

Podcast Transcript: Quality of Life

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.

In this episode we are discussing quality of life for children and young people with intellectual disability and mental health conditions. We have with us Associate Professor David Dossetor. David is a child psychiatrist and medical head of the Developmental Psychiatry Team at the Sydney Children's Hospitals Network. We also have Hadia Baassiri. Hadia is a senior social worker and cultural clinical consultant at the Children's Hospital at Westmead.

So, hi David. Lovely to see you again.

David Dossetor

Always good to see you Pramudie.

Pramudie

From your experiences David. What contributes to the quality of life of a young person with intellectual disability?

David

So, I think about this in terms of, firstly with Maslow's hierarchy of human needs. And that sets, you know, the protection, the shelter, the food, the sense of belonging and attachment. Then on to a sense of purpose. Feeling you've got something to contribute. So you're valued. And then you go on to, transcendence, which I have greater difficulty with, because I always find that empathy will bring you down again, you know.

Pramudie

For those who may not be familiar, Maslow's hierarchy is like a triangle.

David

It is.

Pramudie

Through the base level needs. And as David described, then there's higher order needs as you move up the triangle.

David

And then, and so its purpose, sense a future, creativity and contributing to others that actually are amongst the highest values. And it's remarkable how much that overlaps with the literature on what creates a quality of life.

And so I always feel that, you know, primary school kids is about belonging, adolescence is about working out. What can you contribute because it's contributing that means that you're valued and you get positive feedback and that makes you feel good. And then you come on to the more abstract things like creativity, belief and helping others, and understanding others and closeness, and a belief in future.

And it's that belief in future that gives you that belief that you have free will. I mean, it's a very powerful final achievement of mankind. For children, it's slightly different because as we started by saying, they start as a bundle of reflexes and instincts, and then the first couple of years of life they're learning how to control them themselves. And that's about learning behaviour.

And then that moves on to recognizing emotions, recognizing that other people have different thoughts and feelings and emotions to you. So suddenly you create an internal world. And so hyperactivity goes down because you've got an imagination to live in. And then that creates the prerequisites for developing new attachments outside of your primary attachment with your family.

And so it's a very skilled process of developing those skills, which we pay very little attention to. We assume it's automatic, but it isn't. It has to be nurtured. So it's helping children grow in their early stages of life is where we need prevention, early intervention, and particularly parenting support.

Pramudie

And I guess sometimes, for people with intellectual disability, whether it's because of misunderstanding or our own biases about people's capacity, we might not put as much emphasis on some of those higher order skills like purpose and belonging and having that sort of future focus. But all of those things are a really important part of quality of life for everyone, as it would be for someone without an intellectual disability.

David

Absolutely right. So they too can be valued. They can be participating, they can be loved and they can love. You know, that's what, makes the world go round, really, isn't it?

Pramudie

Absolutely, and keeping that in mind as we care for individuals with intellectual disability.

I think, like you said, it's really important. I also wanted to touch on a different point around this, you know, we often talk about developmental stages, and how there might be sort of uneven development. For example, someone's receptive language might be different to their expressive language. Are there different domains in terms of development and how fast or, development occurs for emotional and social skills?

David

Firstly, well, I'll go back one stage. We actually have very little appreciation of the evolution of the brain and the mind. This is the most important part of being human. The development of your mind and what I observe is that, I have my rules of development. So if you've got delayed development, you're more likely to have uneven development. And you know, when you look at, ADHD occurs at 7% in our community, coordination disorder occurs in 7% of our community.

They co-occur 50% of the time. They're developmentally connected. And so you see that all the developmental disorders like autism like coordination disorder. They're all associated with ADHD, and autism and language problems. And so that the developmental disorders, enuresis as well, you know, they're all connected with each other. If you've got one area of development delayed, you've got a high likelihood of another area being delayed. And so you have to be watchful for that and take account of it.

And so, my feeling is that, well, come back to ADHD. I mean, nobody has concentration when they start. Nobody can sit still when they start. And so it's all about developing competencies to be able to concentrate and, and have intersubjective connection, because that's how you learn self-regulation.

Pramudie

It's interesting that you say that uneven developmental domains are more common in people with intellectual disability, because that might be one of the pitfalls for clinicians. Is that because there is either a significant regression in one area or there is, you know, capacity in another area, you might, if you apply that broadly without realizing

that there's unequal, different types of development, you might either assume someone has much less capacity than they do or more capacity than they do. If you're not sort of actually looking across the different domains.

David

Well, one of the things, I mean I do pay attention to the detail of skills across different domains in my assessment. And the parents suddenly realize you're actually interested in what their child is like. Because if you're just asking them about little few temperamental qualities, you miss the child that's growing. And it's that detail appreciation. You know, I always think, like, sense of time, you know, does he understand what after lunch means? Or next week? Or when his birthday is? I mean, these are they're the precursors of neuropsychological skills. But you can see them by asking the questions. And kids vary so much.

And so you then come across these kids that have specific problems and memory, which is much more difficult to elicit. And then they start confabulating, because they're covering up the gaps in their appreciation of the world. So it's actually attention to detail. But not only do you get to know the child, but the parents really respect you for knowing that child.

Pramudie

Yep. And having sat in on your clinic David, that's one of the things that I've definitely taken away into my own assessments - is to really ask some of those specific questions, because you do learn so much, about the patient and about the family from those answers

David

And the thing that I find most important is developmental understanding of autism, because it's that specific delay in emotional understanding and therefore capacity for emotional communication and theory of mind and peer relationships that is so disabling.

So there's in effect, there's deviant peer relationships, externalizing or internalizing. And then there's delayed social relationships. And that's the autistic spectrum. And it's important to have the notion that those skills can be built. And we need to get better at supporting building those skills. And that's what I think is starting to happen in autism.

So, most children go up a certain grade of social skills, even if they have autism. But I think there's more that we can do to help - well both with understanding what they can learn but also understanding the deficit so we can compensate too.

I'll come back to the cloak of competence notion that we all want to pass for normal. And we've all got lots of things wrong with us. And so, for example, this was written by Edgerton 40 years ago. And so, the person with mild intellectual disability survived independently community, because he knew who he could turn to help him with the things he wasn't competent to deal with, like filling in tax returns or paying bills. And so it's having people you trust to look after the vulnerable side of your development, which is the secret to survival as an independent person.

Pramudie

Thank you so much David. That was wonderful.

David

It's been a pleasure talking to you

Pramudie

And now we're speaking with Hadia Baassiri. Our discussion with Hadia will focus more on working with people from culturally and linguistically diverse populations.

Pramudie

Thank you so much for joining us today, Hadia. It's lovely to have you on the podcast.

Hadia Baassiri

Thank you very much. And thank you for inviting me.

Pramudie

No problem. So we might start with some questions around quality of life. So from your experiences, what have you observed or have people told you contributes to the quality of life for a young person with intellectual disability?

Hadia

Look, when you talk about CALD backgrounds and intellectual disability - so there's a common area when we talk about intellectual disability and its impact on families and quality of life. We talk about exhaustion. We talk about anxiety. We talk about parents'

mental health. So, with people with families from CALD backgrounds, they have the same things. However, culture plays a major role in the way families address deviations in their children's development and may influence the extent to which they subsequently subscribe to various intervention strategies.

So how they interpret. And we're talking about like even the willingness of CALD societies to allocate resources for individuals with disability, including resources for clinical care and rehabilitation efforts, will also depend in large measure on the anticipated role of that individual as an adult. So, these social beliefs seem to be based upon three categories that appear regularly across culturally.

So we talk about value or de-value and attribution. We talk about anticipated adult status, and we talk about, you know, causality. The causes of, the interpretation for, you know, what causes intellectual disability.

Pramudie

So I guess just to clarify for our listeners, CALD stands for culturally and linguistically diverse. And so you were saying that there's different interpretations for what causes intellectual disability?

Hadia

Yes, of course, there are different interpretations because intellectual disability – well, culture interprets different things based on the culture. So people with intellectual disability might not be seen as, you know, vital or important members of the society.

Also, intellectual disability might be seen as a stigma and that cause most of the time isolation for the family and the child. People with disabilities may be protected from outside world. So they keep them inside, and, you know, every member of the family will take a role as a carer, regardless of their age.

So for example, if the family has five kids and the person with intellectual disability is the second or the first. So every sibling has to become a carer, including parents. And the major issue here, when we talk about mental health, I'm talking about mental health of parents as well. And siblings. Okay. So, so parents would feel so guilty.

Guilty for causing intellectual disability. Guilty for neglecting the rest of the family. And also anxiety about the future of the child. What's going to happen to that child when we are gone? So this is a common question I hear from families.

Pramudie

So Hadia, it sounds like there are multiple things you touched on there. One of the first things that you spoke about was around the different cultural beliefs around intellectual

disability. As mental health practitioners or as staff working in mental health teams, are there things that we can do to try and combat some of those things that, you know, potentially, are maybe stigmatizing patients or affecting their quality of life?

Hadia

Of course, of course. Look, it's when anything happens to the child. So families, especially if they don't have any awareness about like what's going on for that child. There are different things. If the child was born with intellectual disability and parents are already told, you know, that the child has intellectual disability at birth, it's a huge anxiety. And they need to deal with that issue. But they know that you know, this child was born like this. So the interpretation can be positive or negative depends on, because I'm talking here about like spiritual interpretation.

So some people might think it's a curse. So maybe we've done something bad in our life. Some people might think, well, it's a gift from God. We need to deal with that. And different interpretations. So when the interpretation is negative, the anxiety is higher. And depends on that severity of the intellectual disability. Intellectual disability can be tricky with people who don't have enough awareness about intellectual disability.

For example, most people from CALD backgrounds, they believe that, you know, intellectual disability has physical indications. If there's no physical indications of intellectual disability, they don't believe it. They think. No. No, it's misdiagnosed or something or wrong or whatever. And families from CALD backgrounds, they use their own resources and their resources are like friends from the same community, or relatives and so on.

And everyone has input because, most people from CALD backgrounds, you know, came from collectivist societies. So they work as one group. If anything happen to their child, they go to their group and, you know, get advice. So everyone would have input. Everyone would say, that anything. So after exhausting all these options, if the child is not fixed, they go to their community GP because he's a doctor.

And we need to know here that, you know, many people who came from CALD backgrounds, they think doctor knows everything. And GP, you know, is for everything. GP and nurses that what we know. And we need to pay attention or that the you know, the health system in their own homelands is different to the health system in Australia.

And we have many refugees, you know who lived the wars and they didn't have access to any health system. So, they come to Australia with no awareness about the intellectual disability. So go back, one step back that, you know, they go to that GP and GP perhaps, you know, refers them to our system, or our service.

They come to us with not enough awareness about why they were referred to us. So we are referred to fix the child. We prescribe medication, of course. They think as we are prescribing medication to cure that child.

So if the child is not cured they drop, you know, they stop the medication and they start going to different doctors to fix that child. So it's really important for us as professionals, when they come to us, to provide psychoeducation. So when I see the family, I provide psychoeducation about the disability. And to me, when I arrived disability, I slashed the 'd-i-s' and we talk about disability and ability.

So we're not here you know to fix the child. And the medication is prescribed to alleviate symptoms but not to cure disability. So the disability is there, okay. But we can improve conditions, and psychoeducation is so important for families just to feel the hope. And so there's hope not about fixing the child. There's hope that, you know, this idea about what's going to happen to the child after we are gone, will reduce some anxiety.

Yeah. And yeah. And also talking about services for, not just for the child with disability. Services for parents because most of them would be. From experience, I see, you know, depression is very common within families. And also siblings. So we're talking about different services for the child, for parents, for the siblings. We talk about NDIS. Many families, you know, they come to us and they have already NDIS, but they don't, they don't know how NDIS is working.

Pramudie

I mean it sounds like there's multiple components to the psychoeducation that you do. Sort of part of it is orienting the patient and their family to the system to sort of NDIS, to mental health, to primary care with their GP, and how that system fits together in Australia.

Then the other part is sort of providing psychoeducation about the child's illness. The parts of it that would have a curative end and the parts of it where maybe it's a lifelong disability.

Could you talk us through sort of how you might be able to do psychoeducation with family? Some of the phrases that you might use. It might be helpful for other clinicians to maybe learn from.

Hadia

Look, it is very, very hard for families to comprehend. Because they are looking for the cause. Okay. It doesn't matter what sort of cause. Some of them can be blaming each other for causing the child's intellectual disability. And most of the time, mothers are to blame for causing that to the child.

So we talk about like genetics, especially when we say genetics they think it's like hereditary and we try to explain no genetics is not hereditary. For example, we had a child who was 15 years old from Afghan background, was arrested by the police for stealing something and having a knife.

And when the police arrested him, they realized there's something with the child. So they took him to the hospital and was assessed and referred to us. We assessed the child; the diagnosis was moderate intellectual disability and autism. And parents had no clue.

So, when we assessed, before I saw the family I was talking to my team. Telling them, explaining about the culture. And people from CALD backgrounds are following certain rules. So during that conversation, none of us is aware that we are following rules. So, if I'm not aware that this family are following certain rules, I might assign the behaviour I'm observing according to my own beliefs, and the attribution most of the time is negative.

So, it's not just awareness for families about here, about the health system. It's awareness to professionals about the culture and what to expect, and pre-migration experience and trauma. So it's not just a trauma about like having a child with intellectual disability, and they didn't know. And you know, breaking bad news, you know, caused a lot of anxieties. It's about their own trauma as well.

So when we saw this family, the child was, you know, his mum was giving him everything he asked for to keep him quiet. Extended family was living with them. And mum didn't want her in-laws to criticize her. Not raising good child because the child is misbehaving. Because parents are judged by the way their children are behaved.

So wasn't any limits, you know, for the child to understand what are the consequences. So this is another interpretation of the intellectual disability. Families think, he has intellectual disability he doesn't understand. So they don't set limits. And it happened that this child didn't have any physical indication of his disability.

So parents didn't agree to the diagnosis. Parents believed that raising children in Western society and supported by teachers and not using their own strict parental style, is affecting their child. So I, usually when I see families I use explanatory model questions. So I, because I want to see how they see the problem.

So for example, I asked Mom and dad. So what do you think your son, what sort of problem does he have? Behaviour problem. So what caused his behaviour problem? When did it start? And when it started, what happened? What do you call it?

I ask some families who I believe that they use their own cultural remedies. And in some cultures, we know that, you know, people use some remedies. Have you used anything? There's nothing, there's no right or wrong. It's just to see if what you're giving to your child might, really interact badly with that medication? Medication we're going to prescribe.

So the family was so reserved, they wanted their own daughter to interpret, and this is not really good enough and not legal. So I explained to the family that we need an interpreter because we need accredited interpreter. And the family was also reserved and insisted.

So, I explained to mum that we understand that in small communities people know each other, so they don't like to say any family problem in front of any stranger. So I explained to the family that we are not going to discuss his criminal activities. We're going to discuss his conditions. And what can we do to improve his conditions. So the family felt more comfortable. So we explained, you know, that there's intellectual disability and they couldn't understand it because there's no physical indications of his disability.

And it happened that the father, you know, loved music. And I explained to my team, when we explain something we need to make sure that our body language is appropriate to our words. And it happened that the psychiatrist was explaining something like executive functioning and the accredited interpreter was struggling with the word - how can I explain executive functioning? And the doctor was saying, look, his executive functioning is not working well. And everyone was looking at the heart. Ah, he's got heart problems. So I asked the psychiatrist, I said, where is the executive functioning? He said, in the brain. I said, where? He said, here. Oh okay, so in the head, right? So we drew a picture of the brain and we, I use analogy. So the brain, the executive functioning, sorry, is like the maestro. And the maestro has, you know, to tell how, what everyone should play just to have a good orchestra and good music. And we showed them the picture and the family felt, oh okay, now we understand. This is the way we include the family in the treatment plan. Okay.

Pramudie

And for our listeners who couldn't maybe see, Hadia was pointing at her heart when the psychiatrist was initially describing executive functioning, her chest, and then pointing at that brain and really pointing out where executive functioning was located. So that body language is really important and being mindful particularly when you're working with someone that may have English as a second language.

Hadia

Exactly.

Pramudie

And so, I guess, you know, one thing that struck me as you were talking Hadia was that, you know, the families and the patients that we care for will have their own stories and their own biases and their own understandings of mental health and of intellectual disability.

But us as clinicians, we'll also bring our own biases, our own stories, that right understandings of intellectual disability. And so, I guess, being mindful of what our own

biases and stories are, particularly when it comes to intellectual disability, because I think, many clinicians who work in mainstream mental health may not see a lot of patients with intellectual disability. And so thank you so much for sharing your expertise with us.

Hadia

You're welcome.

Pramudie

It's been great. So, thank you.

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.