Podcast Transcript: Carer Wellbeing

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 today’s episode we’re speaking about a really important topic, carer’s wellbeing. I have with me Tania Vannitamby and Jodie Caruana. Welcome to the show.

Jodie Caruana

Hi. Great to be here.

Tania Vannitamby

Thank you so much for having us.

Pramudie

To start us off can you tell me a bit about your roles and the service you work in?

Jodie

We both work at the Mental Health and Intellectual Disability Hub at the Sydney Children's Hospitals Network, and this is a tertiary service where we receive referrals from paediatricians and psychiatrists for a second opinion on their child.

So I’m a social worker and also coordinator of the team. And I also work for the school-link program, which is also a program for liaising between Education and Health and mental health for children with intellectual disability and autism. And through that service, we do run a school clinic, which has been a valuable service that we gain, that we’re able to help families via this outreach service

Pramudie

Thanks Jodie. And Tania, can you tell us a little about your role?

Tania

I'm the social worker on the mental health intellectual disability health team at the Children's Hospital.

Pramudie

Wonderful. Thank you. So we might launch into it with our first sort of general discussion about carer wellbeing. So can you tell us what a family focused recovery model is and why it's useful when working with young people with intellectual disability?

Tania

A family focused recovery approach, or model, recognizes and respects the essential role of the family. A young person with intellectual disability is generally very heavily reliant on their parents or caregiver for many of their needs. And usually it's an ongoing dependency. So recognising that role is absolutely essential. And the model itself supports the family in that natural caregiving role, encourages family collaboration and choice in treatment decisions for the young person.

Jodie

So I guess when we're seeing a young person, they don't come alone, they come with their family. And usually it's mum. Could be dad. There are a lot of separated or single parent families. Could be grandparents who are caring for the young person and all the siblings that are in the potential family. And so, yeah, our treatment, I guess, isn't just targeted at the individual child but that care network that surrounds that child because, as Tanya said, they are the main carers for the young person.

Pramudie

So it sounds like families, and parents in particular, are really important, both for sort of assessment as well as treatment planning. Can you tell us a bit more about how you might include families when you're doing that?

Tania

Well we put on a systemic lens. That's absolutely essential. As Jodie said, you can't assess a child without looking at the context of their family sort of situation. So we need to be considering the family dynamics, what's going on in the family, and then we then tailor, I guess, our treatment planning around the needs of the whole family.

Including family starts from the very minute the family walks into our room. And so it's looking at inclusion, and inclusion even starts with, when we contact parents and looking at the needs, what they need, before they come in around that assessment process. How, whether they can come in face to face or whether it's more suitable for their family situation and the caring needs, whether they might prefer a online assessment. But usually we encourage face to face to begin with so that we can actually get an opportunity to meet and observe what's happening in the family system.

So collaboration is key, as I said. So it starts off with assessment. And then it's, the engaging families in discussions about treatment plan from the beginning. So it starts off with what they've found helpful in the past, what they haven't found helpful, what's worked?

Being able to use really clear language in when we explain the treatment and the and give them options. So, you know, usually starts off with medication and then we don't just look at medication. We also try and look at the other needs. So whether it's around behaviour management, stress management for carers, psychoeducation.

Jodie

Often the first line of treatment is targeting the child themselves. So that's around possible medication reviews. Looking at, yeah, optimizing the medications, if needed. In addition to kind of what services are currently involved and that services that support the family and the young person. What behavioural interventions are currently implemented and what could be improved? And then assessing kind of, I guess, what, where the family is coming from. If they've been engaged in any parenting programs in the past and yeah. So just looking at everything holistically. So medication, non-pharmacological interventions, including behaviour support, and what other services are involved. Potentially what carers might be in the home. What respite services the family receiving or not receiving just to give that holistic picture of what's happening for that young person and the family.

Tania

And I think what is key is really listening, really listening to the needs of the parents and caregivers. We as a team, or as clinicians, generally know or have ideas and models that we like to work with. When we see a need, we think, okay, this is what needs to be done. But if we don't listen to the parents first and find out what they, you know, firstly what their challenges are, what their stressors are and what they want from a service or what they think they need for their child.

And we need to be, we need to really show parents that we are committed to addressing their needs and that, you know, really try everything that we can. I think it’s demonstrating that real commitment to helping the family. They need to believe that and really feel that we genuinely care and we’re concerned, and we’re doing everything that we can to address the challenges. And usually, more often than not, it's around that they are looking for medical answers, medication, treatment. But our service likes to, as Jodie said, we like to provide a holistic perspective to care. We know that there are other things that can also support that recovery process – be it, looking at improving connections and relationships and attachment. Looking at behaviour management strategies. We know that they are all, they all support the recovery process. But parents need to be ready for that journey, for that process, for that sort of treatment, for that intervention. And it's about timing.

So I think developing connections and rapport and really sort of holding the family to begin with for some time and supporting their needs. Whatever needs they express to us. That is really important. That's what develops trust and that process then will help support all the other, so the scaffolding that needs to happen to be able to support that recovery.

Jodie

And when children are referred to us, or by the time we see the family, the families are so burnt out. They suffer from so much stress. Marriages might be breaking up. The child is behaving is a way that is preventing them from accessing services or school. Even reduced attendance. So their mental health and their behaviour, and often they're interlinked, is so severe that services that usually provide respite might not be seeing them. So the families are super burnt out. Sometimes there's a relinquishment of care risk. So the families might be on the brink of survival.

So I think we just try and assess what we can do. What will have the most impact in the shortest amount of time, before we implement some of the longer-term strategies. And often that can be with a touch of medication which may address some of the mental health of the child, which then increase, I guess the functioning of the family as a result and some of those behavioural interventions then have a better chance of working.

Pramudie

So it sounds like there's a real deliberate approach to engaging parents and families, and that starts even before the first appointment. And perhaps that first step is around really taking stock of what's going on for the family and understanding that baseline so that you can build from there. And Jodie, you mentioned support for carers and families and how essential that is and often that's overlooked. Do you have any tips in terms of the types of services families can engage in and how you can help families access those things?

Jodie

Yeah, there's quite a few services that we do recommend depending on the needs of the family. If a family member has their own acute mental health needs, sometimes we'll, in some of the clinics that I've run, we'll do a depression anxiety and stress scale as just a general kind of marker on how severe their stress or anxiety or depression is. And I know in some cases when it's extreme, I would refer straight to a GP or give them some mental healthline numbers and then ask them to see their GP for some of their own mental health treatment. But I guess in less severe cases where they may just need some counselling then there is various Carers NSW lines or Carers Gateway, or Tania might be able to give some others where they can get some counselling support.

Tania

They question 'why are you referring me to counselling? It's my child, not me' and I think it helps to sort of say, acknowledging how stressful it is to be a carer but also acknowledge their resilience as well. I think that's really important, and counselling is a way to help them or support them in that caring role and sort of top up their resilience and just to sort of keep them going. Because they are vital to their child and in that ongoing caring that needs to happen.

Sometimes as a clinician you can start that holding space, so just providing that time to listen. It's almost like giving a bit of a sample or a taster of what counselling can look like. So you can start the process and then encourage, because obviously we can't hold people forever, but if you as a clinician can model that sort of supportive counselling or, I guess, how it can be helpful, it might be a way to start.

Pramudie

That's really helpful. You've both touched on how caring for a young person with intellectual disability and co-occurring mental health conditions can be really stressful. And from your experience how does carer stress and burden impact the young person's recovery?

Tania

So children they're highly sensitive to the emotional states of their parents, particularly in early childhood. So parental mental health, especially issues like depression or anxiety, they can really influence a child's emotional regulation, their attachment to their parents and their overall mental wellbeing. For instance, a parent who is stressed or depressed, they may be less able to engage in any sort of positive parenting practices that we encourage. They might struggle in offering warmth and connection with their child, consistency which is essential for behaviour and structure. They are all key to a child's healthy development. So just not being available, in general, that can make it very difficult for a child. So to have a place to go to, to help them meet their emotional needs. So, yeah, it really affects their level of feeling safe and secure.

Jodie

And I think Tania, when you did the Circle of Security program, you did notice that there were, which targets attachment and also identifies, helps the parent identify when their child is needing them in certain circumstances. And I think we found some great results from that program, in helping parents identify when their child really needs them and that can impact on their child’s behaviour in a positive way.

Tania

Yeah, definitely. What we found is that if a parent is not available, and usually they’re not available because of their own mental state. If they’re so stressed it’s really challenging to find the energy to give. But children are always looking for their parents to give them something, all the time. It’s all about being able to meet their emotional needs. And we found that once parents are able to develop that awareness through reflection, it really helps them identify the times where they do struggle to give emotionally and then they are able to change the way they perceive their child’s behaviour.

When they’re stressed and they’re exhausted and when their child is whining, they just see that child as a burden, or it’s ‘Why do they keep doing this? I’ve given them everything. I’ve given them food. They’re watching TV. What’s wrong? What’s wrong with them?’ But Circle of Security, we found, really changes the way parents perceive the child’s behaviour.

So it’s not perceived in terms of the child being a problem or they’re being manipulative. It’s more, ‘Oh this child needs something from me. What is it that they need?’. So even the behaviour itself, the way it’s perceived. We’ve had families who’ve come back maybe by week four, ‘Oh they’re not actually doing this on purpose or yeah, they’re having a meltdown, but their meltdown, it’s ok’. There’s an acceptance around behaviour once they’re able to look at the needs of their child.

But it’s not an instant thing. It’s about parents being able to have their cup filled. Their needs met. So when they’re stressed and they’re burnt out, their cup is absolutely empty. There’s nothing in that cup. So our role as clinicians is working out, how can we fill their cup? So when their cup is empty, they can’t fill their child’s cup. It’s just impossible.

Jodie

Yeah, it’s kind of like the airplane analogy. You know, you put your oxygen on first before you can put your child’s oxygen mask on. And I think that’s the same, similar with carers of people with a disability, in that once their needs are met then they can then more attend to the needs of the child.

Pramudie

So it seems like there's this real bi-directional impact where a child's behaviour can impact families and a family's behaviour can also impact on a child's wellbeing. Based on your experience, how does managing a young person's mental health help in managing carer or parents' wellbeing?

Tania

As you say Pramudie, it is bi-directional. It goes without saying, when a parent is stressed, a child gets stressed. When a child is stressed, a parent gets stressed. It's the energy in the system. And we always see once behaviour starts to settle a parent's presentation in our reviews is very different. They come in with a smile. You know, they have a lot more positive things to say. And we notice that, they say things like, 'oh they gave me a hug today'. And it just changes their whole demeanour. And it brings a smile to our faces as well. So I think really, if we can address the mental health problems of that young person, it's going to make a big difference to the entire family.

Jodie

Yeah, and I guess it's quite stressful having a child with a disability and challenging behaviour. But what we can do, is give the family hope that we can improve the mental health and the associated behaviours of concern. So that then, just the quality of life improves, and that's what we are aiming to achieve for these families. These families are amazing. And the carers are amazing. And they have so many strengths and you know, they may go through, especially during puberty is a time when some of these challenging behaviours and mental illnesses kind of creep in and we can change that. We can really make a positive effect for these families and carers.

Tania

Because when there is a lot of challenging behaviour, that becomes the focus. Managing behaviour becomes pretty much the focus. They wake up worrying about how they are going to manage their behaviour, and they go to sleep trying to manage behaviour. Just getting them to sleep can be quite challenging at times. So, there's such a heavy focus on managing behaviour rather than relating and connecting and just enjoying each other.

So when a young person's mental health is, if they are feeling better, there's more opportunity for doing just typical everyday family fun things, connecting, having conversations, also going out socially as a family because a lot of the times we find that families 'We can't go out. It's too stressful to go out. We can't go out and have dinner as a family'. So it's just being able to do things that other families take for granted. And just doing those things that help build relationships. So there's more time or there would be more energy that can be devoted to building on their relationships.

Also, you talked about hope Jodie. And I think it also provides parents a bit more confidence. As parents we need to feel we know what we are doing and what we are doing is ok and it’s helping. So I think building confidence. If they’re seeing that their child is getting better that might help the parents feel more confident as a parent.

Pramudie

That makes a lot of sense, in terms of as the mental illness or behaviours of concern reduce, because that’s such a huge component of a parent’s everyday life, that their stress levels will reduce. And you also mentioned the Circle of Security program and how improving sort of skills and education for parents can also help them bring down those stress levels, so that the family can have more moments of joy and they can enjoy each other’s company rather than everything really being focused around managing behaviours and managing mental health concerns, which rightfully becomes the main focus when those things are so prominent in everyone’s everyday experience.

In terms of the Circle of Security program that you mentioned, that sounds like that’s been really effective in your experience. Are there any other evidence informed interventions that you would suggest might be helpful?

Jodie

Yes, look we use Stepping Stone Tripple P quite a lot as it has a really good evidence base. There’s lots of different interventions, levels of interventions from I guess intense one-on-one 10-week program, to group programs, to seminars, to three seminars. And look they have made a real difference for some of these families. We did do a study and we noticed that behaviours increased by about 25 percent, so a quarter improved after the parents had completed this program. And also, the stress and anxiety levels, and depression levels of the parents also increased by about 25 percent as a result of doing the program. So I think it had a benefit for both child and family.

And it’s all those positive parenting principles which we need to be reminded of. That doesn’t come 100 percent naturally for everyone and no child comes with a manual. So these programs are, Stepping Stones in particular, was designed for children with disabilities for parents of children with disabilities. And so it goes through all those positive parenting strategies and some behaviour management strategies as well to elicit those behaviours

Pramudie

And 25 percent is actually really remarkable considering that types of families and patients that you would see in your service are people that are at the really severe end of both intellectual disability and mental illness and so the level of distress and the kind of degree or severity of the issues is huge in the service that you work in. So coming from that high level, if you can even reduce it by 25 percent just by interventions around supporting parents, educating parent that's huge.

Tania

Yes, and we also had a lovely story, similar to what Tania mentioned. About how a parent got their first ever kiss after employing some of these strategies, positive parenting strategies. And you think, that's a special moment that most parents take for granted, but positive experiences can come out of increasing confidence in parenting.

Pramudie

Amazing

Tania

The other evidence-based program that we use in our team is PCIT, so it's Parent Child Interaction Therapy. My understanding, it's a program that looks at both improving relationships, so it's attachment based as well as behaviour management. But it is for younger children, one of our trained clinicians has found that to be really helpful program. But it's longer term and a bit more intensive.

Jodie

And children with autism, in particular, can be referred to the Westmead Feelings program. And they have a program for children with mild intellectual disability and that also has a significant evidence base, but the problem is finding a clinician who is delivering the program, because it is quite a long program. But there are definitely groups that are happening around NSW, and you just need to do a bit of a google search to find one near your family.

Pramudie

Thank you. Those are really helpful resources that community mental health teams would be able to refer to or potentially upskill in themselves as well in delivering some of these programs.

Jodie

It’s good to remember that these families have children with lifelong disabilities. So whereas a typically developing child, as they go through the developmental stages will eventually become independent, but these children will always have some level of dependence on their carers which also adds to the lifelong carer stress. And they will remain dependent on their families and so often in the teen years is where we can see some of the carer burnout occur, because they haven’t had a reprieve from the dependent role that they experience as carers.

Pramudie

That’s a really important point.

Tania

Sometimes we notice also there is also the emotions around that. There’s a lot of unspoken acceptance of some loss and some grief as well. Especially around the teen years, as Jodie mentioned, neurotypical children that’s their stage of independence and they’re going away, they’re doing a lot more on their own. And there’s a realisation that they can’t or it’s more challenging for their independence to happen that parents will often tell me that they feel sad for their child, that they can’t do what other teens are doing.

So they sometimes express it in terms of sadness for their child, but I can see that there is also a sadness for them. And it’s about providing them some empathy around that. That’s where counselling can be helpful. Just, I think, as clinicians we don’t have to bring it up but just knowing, just having that empathy around that loss and that grief for parents can help I guess help us in the way that we present information or the way we offer services, in the way we interact with families.

Pramudie

That’s a really important distinction because I guess it’s something that a lot of people that might work in general mental health wouldn’t have really good insight into. So I think keeping that in the back of your mind when you are dealing with families is really helpful.

Tania

Being sensitive to the other layer. There is another layer, and parents don’t always want to talk about it or bring it up because there’s shame around it. There’s a lot of shame and sometimes guilt around feeling the way they feel. It’s just being respectful and being sensitive, because there are times where we might offer, and they decline. You offer and there are reasons. They've got their reasons. And being mindful. Accept what parents want to accept from our services without being really pushy.

Pramudie

And I guess there's kind of that readiness, readiness to change and all facets. In particular here, readiness to accept help and helping them through that journey.

Tania

And it is a journey. Every family comes at a different point in their journey regardless of the age of their child. Absolutely. It's definitely a journey. And being respectful of that journey.

Jodie

Yeah, I'll just add a quick point. We had a family recently who was very surprised when we started asking about their own mental health and the family's functioning. So, I liked your point about readiness, and I think that's a really important point. And I think being sensitive around the fact that not all families are familiar with the mental health model of asking very personal questions.

This particular carer thought that we were just focusing on the child and was very reluctant to discuss anything else that was happening in the family. So I think it's also providing an understanding to the carers that it is a systemic assessment and to answer the questions they feel comfortable answering.

Tania

I think you make a really important point around expectations as well. So, when families come to the service, really defining what the service is about and the expectations. Having a conversation around expectations in terms of how – what the service is about, the parameters of the service, and being really transparent about what it can offer, and not promising things that it may not be able to deliver. I think that's really important.

Pramudie

And I guess that links back to where we started with this talk in terms of that involvement of family and carers starts right from the beginning, even before the first appointment. And that setting those expectations, setting that frame and keeping those lines of communication open are really important.

So thank you both for speaking with us today and for sharing your expertise. I’m sure this is going to be really helpful for a lot of people who want to do more work in this area.

Tania

Thank you.

Jodie

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