National Centre of Excellence in Intellectual Disability Health

Podcast Transcript: Behaviours of concern

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's podcast will focus on helping clinicians better understand and manage behaviours of concern in young people with intellectual disability. I'm joined by Professor Valsa Eapen. Amongst many other titles, Valsa is the chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales, Sydney. She has over 25 years of clinical and research experience on issues of early development and neurodevelopmental disorders, including Tourette syndrome and autism.

Welcome Valsa.

Valsamma Eapen

Thank you. Thank you for having me.

Pramudie

Wonderful. So this episode is an advanced level podcast, designed for clinicians caring for young people with intellectual disability in child and youth mental health services. This means that there may be a fair amount of assumed knowledge. If you would like to access a series of introductory training modules, please follow the links in the show notes.

But before we go into some of this more advanced material, it’s always helpful to start with a definition. So Valsa, can you tell us what are behaviours of concern?

Valsamma

Usually when we say behaviours of concern, it's about, is it causing distress to the person concerned? Or to the people around? Or it is causing impairment in functioning? So the behaviour of concern is preventing the person from participating in things, or in getting on with life in the way they should do, in their daily activities, in relational stuff, etc. So, anything that is causing distress, impairment in functioning, that is a cause for concern would be considered a behaviour of concern.

Previously we used to call it challenging behaviours, but that kind of gets attributed to the person, which is not a great thing. So it may be better that we stay away from

the challenging behaviours definition, then move on to the behaviours of concern, because it's a concern in the specific behaviours, not about the person. And separating those two is critically important in managing that.

Pramudie

Can you give us some examples of types of behaviours of concern?

Valsamma

Could be self-injurious behaviours where they are hitting themselves. Head banging is a common one, or it could be aggression towards others if not to self. It could also be a bit oppositional, not cooperative, not compliant, running away from school or home, or all of those, behaviours which are causing distress and concern for people around them.

Pramudie

And I guess when it comes to child and youth mental health services, where do they fit in? So how can staff and these teams support the management and the behaviours of concern in young people with intellectual disability?

Valsamma

I would say most of the time there is an issue with diagnostic overshadowing. So if someone comes with a bit of behaviour problem and also has got intellectual disability, often the classic thing is to say, oh, that's because of the person's intellectual disability. And usually you miss the mental health condition.

And so I would say that one of the critical things that CAMHS services should do is to do a comprehensive assessment, just to see whether that are identifiable mental health concerns packed within that, whatever is being labelled as behaviours of concern. And secondly, you need to do that in order to have the right referral services or the right supports to be put in place.

And when you are providing the intervention yourself, it's important also that you are pitching it based on the capacity of the child. So taking into consideration the intellectual disability as a contextual factor while intervening for the mental health things that they have come to you, would also be very important.

And one of the examples is that a young person presents with repetitive behaviours of having to open and close the garage doors all the time, and it was just attributed as something that's part of the autism. And when we asked the person as to why he was doing it, it was really to prevent something bad happening. And he kind of was

very clear, there was an obsessional thought. It was an OCD that was running parallel to the intellectual disability and the autism the person had.

So it's very important that we really understand what's the behaviour of concern versus whether that can be due to a medical, psychiatric condition or whether there is a functional role for that behaviour, in which case it's a totally different management that you would be pursuing.

Pramudie

That makes sense. So sort of understanding if there's any underlying diagnosis that we're missing or whether there's a functional need. Awesome. In terms of clinicians in mental health services, they often need to work closely with disability support teams that would support a young person in their sort of day-to-day life. Do you have any tips for how clinicians can ensure that support workers or other team members are prepared and involved in the management of behaviours of concern?

Valsamma

One of the great tips that I could give is to do a functional assessment, because that's where the disability support practitioner would be handy, in terms of daily living skills or shopping or leisure activities and helping the person to do all of those things. So maybe you can use International Classification of Functioning or something that's standardized so that you really have got a way of comprehensively assessing, rather than just kind of make your own mind based on available cursory assessments.

So I would say take your time to look at the functional level across different domains, and so that you can really make use of the disability support practitioner in the appropriate way to support the person.

Pramudie

And I guess in terms of the different types of people that might be helpful in that team, are there sort of key people that you might advocate that a person might need?

Valsamma

For younger kids it may be that if they have significant sensory sensitivities for example, it may be an OT or if there are speech language comprehension issues, maybe a speechie. There are also behaviour support practitioners who are from a psychology background, where it may be also important for the parents to get some support as well in terms of strategies to manage and deal with the issues.

Pramudie

And do you have any tips about how clinicians might be able to help young people with intellectual disability build self-soothing and self-regulation skills?

Valsamma

It's a bit like a baby being co-regulated, isn't it? It's pretty much the same philosophy. So you are going to be staying calm. And you're making sure that you are respecting their space and their kind of concern, which may be sometimes a worry about the safety. It could be about the trust. It could be about acute pain or other things that's the issue.

So in a way, that co-regulation would come from staying calm, reciprocating appropriately to the needs and also to the behaviours at hand, in terms of managing that. We can also help them have an individualised plan for a toolkit, if you like.

Like when you get into these states, what would usually be helpful? And you might kind of pre run this with the young person and say what would work for some people, it's like looking at a picture book. For some it's music, some it's arts. For some kids it's physical activity. Just I know one kid who does five laps around the house or the school when they get agitated.

And for some others it's going to quiet place pre-arranged place to do the library or something. And taking time off to kind of resettle, co-regulate and the person kind of helping that and proactive support is particularly important for that co-regulation.

Pramudie

So it sounds like it might be quite individualistic in terms of the types of things that might work for one person may not necessarily work for another person.

Valsamma

Yeah, there are some that general principles of staying calm, respect, trust, supportive rapport. You know all of those kind of things would be a given. But then on top of that maybe there are additional things that you would put on. It is individualised for that person.

Pramudie

So Valsa, can you tell us a little more about co-regulation?

Valsamma

So it's helping to identify and label the feelings, which is again separate from the person. The person is different from the feelings that they are experiencing. Whether it's anger and sadness, and it's okay to feel big emotions and strong emotions but it's a matter of how you respond to it. And also helping them to understand what the triggers are and then helping them to appreciate the exact feeling that they are having, and then what they might want to do when those big feelings and emotions come.

And if you practice it and role play it at a calm time and then keep trying to do it when you are in a moment of frenzy and you probably will have better success. But if you're somebody is kind of trying to coach them as it is happening, as the person is rolling on the floor, then forget it.

So it's very important that we do it as a proactive strategy to help the person identify the feeling and certain specific ways in which they want to, that they feel comfortable doing it. And they have practiced it a few times so that they will have a bit of mastery.

Otherwise, it's a, they know that they shouldn't be doing what they are doing. And the family may be too upset or the friend may be too upset, and you've missed the boat and it's devastating for the person as well. So giving them some proactive strategies would be really, really helpful.

Pramudie

So it sounds like a lot of the work is done outside of the actual behaviours of concern. In terms of preparing the team but also practicing and preparing with the person, so that they are able to put those skills to use when they are in that really heightened stage.

Valsamma

Yeah, I mean what you react to would be just maybe minimal. Giving them the space and taking them to a quiet room or something rather than try to actively do anything. But it's proactively that you're either preventing the escalation or what you've rehearsed before to be practiced at the time.

Pramudie

And I guess when this sort of preparation is not put in place, it’s really challenging for families and things can escalate very quickly and families are not left with many options apart from maybe calling emergency services.

Valsamma

Sometimes when people come to the emergency room or in heightened, aroused situations, we need to reflect on what strategies and approaches we are doing. And it may be counterproductive if people in uniforms like police or others are escorting the young person and they feel already very, very threatened and anxious and having a trusted person being available, de-escalating, calmly talking etcetera can be really, really helpful in those situations.

That's what safeguards should do. Kind of respond to the crisis where and when it's occurring so that you are helping the person de-regulate, de-escalate, helping the family contain it. There's nothing that can be achieved by going to the ED. And otherwise, if they have nothing, then the only option available is to call the ambulance and go to the ED.

And the same for the ED physicians. The ED physicians wouldn't have the time to do it but training the CNCs and the nurses who are doing the general observations and hanging around. They're incredibly busy people, but teaching and training them about de-escalation behaviours - yeah, it's definitely better. And when it is occurring, where it is occurring, if you can go and respond there, even better, as the Safeguards should be doing now.

Pramudie

And do you see a role for things like communication assessments or communication supports in the management of behaviours of concern?

Valsamma

I mean there are two aspects to that. One is that every behaviour is a communication. And so you need to understand what the behaviour is telling you, as a means of communication. But equally we need to understand what their level of language skills are, and their communication levels are.

And there is a rule of thumb that you should always respond with the number of words they can say plus one. So if you're dealing with a nonverbal young person, then you just talk to the person with single words. And if they can do two words, you do two plus one, three words. So it is important to understand what the level is in terms of their language abilities.

And sometimes that can be a huge variation in expressive versus receptive. They can rattle off various things and talk philosophically about things that they are interested in, but their comprehension may not be that great. So language assessments can help you really understand where this person is at, and then we can appropriately support them.

Pramudie

And in terms of, I guess, nonverbal language, are there specific techniques or things that are helpful in understanding that better?

Valsamma

I mean, in terms of testings, of course there is the verbal and the nonverbal tests, and you can pick the nonverbal part of the testing to see how they are doing.

But sometimes we say that if you haven't had the opportunities, for whatever reason, if you don't have language, your opportunities to do things may not be that much. And sometimes we talk about could we have culture fair, language free type of assessments to really get to where the nonverbal kids are at. And we do struggle a little bit when there is no language. And we have tests that would look at the nonverbal side, but it's yeah, it's a bit of a hit and miss.

Pramudie

Could you explain that a little bit more, the culture free...I don’t think I’ve heard that before.

Valsamma

Language free, culture fair. Because sometimes in tests, people who have had experience doing certain things versus not, would come in the way of you getting the testing with the right scores for that age.

So if you say that culturally someone has not been exposed to that, somebody else would put on the dress for you, you are not required to put on the dress or t-shirt at a particular age because everything is done to you. Or others who don't use spoon for having the food. The questions might be about can they use spoon when they are, you know, without spilling or something.

So that's what I mean. Some of these tests have got a cultural underpinning or experience and opportunity based, you know. Relevant testing versus what would be the correct level of this person's understanding versus what experience and opportunities this person has had, might have an impact on what the test results would tell you.

Pramudie

Yep, that make sense in terms of putting everything in the context of the person and what their previous experiences are, even when you are doing testing. Could we talk a little bit more about the impact of behaviours of concern on families?

Valsamma

Usually families would tell me sometimes that it's not so much his autism or it's not so much his intellectual difficulties, but it's the behaviours that are preventing them from enjoying him being able to go out. And sometimes that's what prevents them from even getting entry to school programs. So the educational programs are also very dependent on what behavioural issues that the person has.

Right. So parents often give a lot of emphasis to the behaviour because it's a great deal directly of relevance to them. And it also affects the siblings sometimes, especially if there is aggression or a particular way of doing things that they have to do it only that way. And you are busy in the morning and you're trying to get out of the house and get people out of the house.

It can really be very stressful and there is a lot of mental health consequence from children who have got disruptive behaviours, and behaviours of concern way more than in what intellectual disability or developmental disability on its own would bring to the table. And quality of life for parents have been, systematically been seen in repeated studies - that has got a lot to do with the behaviours.

Pramudie

So sometimes the behaviours of concern are much more debilitating than the underlying intellectual disability might be.

Valsamma

Yeah, people accept that people have got strategies put in place or they take it as a given. But these are variable. They come and go. You're always trying to understand what this is doing. Did I do anything wrong? And there's a lot of blame and guilt and all of that that goes on as well in that, parenting is that the problem? And it kind of really gives a really tough time for the parents.

Pramudie

And I imagine it can be quite traumatic as well for some of these families that are witnessing some of these behaviours.

Valsamma

Yeah. If and when it is very extreme and running away or those kind of things are of real concern for the person’s safety. Aggression, especially towards younger siblings. And then, I know parents who would say that we cannot go together anywhere. We'll have to split, take one child at a time, and then that just kind of is really so, so hard.

Pramudie

And is there much family work that child and youth mental health services do to support parents and families?

Valsamma

There are parenting programs of various descriptions. And also in the earlier years there has been parent child interaction therapy, the dyadic therapies, single session family therapy. Yeah, there are. But CAMHS services sometimes wouldn't have the opportunity to do those things because it's in the NDIS, and the pathways for these kind of supports, they are kind of directed to the private sector with the NDIS providers these days. But yeah, there are a whole heap of those parenting programs that are in the toolkit for CAMHS physicians to do.

Pramudie

Sounds like it's maybe possible to link in families, not necessarily through the CAMHS teams specifically, but through NDIS to some of these programs.

Valsamma

Definitely. Because that's one of the things that they do very well. The behaviour support plan and the, yeah, as we were saying earlier about the disability support practitioners and all of that now sits within the NDIS. But the assessment is important so that you can put them through to the right services.

Pramudie

So what about the use of medications? How can clinicians help to ensure that these are being appropriately used?

Valsamma

Probably first and foremost is to use non-pharmacological approaches first and see whether that would give you the benefit that you are looking for. And also being mindful that people with intellectual disability are at increased risk for side effects.

And so avoiding polypharmacy. Start slow. Go slow. And also, appropriate choice of targets. You can't just kind of medicate behaviours of concern. You have to have specific targets for which you are using the medication. Whether that's ADHD or whether it's OCD, whatever that is. So you've got to have specific targets, and you have a baseline measure of what that is looking like.

And then you're monitoring very carefully as to whether that's moving and changing rather than just kind of, yeah, I'm going to start a medication and hope for the best. That's probably not the best way to do it. Also, you need to be considering when you are using the medication, the appropriate choice.

And trials first, maybe a very short period of time. And keeping that option open, that this is probably going to be it. We're going to trial it, see whether things change. And always keep that discussion open so that it's not forever. And that's important to that review and monitoring very closely and carefully.

Pramudie

And it seems like there's quite systematic monitoring that's done for people with intellectual disability when you're trying to understand the response for a medication. Whether it's a positive response or a negative response. Are there some specific types of monitoring that you would recommend, that should be done?

Valsamma

One that comes to mind is the guideline for the cardiometabolic monitoring if you are starting antipsychotics, for example. And again, that includes not only the weight and the circumference, but also the blood tests and making sure that that's done periodically. That's very important.

Otherwise you might be giving the person a medication and then if the reviews are not done and these testing and monitoring is not happening, by the time you recognize, you would be very late in the piece and families would rightly be very concerned about the physical side effects coming from a medication that is used for mental health problem. And cardiometabolic side effects are not one that one would take lightly.

Pramudie

Absolutely. And in terms of, I guess, looking at the behaviours themselves are there specific types of monitoring that you would recommend in terms of behaviour support practitioners, or that the team can do to understand whether a medication is having a positive effect or not?

Valsamma

Again, as I said that, it is important to have the baseline first. Very much about the target. Where the baseline symptoms are sitting at. So that you can see where it's going when you review it. And various scales can be used depending on the target symptoms. The Spence Anxiety Scale, or Yale-Brown Obsessive Compulsive Scale or many of those things would help you, whichever is your target symptom, to say

where you are starting from. And you are looking at the benefits, but also using side effects scales would be very important too.

And it's not always possible for parents to think about something as a side effect. They wouldn't even think that is a side effect if you don't know what you're looking for. So, it's again important to look for both the benefits and also the side effects using as much as possible objective rating scales or questionnaires.

It could even be a visual analogue chart that you put on the fridge. And then you kind of go day to day how things are going. Otherwise, when they come back after 3 or 6 months, they would be saying something that happened last week, that would be all on their mind. Either it was good or bad, and everything else that happened all along would be totally gone. So it's very important to keep that monitoring in an objective way, in a standardised way, all the way through, starting from baseline.

Pramudie

So we might zoom a bit more into medications or pharmacological treatment. Can you talk us through some of the important considerations when prescribing medications for behaviours of concern in young people with intellectual disability?

Valsamma

Definitely there is the increased risk for cardiometabolic side effects. And so that may be also exaggerated by the lifestyle. Like the sedentary lifestyle that sometimes goes with intellectual disability. And therefore, it's important consideration to give advice on diet, exercise, sleep and all of those things.

And it's again important to see whether there may be an increased risk for movement disorders or other central nervous system side effects. Because if there is already a history of damage to the brain as part of the intellectual disability aetiology, then a compromised brain is going to be much likely to have produced more of the side effects from the medication.

And also when you've got either another medical condition that's running parallel - one example is, constipation is a very common - gastrointestinal symptoms are very common in developmental disabilities and intellectual disabilities. And medication that you give may worsen the constipation or make things worse. Or sometimes that may be a drug-drug interaction. So there are important considerations in terms of looking at all of those aspects when you are starting and maintaining medication.

Pramudie

I know we often think of mental health teams as being responsible for prescribing medications, but deprescribing is equally as important. Can you talk us through some of the principles around deprescribing for behaviours of concern?

Valsamma

First and foremost, every review should have a review of all medications. And if you are thinking about deprescribing, then identify one at a time as to which one you might want to kind of go with first.

And then once you've identified that target medication that you want to cease, you will do a very detailed plan. And that plan would be done in consultation and partnership with the family and the caregivers as well. And then you do the plan, execute it and then do the review.

But also, always be mindful that if things don't go well while you're doing it, it's a pause button or a stop button, go back button. That's all possible. And it's just getting everybody on board for that as a process rather than as an end game that you're going to go through. It may be that somewhere along the way you might stop with a very small dose. Maybe that's where you want to be rather than totally off. So it's a journey that one prepares the family and the young person to go through as a true partnership.

Pramudie

And sometimes there might be some resistance from teams or families, or fear understandably around deprescribing - particularly when there are behaviours of concern. Do you have any tips for clinicians who might face that?

Valsamma

I would try to understand what the beliefs or attitudes are behind that fear. It may be if we understand that, then we can counter it or educate them or find alternative ways of managing that thing that they think is going to come back, the thing that's going to be worse or whatever it is. So understanding where they're coming from, what their reluctance is and barriers are would be important. And then whatever it is, then we try to address that.

Otherwise, it's always good to have that proactive discussion right when you're starting. That's the best time to have the kind of conversation about the deprescribing that might come along the way. So from the beginning, you're kind of getting them onto a contractual agreement that we are going to see how it goes. We will review. Initially it would be three, six weeks and very, very, short intervals. But then when it's going well, you might want to give it a bit of time.

But at every review that conversation happens. Is this needed? Can we have a kind of go without it? And what might be the alternative approaches that may be available that could take the place of the medication? Now that things have progressed a bit, maybe they are better able to engage with behavioural supports or better able to have parenting supports put in place etc.

So it's again, having that conversation at every review and giving them options and opportunities for alternative things. But for some others, it may be a blanket worry that if you don't want to be like where we were, and if that's the case, that's why I'm saying that if you have that conversation right at the start when you're doing it.

And we can also explain it through educational means as to what the medication is actually doing and what might be other ways in which we can get the same benefit once that acute phase is gone away and they are able to better participate in other methods of treatment as well.

Pramudie

So it sounds like a really collaborative approach where you're sort of walking with the family as they go on that journey of deprescribing.

Valsamma

Indeed, because that's the only way you could do it. The earlier you start that discussion, right from when you're starting it, the better. Because you're going in with that expectation. It's a short trial and we will see whether we need to continue it or not, is the question, rather than here it is.

Pramudie

And it sounds like there are so many different elements to helping teams and young people manage behaviours of concern. Do you have any tips for clinicians working in child and youth mental health services who want to develop local service protocols for management of behaviours of concern?

Valsamma

I would say the NDIS document 'response strategies mapped against the escalation cycle' is a good one. So the teams might want to kind of say what the baseline service strategy response might look like. So that it's a preventative stuff put in place at the baseline, then warning signs when it comes.

What might be your response strategy there? And then the escalation, the peak of escalation, de-escalation and the recovery. And so if you've got service strategies put in place along that continuum of that NDIS cycle that they have come up with, that probably is a good framework to use.

Pramudie

So Valsa, if there's one thing that you would like CAMHS clinicians to know about behaviours of concern, what would that be?

Valsamma

I would say, do a comprehensive assessment to understand what the behaviour of concern means and also about any co-existing underlying mental health conditions. Because we are best trained, and we are the people who can do that. Nobody else can. And therefore, it's on us to really understand the behaviours of concern when it overlaps with mental health concerns. And doing a comprehensive assessment is something that we should be doing.

I would say in that assessment you would be thinking about, are there medical reasons for the behaviours of concern? It could be lack of sleep. It could be gastrointestinal problems, like pain. It could be earache and toothache sometimes. And they will be doing hitting and self-hitting and hitting on the wall, and all of those things. But it would be a medical issue that's underlying that behaviour of concern.

Sometimes it's a psychiatric condition, like it could be sadness and depression presenting as irritability, aggression. Or it could be obsessive compulsive disorders, where they have to do things in a particular way, which time and time again it would either wear them out or use up a lot of time. And the third obvious one is the functional role of the behaviours of concern - so medical, psychiatric and the functional role.

Pramudie

That’s a really important point to highlight and perhaps a good place to wrap up our conversation. Thank you so much Valsa. It's been lovely to have you on our podcast.

Valsamma

Thank you.

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.