinical treating teams and help them to feel comfortable within the mental health system, because it can be a really scary experience, I definitely agree. Um... I think our

aim is to help people feel comfortable and like they're able to speak up for their own needs and rights and understand what's happening in all steps of the journey as well.

0:13:32.5 Skittles: If we're to understand show us or explain to us for the second time, a bit slower, so we can take it all in and get to know what you're saying.

0:13:44.3 Jane: I think that's a really good point, Skittles, 'cause when we chatted about this, and you talked about it being really important, sometimes things need to be explained more than once.

0:13:54.1 Skittles: Yes.

0:13:55.4 Jane: Why?

0:13:58.4 Skittles: Because it's very hard to take it all in at once, so sometimes some people need to be told a couple of times, just so they're aware of it and be sure that that's what you said.

0:14:12.6 Diana: And I can imagine it would be harder also because you're in a stressful environment, in an environment where you probably don't wanna be or yeah. That would be important for sure.

0:14:22.7 Zarafa: No one explained to me about how it works. I was just put in an emergency room and had to wait for someone from the acute team to see me. They asked about my suicide levels, but they didn't explain much. They wouldn't put me in the mental health area. When they come to my house, they didn't really listen to me or explain anything or take me seriously, they just kept saying all the things I had to look forward to. I nearly died twice in their hands, they ignored the warning signs. They didn't explain a lot. All they did was come to the house and do a check up, and they said they would do a follow-up session and that was it. It was pretty confusing. They also took my bag away from me, my backpack, and then I have a medical assistance bear, they even tried to take her away, which keeps me calm, and didn't explain why they were trying to take her from me.

0:15:31.7 Diana: I'm sorry you had that experience.

0:15:34.6 Zarafa: Thank you.

0:15:37.2 Skittles: Like it's not right for them to hard us down, to say the nurses could inject us til we fall asleep. And another part I was listening to, it's very hard to make a complaint to the hospital, the way you get treated there, especially when they've got the cameras turned off or they don't believe us, and they do not take the matter further.

0:16:03.1 Alison: Some people in our group said it was hard to understand what depression or anxiety was, how do you help your clients understand those feelings?

0:16:11.9 Diana: Thanks for the question. Again, I think it's really important to think about what each person is going to understand, so you could talk about symptoms that they might experience with depression and anxiety, or just generally how some people might feel if they have depression or anxiety. We can offer to support them to speak with the clinical team to help increase their awareness and understanding of what they're going through, and also explain that everyone does experience things differently, and that's okay.

0:16:45.2 Jane: So I'm just wondering, I might throw it over to Skittles first, if that's okay, and then we'll go around. So Skittles, when we chatted, you said anxiety and depression, these are tricky words to understand, did you feel like you had a good understanding of these words when your doctor talked to you about it?

0:17:05.2 Skittles: No, 'cause they never explained it to me, what I've got, they just told me you got depression and anxiety. I'll give you some pills, you can take them pills, but never explained to me, what I've got properly and that's what they need to do. I felt really angry and upset.

0:17:23.3 Diana: Sometimes it's nice to know what else you can do other than just take medication because medication isn't the be all and end all.

0:17:29.5 Jane: Zarafa, do you have any thoughts on this one?

0:17:31.9 Zarafa: From memory I don't think it was explained to me very well, because my caseworker did work with me and explained it to me, and another worker come out and she explained it to me. At the time I was diagnosed, they said it was post-traumatic, and I was like, "What the hell does that mean?" That was from my cancer, abuse and the things you went through, and then they said borderline, and that was from... from the rape, they didn't really explain it. That needs to change. We get diagnosed with them, did we get it from when we were born or was it from the trauma? That was confused me. If it wasn't for my caseworker, I would not have known. She gave me a sheet and showed me, which categories I fit in. They need to make sure what we understand and explain things to us. They tell you these things and they say, "But we can't say for sure, until you've seen a psychiatrist." It's confusing. They change the story and it confuses you more. It's not explained to us. How do we work out how to work through this and better ourselves and learn what ways to help with this diagnosis? I was just told to take antidepressants.

0:19:11.1 Diana: I think sometimes rather than just, yeah, talking about the actual name of the diagnosis, it's useful to talk about what you might be experiencing and how to work with that.

0:19:20.9 Alison: I think that anxiety is a feeling of when you get really scared inside and the depression is really sad, and I agree with what you were saying about the other stuff, example, if you don't wanna take medications, one of the things I do is go for a nice walk, have some sleep, even call up a family or friend and I start to feel a good better and have a cry sometimes, but it helps. Let the emotions out.

0:19:44.7 Jane: Experts in our workshop regularly shared that they thought mental health workers passed them on. They said that it felt that workers believed they were too hard to work with because of their dual disability and experiences of violence. This often resulted in some of our experts feeling really upset and hurt. Being considered 'too hard' to work with, certainly does not instil feelings of hope for recovery. This is a difficult area to work in, there

is a lot to consider at this busy intersection of mental illness, intellectual disability and violence. A lot of support is needed but every single person is worth the effort and understanding.

0:20:19.7 Alison: How would you support someone who has an intellectual disability and experience of violence?

0:20:26.5 Diana: I think the first thing that's important to do is ensure that they're feeling safe. We can discuss strategies and options to stay safe, and support them to speak to someone if they haven't, like if they need to call the police or a DV service or whatever it might be that's best suited for them. We can also ask if they want a link in with a psychologist or counsellor to talk through their experience and come up with steps to move forward.

0:20:53.5 Alison: Hmm... I like that answer.

0:20:56.0 Skittles: They can be there with us with that, and also for us to be through that'd be good idea when they go to hospital tell the doctors and the nurses the situation and what we've been through, so they understand.

0:21:15.0 Diana: Yeah, so just taking the time to chat and be there, but then also helping to support you to speak to others as well. Yeah.

0:21:21.7 Skittles: Yeah.

0:21:22.2 Kaitie: Yeah. I think that's a really good point, Skittles, around the idea that sometimes mental health workers can help tell other services what's happening around your safety or whether there's violence happening, and that kind of thing, to make sure that everyone's on the same page, 'cause that can be really hard to talk about when you're really upset or really scared, or going to hospital or something like that.

0:21:47.7 Skittles: It is, it's very hard, especially when they don't understand what we've been through, and it feels like we're going through trauma again, the way they treat us. So it'd be good if they could tell them to stop this from happening.

0:22:01.8 Kaitie: That's another good point even if you're not in immediate danger, like someone's gonna hurt you straight away, but maybe if you've been through violence, there might be things that are extra scary about going to hospital.

0:22:13.5 Skittles: It does, because especially when you had that experience, then you think when you go to hospital, and especially when they get males search ya, a place in your mind, and it takes you back from them days, what happened to you, and you're thinking, "Is this gonna happen again?"

0:22:30.2 Kaitie: So there are a lot of different responses needed, it sounds like depending on what's happening. For example, communicating trauma history to hospital staff, if the person is safe and currently from violence or alerting them to safety issues that the person is currently experiencing violence.

0:22:47.5 Alison: Now, let's go to the next question.

0:22:49.3 Kaitie: Thanks Alison.

0:22:50.6 Skittles: Do you believe clients when they tell you they're being hurt by someone?

0:22:55.2 Diana: I think it's really important to always take what a client says as the truth, and then we can follow through from that and assist them to access the support that they need to work through and understand what's happened or what is happening, and how to stay safe in the future.

0:23:10.7 Jane: Alison, what do you think about this?

0:23:13.5 Alison: I think it's very important to believe the client. And also, I've got another one here; in our groups, people said that they felt people didn't believe them, 'cause of their intellectual disability. It's not fair that people don't believe them straight away.

0:23:33.6 Skittles: Because then we know we can trust them, they believe us, 'cause half the time when we tell people, they don't believe us. They think we're making it all up when we're not.

0:23:44.1 Diana: And you're not gonna wanna keep talking to someone who you don't think believes you.

0:23:47.0 Skittles: No.

0:23:47.4 Diana: Yeah.

0:23:49.5 Alison: 'Cause you haven't been in their shoes. Next, we will discuss the myths that surround the people who have a dual disability and experience violence. A myth is something that people in the community might think is true, but we know is not. Myths can be incredibly dangerous, and when believed by service providers can result in a person with a disability not receiving the support required to recover from violence or mental illness. So let's bust some myths!

0:24:22.0 Zarafa: Some people think that those with intellectual disabilities and mental illness cannot be helped. What do you think?

0:24:31.0 Diana: I think everybody has the ability and capacity to move forward in their life, but there's no one-size-fits-all. I think we need to look at individual needs and ensure that the right supports are in place for each person.

0:24:47.6 Jane: What does everyone else think about this myth?

0:24:50.0 Skittles: It's really bad 'cause they're pushing us away and they won't help us, and when we do need help, and we're trying to get help to make us better.

0:25:00.9 Diana: And think if someone doesn't think that you can be helped, they're probably not gonna try very hard.

0:25:04.7 Alison: People might think this because you might not have heard bad things about people with intellectual disabilities and mental illnesses in the past.

0:25:14.5 Zarafa: People think there is no hope, it's sending a bad message, bad vibes. It makes them think we will never get better, that there's no cure. I always thought I'd never overcome what I've had to overcome, it made me suicidal. It's the wrong message because there is hope. You might not go back to your full self, but there are people who can help you to get a better area of life and show you what can help you. There's groups, all sorts of things, there is some light at the end of the tunnel, you just need to have people believe in you, give you faith, keep encouraging you, saying, "You are doing much better than you think, look how far you've come." I couldn't see that when I was unwell. It's important that you give it a go, it's better than killing yourself.

0:26:11.6 Diana: I think sometimes the more you are told that you can't do something, the more that you start believing that, but then the other way around, the more you're told that you can do something, you're gonna have more hope, and you're gonna know that you can do it.

0:26:24.8 Zarafa: Yes, that's correct, thank you.

0:26:27.8 Kaitie: I think when we were talking about this, Zarafa, it reminded me of that, kind of advice to workers around holding hope for people. Making sure that you're holding hope for someone when they can't hold it for themselves. And I think that's a really important one, 'cause mental health recovery can be all about having hope for things getting better in the future, and it's really hard if you're having service providers or workers tell you that there is no hope.

0:26:52.5 Zarafa: Yes, that's correct.

0:26:54.2 Diana: I really like that, holding hope for someone. We talk about that in the training that we do at work; around holding hope for someone until they're able to hold hope for themselves.

0:27:05.0 Alison: I think that brings us to an end, let's finish up.

0:27:08.3 Skittles: Thank you for coming today and thank you for listening to us, we appreciate you coming today, and thank you for being on the podcast today.

0:27:16.6 Diana: Thank you so much for having me. I really enjoyed speaking to you all and getting to hear a bit about your experiences, and I really appreciate everything that you shared.

0:27:25.1 Kaitie: This is a really hard intersection of things. Violence, disability, mental illness, it's tricky. It sounded to me that the main points for mental health workers is to help communicate to hospital staff if a person has to be admitted, to fully explain diagnosis, medication, the mental health system, and to help a person connect with other organizations, like DV workers or sexual violence workers if they're experiencing violence. The experiences of trauma can impact a person's capacity to deal with all this complexity, so as always, at the heart of the discussion, the advice was, slow down. Thank you for joining us and I hope to see you next episode.

[music]

0:28:04.5 Alison: We have made a booklet with information about The Listen Up! Project, this is information about our host, how we did the project and some other stuff that may help workers. You can find it on our website, see the notes to 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.

0:28:34.1 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 project 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.