National Centre of Excellence in Intellectual Disability Health

Podcast Transcript: Communicating with young people with intellectual disability

Pramudie Gunaratne

Welcome. This podcast series is part of a larger intellectual disability mental health training program developed specifically for Child and Youth Mental Health Services in New South Wales. I'm your host, Doctor Pramudie Gunaratne.

Today we have the pleasure of speaking with Katherine Shannon. Katherine is a senior allied health clinician working at the Western New South Wales Local Health District. And she's part of the specialist intellectual disability health team. Thank you so much, Katherine. It's lovely to have you on the podcast.

Katherine Shannon

Thanks for having me.

Pramudie

So today's podcast, we're going to be focusing on communication, particularly with children and young people with intellectual disability. So, we might start Katherine, if you could tell us a little bit about your role in the service that you work in.

Katherine

So, I am employed by Western New South Wales Local Health District as part of the Specialised Intellectual Disability Health Team.

I'm employed as the senior allied health clinician, but I have a background in speech pathology, and I've worked in the intellectual disability field and with some children and young people with complex trauma for close to 20 years. So our team covers three LHDs. So, we're based in western New South Wales and we have an outreach clinician in Murrumbidgee LHD and another one in Far West.

So we're a specialist consultation only service and we see people for a specialist consultation. So, the makeup of each SIDHT team is a little bit different. Our team has myself, a social worker, a CNC, a rehab specialist, a psychiatrist and a paediatrician. Every team's a little bit different in their staffing profile. And our team roughly does, 40% capacity building and 60% clinical work. The amount of capacity building provided by other services does vary a little bit.

Pramudie

And in terms of, I guess if we focus more on communication, we know that communication is fundamental to building the therapeutic relationship. So if mental health staff are not able to communicate in a way that meets the needs of the young person, how does this impact you know, key factors like building rapport with the client?

Katherine

I think preparation is key. I think as allied health clinicians, or clinicians in general, often we're really busy, and we might think that we can attend appointment without some preparation. But for those people with communication impairments, preparation is really, really key. And sometimes I think that we might not be able to jump straight into the doing - what you said, that therapeutic relationship is so important.

So, we might need to start our appointments by thinking about how can we connect? And is that through some play? Is that potentially through observing an interaction between the child or young person and the parent or carer who's brought them along for the appointment? I think you just really want to try and reduce the cognitive demand, and make that child feel comfortable. So I might need to make reasonable adjustments, and we might need to sit and take some time.

Pramudie

Great. And in terms of, practically with that preparation, are there, you know, specific tools or things that you might use to be able to guide a clinician who may never have worked in the space before?

Katherine

Yeah, yeah. Look, in terms of tools, I think there's lots and often use that the toolkit analogy that, you know, we as clinicians, we have all of these tools in our toolkit and we just pull out the ones that we need for the time. So I think in terms of preparing, I'd be wanting to have a look at as many medical and allied health reports are as available.

Just to get a sense for or, if they've got a cognitive impairment, their level of cognitive impairment. If they have sensory needs, you know, what are the strategies that the OT might have recommended? And from a communication perspective, what supports are being used to support them with familiar and unfamiliar communication partners? If you don't have all of those, I think one of the other documents I would really like to know a little bit more about is if they've had a cognitive assessment, how they performed on that. And hopefully there's someone in your team, if

psychology is not your discipline, that might be able to help interpret that. So looking at the domains and what their strengths are across their cognitive profile.

So I guess I've worked a lot with people with autism spectrum disorder, who will often present on their cognitive assessment as having sort of strengths in those visual domains.

So, if you know that, knowing that you can have some visuals prepared or checklist or a visual schedule to help support that appointment. And similarly, if they don't have strengths in working memory or auditory recall, you know, being really mindful of that in terms of how we prepare for our appointments and mindful that the kids we work with might have an uneven profile across those domains - which actually means they're going to have difficulty with all of those mediums in which we might communicate with them.

Pramudie

That makes a lot of sense. I guess as mental health clinicians, you'd be very, you know, used to looking at a patient's psychiatric history or their medical history or the developmental history before an appointment and getting all that information.

And I guess an additional thing that would be required with people that have intellectual disability would be getting that communication history prior to the assessment and really being thorough and understanding what their needs are. So that makes a lot of sense. As part of the preparation for that appointment. I'm mindful that in a lot of services, people might have limited access to sort of alternative or adjusted communication tools.

Are there some basic strategies or techniques that you would recommend for clinicians, where they might not have all those strategies and tools available?

Katherine

Yeah, and I think that there are some tools and strategies that really can be implemented by anyone, not specifically by a speech pathologist. So, you know, looking back on how we're preparing, is something like a social story appropriate in terms of “This is where you'll come. These are the people that you will see, and this is what we might do in our in our appointment”, and using pictures and simple language.

So, taking that sort of plain English or Easy Read approach when preparing those as well. Knowing that some of the words that we use are really, really, tricky to read and understand. So, trying to stay clear of any words that have three or more syllables, and using pictures to help prepare that. I guess, once the young person comes to an appointment, using a visual schedule during the appointment to help kind of say, these are the things that we're doing and that doesn't need to be fancy.

Like, I think back to sort of early in my career and we use a, you know, something like board maker with a simple set to make this, you know, look pretty and beautiful, laminated. But honestly, a checklist if someone's got literacy skills, where you write out the words together, or some scrappy drawings is fine.

If these children and young people we work with, working with have symbolic communication skills and they can understand that, you know, your picture of a table indicates that, you know, we're sitting at the table first and then your picture of this means that that's what we're doing next, then that's completely fine. It doesn't need to be bright and shiny and glossy. It's there as an adjustment to try and help better support them to participate.

Pramudie

And I think one of the wonderful things about using those sorts of tools, like Easy Read or visual scales and visual tools, is that even for patients that don't have intellectual disability, it can be really useful. So, if you develop these skills and develop these tools within services to be able to cater for this population, it really applies across the board as well.

Katherine

Yeah, absolutely. And look, I've shared that the crummiest, dirtiest picture in training that I've provided before. Just remember sitting at mealtimes with my own children when they were younger and thinking, gosh, I'm just repeating myself that we're not making any progress. Had a scrappy picture of a chair, a knife and a fork just to encourage them to try and use it.

You know, just a little clear checklist. It was putrid and it was just, you know. They could almost look at it themselves and reduce some of those communication demands and go "Oh that's right. These are the things I need to follow, to do things this way". So and, you know, we've got those clients that might be really anxious about starting the appointment or missing out on school. And look, when we do these things, we're finished and off you can go. Or that's where you're going to next. So really help to best support them.

Pramudie

And sometimes it's just really simple things that can help improve the quality of the assessment, and just the experience of it for the client and for everyone.

Katherine

Yeah. And look, sometimes with those visual schedules, they might be able to choose which one do you do it in. So it gives them a bit of choice and control within the appointment that might improve their engagement as well.

Pramudie

And looking back over your clinical work, can you think of an example where changing the approach in your communication had a big impact for the young person?

Katherine

Yeah, absolutely. I'm thinking of someone that that we have seen, you know, in our clinic. And every stakeholder says we really, really struggle to engage them. And so we did make some adjustments to the way that we provided our appointment, but we also made sure that the young person was prepared for their appointment.

So prior to seeing them, we provided a social story with the photos of who was in our team, when and where the appointment was happening and what we were going to do. So I think what things we are going to ask you about your health and medication. How you're feeling, whether you're feeling happy, sad or worried. One other thing. I can't remember.

And that was provided to them by the people that knew them well, before the appointment. And then what we did is we made some reasonable adjustments to try and make this appointment a success. So we were fortunate that a couple of the clinicians on our team could see the young person in person, and the rest of the team, because we're a telehealth service, joined virtually.

So we offered a hybrid model, which I guess, isn't something that we would normally offer. So I guess it's, you know, just encouraging people to think about how can we prepare someone with a social story? Can we make some reasonable adjustments? And then it's like the social story almost became the visual schedule when the appointment came, because I took a printed copy with me that said, we're going to do this, this and this. Which one should we do first?

And so it just really was really seamless. And for someone that so many stakeholders had said, we really struggle to engage this young person, we actually didn't have any difficulty at all. So that was really fortunate. Where all of the preparation that we did actually came to fruition.

Pramudie

And I guess it links back to what you were saying before about preparation, because sounds like there was a lot of thought that went into that appointment and how to maximize that time for the person.

Katherine

Yeah, yeah. And I think putting that time in often pays off in the length of the appointment or how many follow up appointments that you might need.

And that doesn't always happen. Like in terms of reasonable adjustments, sometimes you'll need to offer more appointments or more time for an appointment. But for this person, I think the preparation was absolutely key.

Pramudie

And I guess with young people in particular, there's often parents or carers involved. Do you have any tips on how you can help engage with parents and carers and to sort of maximize the information and communication with the patient as well?

Katherine

Yeah. So, I think involving those parents and carers before your appointment is really important. So, they know and then they might be able to help if the communication initially in the rapport building is a little bit challenging. So you might be able to say bring something, a preferred item or something that they really like that they might be able to show you or talk about or you know, they might have some you might have some photos of the dog or the family on the phone that we might be able to look at together.

So preparing the parents as well for the appointment. I guess we always assume competence with the young person. So mindful that we really want them to be the person that we're talking to first about their own health, mental health needs. But also checking in with them that sometimes I might actually check with the parent or carer that's come with you, to check that, if I've got any further questions so that, you know, they are giving you permission to do that from the forefront.

And I guess mindful that, not every child or young person will have the same level of tolerance for parent or carer involvement in an appointment. So, some might be, some might actually say, can you, can you talk to such and such, not to me. And some might want to want to guide that themselves.

And then I think lastly, and it's probably hard without a speech pathology assessment. But verbal competence often masks receptive language and problem-solving difficulty. So someone can come across as being really good at talking. But

actually their ability to understand and follow through with what you might suggest or be implementing might be a little bit tricky for them.

Pramudie

That makes sense in terms of really understanding the person's communication needs. And I guess the person, the person's parents or carers may also be able to provide some of that information prior to the appointment, as you were saying.

Katherine

Yeah.

Pramudie

Is there anything else that you think would be helpful, for mental health staff to know or understand about communication?

Katherine

Look, I think just actively adding to that professional toolkit, being mindful that there are things out there. Sometimes I think that one of the simplest strategies we can use in our appointments is teach back, so that, you know, explaining something, getting the young person or the parent if they're going to be responsible for it, to explain it back to you and then seeing if you need to modify your instruction. You can do that during an appointment or based on the homework that you might be sending someone home with or the follow up, you know, maybe they need to go back to their doctor to see them for something. So it is honestly the, like one of the best tools out there that I think as health professionals in any discipline we can be using with our clients.

Pramudie

That makes a lot of sense. Thank you so much. So, Katherine, you mentioned that your service does capacity building. Can you tell us a bit about what that means?

Katherine

Yeah, sure. So our capacity building really is quite varied. So we provide some capacity building to New South Wales Health staff. We provide some capacity building to the disability sector, and we provide some capacity building, that might be related to the individual needs of a client. So I honestly think that our team provides a very person-cantered approach.

So often we don't, there might be aspects of what we do that gets duplicated, but generally it's tailored specifically to the service that might request some support or to the individual client need. So we, as a specialist consultation only service, we don't want to replicate existing services. But if we can say that we've got some skills or some value to add, particularly to support a young person and their health outcome, then we might meet with key stakeholders to help with that.

Similarly, you know, we've provided education around theatres and emergency departments, so that they can better support people with an intellectual disability or a particular client when they present to that service.

Pramudie

And does that mean if there are community mental health staff in western New South Wales who do require some assistance, they're able to reach out to the SIDHT team to be able to get that guidance?

Katherine

Yes, yes. And look, every SIDHT does provide some capacity building, but the amount of which varies based on the structure and their way of working. But in any LHD really, you could reach out to your SIDHT or your outreach worker if the SIDHT isn't physically located within your LHD to see if they can help provide some capacity building and it could be related to a specific client, or it could be at sort of a high, more systems level for your team and your service.

Pramudie

Great. That's really useful to know. Thank you. So, Katherine, you mentioned that sometimes there might be a difference in people's expressive versus their receptive language. In terms of how we can use a cognitive assessment to better understand that, can you talk us through that a little bit?

Katherine

Yeah. So I guess I'd be looking at their profile on that cognitive assessment. So if a child or young person has stronger skills in more auditory based assessment subtests and the working memory subtests, but in the verbal skills they didn't perform as well. Then I guess we might think that they have stronger receptive language skills than expressive.

And I guess, we've all worked with children, young people for whom they may have stronger skills in either receptive or expressive language. So for those with stronger skills in receptive language, we may hear parents, carers or teachers tell us they understand everything that I say.

But then we don't see an alignment in their talking or their expressive language skills. So I guess in the absence of a formal speech pathology assessment, maybe you'd get some clues through their cognitive assessment about whether they may have stronger skills in one area than another. So if they have stronger verbal skills than receptive skills, then you might see that they've got some difficulties with some of the sort of verbal, the comprehension tasks, the working memory tasks, those sorts of things.

So for someone that might have stronger expressive skills, you might see that they have lower scores in their sort of comprehension or working memory type tasks. But are really quite verbal and able to talk and engage a lot during your appointment or your assessment.

Pramudie

What about working with young people who may have very limited verbal skills? How would you do that teach back process with them?

Katherine

Oh, I guess if they don't have strong verbal skills and I guess often, like in terms of the capacity building piece, sometimes that comes into working with the parents and carers. So, I sort of have often said, well, I've said many times during my career that I'm not a tabletop speech pathologist. Like I don't tend to sort of sit at a desk and do 1-to-1 therapy as often as I would do work that involves building the skills of the people around the person with the communication impairment or seeing them in a functional environment.

So I kind of think that in that instance where your clients may have limited expressive and receptive language skills and yes, we would really need to think, and probably work with their speech pathologist or know specifically what they're recommending. But also, you know, we spend so much of our day with other people and not with the clinician providing this direct type of therapy that sometimes the gains we can actually get by working with the support network of that child or young person are, you know, 100 times more, 100 times better than what you as a direct clinician might be able to gain if you're relying wholly and solely on working directly and only with the child or the young person. You really want to make sure that it's targeted and meeting their needs.

Yeah. And maybe you need to use the, they may be non-verbal, but they may use a communication aid. And so you may need to be using that with them. Often a partner will communicate to the person with the communication aid, using their communication device. But if they don't have, if something hasn't been implemented, then yeah, I think that there's a lot more to that than, either we can or we can’t. It's who else can we talk to and involve in this approach?

Pramudie

That makes sense. It sounds like it's really helpful to gather all the stakeholders, including parents and carers, to help inform the best way to communicate with the young person. You also mentioned communication aids. Do you have any tips for how clinicians can learn about different communication aids?

Katherine

They could get some advice or support from the existing speech pathologist. Yeah, I guess I'd be wanting to know how do people communicate with them. And so it's shared as part of the module you guys have already developed through the Core Concepts in Intellectual Disability Mental Health on communication. There is a communication needs assessment tool that our SIDHT put together that looks at, it was developed for our service where we're a virtual only service, so it asks if people have participated in telehealth or not before, and what made that a success. But there's other questions in that that I think that would be helpful if you don't know where to start, and that's embedded in that training. So I guess I would be talking to parents and carers, looking at existing reports.

There are so many different types of communication aids out there that, you know, I often say we're very much an interdisciplinary team that works across professional boundaries, but still within our scope of practice. And I guess that's probably something that clinicians need to think about - is that inside or outside of my scope? And where and how do I get the extra support I need to be able to best support this child or young person in the assessment or therapy that we're providing?

Pramudie

That's really helpful. It seems there's an endless list of communication aids. It would be impossible to be across all of them.

Katherine

Oh, and look, I've worked in settings where they try and implement - everyone has Proloquo2Go and I'm like, that might not actually be appropriate for, every client's needs aren't the same. So maybe this person needs this, and this person needs this. So that's where you really need to lean into the skills and expertise of a speech pathologist for some really specific advice.

Pramudie

We've covered a lot today, Katherine. Is there anything else that you'd like to add?

Katherine

I think clinicians are probably already doing a lot that we would refer to as a reasonable adjustment without even realising it. You know, sometimes when we go to consult with someone, it's like, oh, you know, we're letting them in through the back door or meeting them at a different entrance to the hospital because this entrance is problematic.

Or we make sure that we always have the same clinicians that know them well, working with them. So I, you know, just want to reiterate, I'm sure you guys are already making reasonable adjustments. You might not call them that. But maybe share those wins amongst your teams. Because that professional toolkit, we can all just keep adding to it as we hear and learn more.

Pramudie

That's a really great, positive way to wrap up this podcast. You're right. There's so many things that we all probably do that come quite naturally, and it's important to acknowledge that as well. So thank you again, Katherine. It's been wonderful to have you on the podcast.

Katherine

Thanks for having me.

Pramudie

Thank you for listening. This training program has been developed by 3DN, part of the National Centre of Excellence in Intellectual Disability Health and the Academic Unit of Infant, Child and Adolescent Psychiatry Services at UNSW. in partnership with the Developmental Psychiatry Team at Sydney Children's Hospitals Network. These podcasts form the advanced level of this training series and follow on from our e-learning modules and webinars.

For more information on the training program, please visit the project website at 3dn.unsw.edu.edu/cymhs. You can check the show notes for the link.