National Centre of Excellence in Intellectual Disability Health

Podcast Transcript: Treatment and Management

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 episode is about treatment and management of children and young people with intellectual disability and mental health conditions. We're very lucky to have two very experienced clinicians with us. Today 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 Louisa Carroll, who is a clinical psychologist and educationalist at the Neurodevelopmental Disability and Intellectual Disability Mental Health Teams at the Children's Hospital at Westmead. First we'll speak to David and then we'll chat with Louisa.

David, it's wonderful to have you again for this podcast. So thank you so much for giving up so much of your time.

David Dossetor

Thank you for having me.

Pramudie

I guess this podcast is mainly talking about treatment for people with intellectual disability and mental health dual diagnosis. So what do we know about the effectiveness of treatment in this population?

David

Well, when you consider the effect sizes and the levels of evidence of different treatments in children and adolescents with intellectual and developmental disability, IDD, only parenting programs, which is meta-analysis and Cochrane levels of evidence.

Second most powerful is the effect of behavioural intervention. Education. Schools have a huge database showing effectiveness on skill building, including social competence, which is of central importance since the capacity to make new affectional bonds or good quality peer relationships is the best predictor in childhood of mental health in adulthood 30 years later. However, the effects of education take

months and years. Parent training and behaviour management takes weeks, maybe months.

The evidence on medication is variable and depends on the type of medication and the diagnosis and often relies on evidence from different populations. But medication tends to work in days to weeks when appropriately used. What we know is that there are situations in which medication is the primary treatment. For example, medication for ADHD is proven to be more effective than other treatments, which may be important as complementary multimodal treatment.

Undoubtedly, in autism and IDD, anxiety, depression can be so severe that medication is the necessary primary treatment. It often helps sufficiently to enable young people to have a capacity for engagement in other treatment approaches.

Pramudie

So I guess it sounds like that multimodal approach is really important. So you've spoken about how particularly with specific diagnoses, medication is essential. But then also parent education and behavioural interventions have good evidence in terms of their efficacy as well.

David

Absolutely. Absolutely. While there are benefits of focusing on a strengths-based approach, it's also important to focus on the skill building approaches to enable competencies. This may be the specialist approaches of improving coordination and self-care skills with physiotherapy, or sensory processing skills and attentional skills from occupational therapy, or language and functional communication skills from speech therapy. Most important is the building of emotional understanding, emotional perspective taking and emotional problem-solving skills which are the prerequisites for social skills. All these skills contribute to emotional regulation skills and independent self-soothing skills, which is the precursor of peer relating skills and also the predictor of all major mental illnesses.

Pramudie

So it sounds like maybe there's a bi-directional relationship there. Where helping patients develop skills might then mean that they're able to better self-regulate, better manage their emotions. But at the same time if you treat mental illness then that would allow them to develop those skills more as well.

David

Yes, well, I think mental illness is when you've fallen off the track and all treatment is about regression towards the mean. So you're trying to get people to come back to

normal pathways of development, enhancing skills and in particular, attachment. And so, it's when things are so impaired that you need psychiatric input to give you a chance.

Schizophrenia, you know, medication dampens the symptomatology, but progress is about regression towards the mean with rehabilitation and supports and integration into useful function in a community.

Pramudie

So if you treat the ADHD, or you treat the schizophrenia then the patient is able to get back to their normal trajectory of development or at least as close as possible to that.

David

Absolutely. Absolutely. ADHD and autism are highly biologically driven. So you have to actually tackle what the weaknesses are and the skill building approach is absolutely essential.

Stepping Stones Triple P is in effect teaching applied behaviour analysis skills to parents in a normalised setting. It has the best evidence of cost effectiveness as treatment. It also has a lot of information on the barriers to implementation.

Pramudie

So David, could you tell us a bit about those barriers?

David

It's a human failing to assume that children are small adults, and they have complete understanding, and they know everything I'm talking about. And in particular, it's you know, talking too much is one of the failings of managing oppositional behaviour for example. It's actually the behavioural intervention that matters. And yes, communication becomes important, progressively important over time. But early in development, behaviour management is what changes behaviour.

Pramudie

So parents might be overestimating how much of that verbal communication the children are understanding?

David

…is meaningful. Then of course, there's the failing of understanding the emotional content too. But actually it's the intervention of, it's time to calm down and chill out, that really matters.

Pramudie

And I guess it's not something that, you know, everyone's trained in how to effectively be able to implement behavioural strategies. Whereas I guess most people are more comfortable instead of talking someone down because we would use those skills more frequently in general life. And so I guess the programs you've mentioned, like the Stepping Stones Triple P programs might help parents develop those skills in terms of behavioural management skills.

David

Absolutely. And so there's no doubt that parenting skills have long term impacts. So such parenting behavioural intervention also creates parenting confidence. That in turn improves parental mental health, and the quality of marriages. It makes you feel good. It improves your life in so many ways. So parenting skills involve promoting positive prosocial behaviours and reducing maladaptive behaviours. All children have to learn the skills of self-regulation. And this involves a sanction of loss of parental attention and developing the skills of chill-out, for example on the bottom stair or progressing to time in your room.

However, some families are non-compliant with behavioural skills and we use the Circle of Security, which is an attachment orientated approach, which provides insight which can help motivate them. The integrated family therapy was designed for treating conduct disorder also uses attachment theory potentially to strengthen outcomes.

Pramudie

And can I check, these programs that you mentioned, Stepping Stones, Triple P, Circle of Security, are those programs ones that community mental health teams can refer families or parents to?

David

The Stepping Stones had a community wide mass intervention research program probably five years ago now. So it's a question of finding who is still doing it. It has several levels. So in fact, our team do some of the seminar versions. So the lowest level of intervention is three seminars. Then there's a sort of middle grade one which is GP orientated. Then there's the – Stepping Stones is the one that really gets into

the ABA. But their latest version is for families that have intergenerational trauma. So you need to focus on helping the parents get self-regulation.

Pramudie

This sounds like one of the unique challenges of working with children and young people. So it's not just treating or helping management of the child but also helping the entire family, and these might be some programs that community mental health teams might be able to refer to help parents.

David

There is a growing movement in paediatrics of the first thousand days and they are focusing around developing in this country, it sort of the movement started mainly in Victoria, of family centres. So you start with the antenatal care, you then do the post-natal care, pick up the post-natal depression, then looking at development and picking up autism early. You're teaching the parents to learn to play with their kids and then moving on to the broader parenting skills and you link that with legal advice for your domestic violence, financial advice for your debts and entitlements to Centrelink. And it's particularly focusing on the vulnerable families. And I think this is so needed in our community, that we focus on the vulnerable families and enable them to be proud of their role in raising kids.

Early intervention is what matters. And so, unless we look at the development of children - the quality of peer relationships at seven is the most predictive factor of adult mental health. You know you're either too internalised and anxious and neurotic that you can't get close or you're so antisocial that nobody wants to come near you. That isolationism scape goats you basically, and you don't learn how to make friends. It's that developing new attachments that is what is key to being human.

Pramudie

And I think all the points you're raising about addressing those social determinants of mental health are really important and it's part of the effective treatment for people who come to our services, but I'm afraid that I might be distracting us away from what's within the remit of the community mental health clinicians.

So I guess maybe if we go back to some of the interventions that maybe the families or the clinicians might be able to help with.

David

So it may be accurate to say that in mainstream families, their family relationships are the strongest predictor of childhood behaviour. This doesn't necessarily apply in

families with IDD and autism, as childhood disorders can have more impact on parental wellbeing and relationships than the other way around.

This means that family intervention has to consider the mental and psychological wellbeing of parents and siblings. And in my practice, 50 percent of the parents have got burnout, anxiety, PTSD or depression that needs urgent treatment.

There are also genetic drivers in the child of the way a parent responds. I find this fascinating. That the genetics of externalising behaviour and the child creates hostility in a parent. And conversely, the internalising child creates emotional overinvolvement. So this is instinctive, basically is what it comes down to.

Pramudie

And it might not be something that I guess clinicians or parents would have insight into themselves.

David

Absolutely. And so, I often use it to say, now you know you have a choice to outsmart the genetics of your child…and get them to change the way they behave to their child.

Pramudie

And if we look at different models of care, can you talk us though the evidence for different models of care?

David

Well, it should be noted that there are models of tertiary intervention that are seen as highly effective. I mean, the intervention that the Children's Hospital MHID Hub had recently was complementary independent evaluation. Reported improved access, improved mental health, improved collaboration and capacity building through our webinars, case discussions and training opportunities. In particular, specialist expertise in medication management and behaviour management were noted.

There's a short-term service for young people with IDD presenting acutely to the Royal Children's Hospital emergency department, which was similarly successful. This involved an assessment and review of medication and treatment by a paediatrician and a child psychiatrist, followed by six-weeks follow-up with a CNC skilled in behaviour management and family support. And they had really positive outcomes from all stakeholders.

Pramudie

So if we switch gears a little bit, could you tell us a bit about the use of medications?

David

I generally take the view that it’s my job to advise parents as far as possible, and as far as possible the young person, on the merits of prescribing for psychiatric disorder. For acute and crisis management, medication can be needed.

Certainly, having crises constructively managed at home does less harm than four or 24 hours waiting in an emergency department, only to be sent home. Further, I adhere to the view in IDD that managing violence is best done in the community. It's not a reason for a psychiatric admission unless there's a defined mental illness.

Certainly, there's a greater risk of side effects in IDD. There's a greater need for medication, especially when other non-medical approaches to treatment fail. There are a growing number of treatment algorithms. And so stimulants is primary, clonidine, guanfacine, atomoxetine is secondary. Major tranquilizers and mood stabilisers are tertiary.

In IDD there are differences in the way medications work which changes the order of preference, both because of differences in the effectiveness and the risk of side effects.

There are also sensible rules of prescribing, such as remaining available to manage concerns and support dosage introduction and only changing one medication at a time. So you know what has made a difference, for better or for worse. Obviously, you document the condition you're treating and provide a metric of the symptoms of primary concern to measure change.

Pramudie

And how important is collaboration in managing the mental health in intellectual disability?

David

I find our team has a strong interdisciplinary culture where we learn from each other, have high levels of professional independence, and are open to asking each other for help. We have a culture of continuous learning and clinical research. In particular, we share the stress and adversity of these families, and we also celebrate the miracles of change and improvement that we witness.

Pramudie

And when it comes to your patients when they reach adolescence and entering adulthood, are there any specific issues with transition in terms of ongoing treatment in adulthood?

David

Adolescence in my experience involves an endocrinological and brain rewiring storm that intensifies vulnerable behaviour from 12 to 23. At which time hyperactivity and temperament then settles down significantly.

Pramudie

Absolutely. I think I certainly notice that in my own practice – where you're entering the teenage years, there's all those hormones and the frontal lobes haven't quite developed yet. And then when - often from you David, when the patients move on to seeing myself or one of my colleagues in adult psychiatry, we notice there's this natural simmering down of some of those symptoms, which then gives us the opportunity to reduce some of the medications which might have been necessary when they were going through that storm as you described.

David

I did a seven-year follow-up study of adolescents, a very high need group of adolescents and their families. And that level of hyperactivity and intensity just mellowed in early adulthood.

Pramudie

I guess even without mental illness, just in the general population, we all know that adolescence is a time of turmoil and as you enter your mid-twenties that starts to settle down gradually, and people with intellectual disability are not an exception to that.

And do you think we understand the differences in effectiveness of different interventions according to the young person's level of impairment? So I guess if someone's got mild versus moderate or severe intellectual disability.

David

Well, I think about it in developmental age terms. This is an intriguing question, and I often think about it because it makes one think about the developmental processes

of developing your mind. Treatment should involve development enhancing processes to optimise this.

An underlying human feature is the vasovagal theory of attachment, which brings a primacy on developing and learning from relationships. For example, problem features of autism are emotional responsiveness in the first year of life; a capacity for joint attention and awareness of otherness in the second year; and the development of theory of mind in the third year, necessary to move from playing in parallel to turn taking. In later years, problems of emotional understanding and relationships remain.

Not surprising, the frontier of early intervention in autism involves early identification and a parent intensely teaching emotional learning and reciprocal skills. This is really exciting early intervention. As I've said, behavioural intervention is the bedrock of nonverbal communication and learning.

Pramudie

David, before we wrap up is there anything else you'd like to add?

David

So finally, the reward of working with young people or with IDD is witnessing them make the thrills of discovery along the pathway of development. In fact, none of us know what our destination is. It's that pathway of discovery that keeps us going.

Pramudie

And that's a wonderful note to end this podcast on. So, thank you so much David.

David

Pleasure. Thank you Pramudie.

Pramudie

So now we have Louisa Carroll. So lovely to have you today, Louisa. Welcome to our podcast.

Louisa Carroll

Thanks, Pramudie. Nice to be here.

Pramudie

Great. And so just to start off, we know we often need to tailor interventions to fit the needs of young people with ID. So do you have any tips around how people that work in sort of a general mental health setting, how they might be able to better tailor interventions for this population?

Louisa

Yeah. I mean, I think it's really important to think about individualizing. So, using the expertise of the family, using the expertise of other people who know the young person well. So whether that's support workers or educators or whatever else. So that when you're tailoring interventions, you're kind of building on the scaffold and tools that they already have in place in their regular real-world environments, rather than trying to reinvent the wheel.

Pramudie

That makes sense. And I guess, before you might recommend any specific treatment options for a patient or for a family, are there particular skills that you might need to assess for the patient or things that you take into consideration?

Louisa

So I mean, definitely think about verbal ability, I guess particularly often that discrepancy between receptive language and expressive language. So I can think of a lot of kids that I've worked with who superficially might look like they actually have quite good language abilities, but then when you get down into the bones of it, their understanding isn't actually as sophisticated as what their spoken language might suggest. And that can lead to all kinds of complications, I think, in terms of people expecting a standard of behaviour that's well above what perhaps they're seeing and then judging or having expectations on the child's behaviour that are unrealistic, given their ability.

Pramudie

And in terms of how you do that assessment with understanding the different domains, I suppose, in terms of skills - is that through a clinical interview, are there specific tools that you'd recommend?

Louisa

Yeah. So I mean, I think probably to expand on what you're asking for - I mean, I think if there have been formal assessments done, then obviously an IQ measure, an

adaptive behaviour measure, those sorts of tools are useful. But I think a lot of it also comes through observation. So it’s nice to meet the young person in the flesh. And I think sometimes you'll interview a parent first and you get one sense of what you're expecting to walk into the room and then you'll meet the young person and it's quite different. So I think it's nice to have those different perspectives, I suppose, when you're trying to work out.

Pramudie

I guess, as with any treatment, people respond to treatments quite uniquely. And from your experience, have you observed, I guess, differences for people who might have intellectual disability compared to a general population of children or young people?

Louisa

I mean I think we're thinking about treatment gains, it probably depends how you define it. I suspect probably in comparison to sort of typically developing kids, the expectations that I would have from therapy might be - we talk about smaller increments as being a measure of a successful intervention. And that's, you know, partly because I think small changes can make really big differences in terms of quality of life and functioning and things.

And also just because of the crudeness, if you like, of the measurement tools that we have. I mean, if you're looking at intellectually disability, that's sort of the bottom two percent of the bell curve. And you look at most of the measures we have, I mean, that's that all lumps into one, one centile ranking. You’re looking at gradations in that tiny bit of the bell curve. I think most tools don't actually measure that sensitively at all. You need to look at other, I guess more functional changes.

Pramudie

So it sounds like when it comes to offering treatment plans for people with ID, it might be that you sort of test how things go and then you can sort of look on how skills are developed over time. Whether it's working, or whether it's not working. Is that sort of the approach that you would normally take with a behavioural intervention?

Louisa

Yeah. And I think just looking at very, like noticing very small changes. I mean, I think sometimes you might do like a baseline of what someone's doing before you intervene and then compare how it is after you've done intervention for a little bit and then compare what happens to when you take the intervention away, and those little

shifts might be all the changes that you get. But that's actually a successful intervention, rather than if you put that up on a standardized measure that it's still going to be like a scale score of one. So it might look like there's been no change, but actually there's been functionally a very significant change, and that's corroborated by school reporting more settled behaviours, parents reporting more settled behaviours, and the person just presenting as happier and better adjusted I suppose.

Pramudie

So it sounds like when you're treating a patient with intellectual disability, collecting that baseline data is really important.

Louisa

Yes.

Pramudie

It might not match the baseline say of the general population, but something quite specific to the individual.

Louisa

Yes.

Pramudie

And then you're kind of working off that baseline and continue to collect data as you start a treatment plan.

Louisa

Absolutely. I think even with mental health based issues, often you're looking to return to a baseline that might not look like a good level of functioning at sort of an objective level, but in the subjective experience for that young person, you're actually getting them back to a level of functioning that is where they were at before they became unwell.

Pramudie

So I guess maybe less reliance on standardized scales that we might use for the general population, because that might not reflect what's actually going on for the patient. And so if you're working in a team that does use scales, I guess if you're working with someone with intellectual disability, trying to modify the types of information that you're getting to be more tailored to that person and their skills and their baseline.

Louisa

Yeah. I mean, I think there are some specialised tools for young people with intellectual disabilities. I think of the DBC particularly, that does have norms that are separated out for mild, moderate and severe levels of intellectual disability. But yeah, I think more broadly, a lot of the tools we have just aren't sensitive.

Pramudie

So capturing the actual changes that are happening for the person. Yeah.

And in terms of how interventions can be used as a means of, I guess, testing your diagnostic hypothesis. So if you think that, you know, this is anxiety or, there's psychosis, this patient has ADHD - is it, are there ways in which you can kind of use an intervention to be able to then test that hypothesis?

Louisa

Yeah. I mean, it's an interesting question because I think to an extent this is true for all patients. Like it's not specific to IDMH. I mean, I think if you're doing a formulation, really that is a hypothesis, right? I think these are the factors that are making the problem worse. And I think by treating these factors, it'll help the problem.

But I guess within that, yes, there are things that you might think about. So, I mean, something like self-injurious behaviour I suppose is quite a common referral presentation that can sometimes be symptomatic for mental health issues, but it can also be symptomatic of pain experience for the person, like toothache or something like that. It can also be symptomatic of a more sort of developmentally, in inverted commas, normal more attentional attachment focused behaviour.

And it's like if you were trying to tease it out for a young person with ID. Yes. You might look at increasing the level of sensory stimulation, for example, to see whether that's effective in helping reduce the behaviour, what you might look at withdrawing attention and then your hypothesis test to see which, which of these possible hypotheses is actually contributing to the behaviour.

That being said, I think sometimes it's not that clear cut and often you will intervene on all those levels and you'll see a change. But it won't actually necessarily be clear

which ones specifically was critical or whether it was actually all factors made at the same time. But that if you just intervened with the one, you might not actually get enough change. And then you can end up dismissing things which are helpful because the level of change that you're getting for each individual thing isn't enough to be detectable on your measures.

Pramudie

So sometimes it might be something linear where there's a clear diagnosis and treating that has a sort of flow on benefits for the patient. But a lot of times, particularly when there's more complexity, there's multiple things, and so you kind of need to treat all those different things to be able to get that synergy in terms of treatment.

Louisa

Yeah, nice choice of words.

Pramudie

And when it comes to sort of the influence of pharmacological strategies - so, you know, we talked a bit about this earlier with David as well, but sometimes medications can enable a person to better engage with therapy.

But then sometimes the side effects of medication might limit the young person's ability to engage with therapy. So do you have examples of those kinds of situations, and, you know, how to maybe assess that or manage that?

Louisa

Yeah, I mean, I guess in many respects that is a question more for my medical colleagues. But, I mean, I think certainly we've seen cases where behavioural activation in response to an SSRI for example, has really changed the trajectory or the expectation of what you might expect for a young person's recovery and their response to treatment. It's very hard to intervene psychologically with behaviour strategies for someone who is sort of responding in that way to a pharmacological intervention.

I mean, I guess from a psychological perspective, often I'll consider it from the opposite way around in terms of looking at someone who, you know, looks like they would have the capacity to take on board a psychological intervention once their ADHD, for example, is better managed or once their anxiety has sort of had the edge taken off it.

And then I guess it's about trying to time the judgment because I think, you know, understandably families have a lot on their plates and they can sometimes try

something and then once they've tried it they're like, oh, I've tried that, that didn't work and so to bring them back to a therapy that they've attempted in the past unsuccessfully is often harder than to kind of to introduce something when you think the client's ready for it. And so then I guess it's around trying to get the pharmacological aspects optimized enough to have the client ready to take on board the psychological strategy that you're wanting to implement.

Pramudie

Sometimes the benefits of medication are that it allows the patient to engage more with therapy.

Louisa

Absolutely.

Pramudie

And I guess, does that mean that you need to sort of time or prioritise how you sort of start different interventions or, you know, first you try and tackle certain symptoms and then you might need to work on the next step? Would you kind of come at it as a team, kind of doing everything together?

Louisa

Yeah. I mean, I think probably I'm lucky. I have the luxury of working within a multidisciplinary team. I guess part of that is we often seem to see kids who are at the pointier end, if you like, in terms of that they've been through other services before they get to us. But I think that does mean that often we are doing things in synergy. I think that's the word that you used before, in terms of the medical practitioners prescribing and then the OT might be doing some sensory strategies while the psychologist is doing some behavioural strategies or whatever. So we kind of get, get everything at once.

Pramudie

And I guess for community teams that might be kind of enlisting the NDIS practitioners to be involved in providing kind of a different modes of therapy while also working with the community mental health team. In terms of getting, if there's no inbuilt allied health as part of the community team, trying to see how you might be able to enlist allied health from the, through NDIS providers or other means.

Louisa

Yeah. And I think most of the cases that come to us, almost they're required to be linked in with the NDIS already. So I guess it is some of that more structural intervention is happening. And so our contribution is sort of the mental health bit on top of the underlying disability supports.

Pramudie

And often mental health conditions are unrecognized or untreated in people with intellectual disability. Can you tell us about your experience when that underlying mental illness is well treated?

I guess it's one of the great things about working in your service is that you do have an eye for mental illness and helping and sort of engaging patients in treatment. So I guess when it works well, what does it look like?

Louisa

I think it's that return to baseline, isn't it. I can see, and again, maybe having worked in the area for a while you get better attuned to it. But like, you can definitely see the improvement in quality of life. You can see the improvement in mood. You can see a sort of a calming in the demeanour, even as it comes into a therapy room. That gives you that feedback that things are making a difference. Even the relief of families, I think, is another really important sort of contribution I suppose that intervention can make.

Pramudie

Yep.

Louisa

I think it can be quite cyclical as a young person becomes unwell, it puts extra stress on the family and then the stress of the family feeds back into the young person's sort of mental unhappiness or anxiety. And it can become quite a vicious cycle where, sort of behaviours might deteriorate as a consequence, which puts even more stress on the family.

So being able to get in there and to treat those symptoms, I think helps create a virtuous cycle, if you want, to sort of send things back to a point of equilibrium.

Pramudie

So the patient kind of returns back to baseline. The family sort of returns to baseline as well.

Louisa

And the stress levels go down in the family, which means that the young person's recovery I think tends to be more assured, because there's more resources in the family around the young person to help them stay well.

Pramudie

And they kind of get back on that path of skill building and normal development for that individual. As opposed to that being kind of waylaid by the mental illness and the associated stress for the individual and for the family.

Louisa

Yeah. And I think you see a loss in a lot of functional skills as a consequence of mental ill health. Which again, if you're working off a fairly low baseline could be really significant.

Pramudie

So it's not just that they don't continue along that pathway of development, but it's also that skills can regress during that period where mental illness is untreated.

Louisa

Yeah. Or you get really disruptive behaviours, which kind of again, just sideline everything else because all the attention ends up getting focused on trying to manage. Whether it's just the head banging or whether it's sort of more, sort of aggressive behaviours or whatever it is.

Pramudie

And I imagine it's quite disruptive for social relationships as well, in terms of building relationships with family or with carers or at school when you have all of the symptoms of mental illness occurring at the same time.

Louisa

Yeah, yeah. I think a lot of kids can end up being excluded from a lot of their support environments, and their educational environments, which puts even more strain on the family at home trying to manage.

Pramudie

So navigating the mental health, navigating the health system can be quite challenging for people with intellectual disability, particularly when there's mental illness on top of that as well. And I guess for community teams, in particular, they're quite resource constrained. So do you have any tips around making reasonable adjustments to service models or to the spaces where, you know we care for people with ID, that clinicians and community teams might be able to do, that would help them care better for this population?

Louisa

Yeah. I mean, I'm probably a little bit of a, I probably don't have as much sympathy as perhaps I ought to in that I, I think we need to make intellectual disability mental health mainstream, if that makes sense. I think it's very easy to sort of say, oh, I do mental health but I don't do ID. But the number of young people who have an intellectual disability who also have a comorbid mental health difficulty is, it's so significant that I don't really think you can call yourself a mental health clinician if you're not prepared to provide mental health services to people with ID as well as the typically developing population.

And I think, historically perhaps, mental health services haven't been as embracing of that as an idea as perhaps we would like them to be. Yeah, or they should be. But a lot of that, I think, is around cultural change and a cultural expectation that comes from leadership - comes from the top in terms of saying, well, this is core business. This is something that you need to know how to do, this is something you should be doing. And then it ends up being incorporated into the service because you just assume that you're going to do it.

I mean, I think when you do your training as a clinician, I can only speak from the perspective of psychology, but it's not like you get really intense training in one area and nothing in intellectual disability. Right. You get a little bit on intellectual disability, but you only really get a little bit on everything. You maybe spend a couple of weeks on this in intensity and then a week on this and then a couple of weeks on something else.

I think when you graduate, you don't actually have a lot of experience in anything. And so the experience you build is the experience you're exposed to. And so if you go to a service and you work in mental health, but you're not exposed to anyone with a disability because disability is othered, you end up not getting the experience and

then you end up feeling like you don't have the expertise because you don't have the experience.

Where if it's sort of mainstreamed from the beginning, that everybody sees it and then it becomes part of your experience and skillset, then everyone can do it.

Pramudie

Yeah. I mean, I don't think you're being unreasonable at all. Like, I think when teams say they don't see people with ID, that's discrimination based on IQ. And we wouldn't tolerate that for any other sort of characteristic of the human population.

But for some reason, it seems like it's okay to discriminate based on IQ. You know, an IQ less than 70, then we're not going to see you. It makes no sense. But I guess, like you say, it's a cultural shift that's required.

And I guess in terms of the types of reasonable adjustments that might be helpful if there's clinicians that really want to see people with ID, and they want to make it a sort of a safe space for people with ID and their family, are there specific things that you might do in your practice that, kind of help make it sort of a more therapeutic space?

Louisa

Yeah. I mean, I think the obvious things around the sort of the sensory environment and the noise and the busyness. I mean a lot of services would have waiting rooms where you've got a lot of different people coming through, and it can be noisy and crowded and probably quite intimidating for typically developing adolescent, if nothing else. But you can imagine that much more so for a young person with an intellectual disability, potentially.

I mean, I like to be flexible with the way I deliver services. And if someone's not comfortable coming in and the weather's fine, we can meet at the park across the road, and we can have a session while we talk, or we can be side on rather than face to face.

I mean little adjustments that don't that really require huge cost or anything like that. They're just a way of thinking about things a bit differently that can make the engagement much, much easier, I suppose, for the young person. I mean, I think there are also now things like telehealth that, you know, sometimes have an applicability - doesn't always work well as a medium for people with intellectual disability, but certainly for liaising with families and things, I think, can help not having to travel in long distances.

Pramudie

And one of the themes that we've had as we've been doing these podcasts is around, sometimes there might be some resistance from families in terms of, you know, accepting diagnoses or engaging with treatment and, you know, there's lots going on in these families and it can be really complex environments. Do you have any tips for clinicians who might be encountering that sort of thing, in terms of how you can help families and patients engage more in treatment plans?

Louisa

Yeah, I mean I probably didn't relate to that so much as an example in that I, for the most part, I've found families really, desperate is maybe a bit strong but really keen to have intervention like really feeling like they're struggling and wanting some, wanting more support in any way, shape or form they can have it. Yeah. So I suppose engagement if anything is felt, you know, perhaps easier than it should be as a clinician in terms of not having to work as hard as I might have to with a family that wasn't so motivated to get help.

Pramudie

And it helps to know that there's two sides to that coin. You know, there's people that really do want to engage and you can harness that and help patients get treatment that's hopefully going to be helpful for them. So that makes a lot of sense.

Thank you so much, Louisa. It was lovely to speak to you. That was a great point to finish on.

Louisa

Thanks for having me. It's been a pleasure.

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.au/cymhs. You can check the show notes for the link.