National Centre of Excellence in Intellectual Disability Health

Podcast Transcript: Transitions to adult services

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

Today we're speaking with Rachael Havrlant from the Agency of Clinical Innovation Transitions Care Network. We'll be discussing transitions for young people with intellectual disability from paediatric to adult mental health care.

Hi Rachael. Thank you so much for joining us today.

Rachael Havrlant

Thanks. It's great to be here.

Pramudie

So, in this podcast we're focusing on transitions from child and paediatric care to adult care. And so we might start, Rachael, if you could just tell us a little bit about your role and the service that you work in.

Rachael

Thanks. So I look after the ACI Transition Care Network. So the network was created 20 years ago this year, to help address the needs of young people with chronic and complex conditions as they move from paediatric side of health care, children's side of health care to the adult side of health care. So my role as network manager, we look at statewide initiatives and statewide processes to improve transition care across the board.

Pramudie

Amazing. That sounds like a really much needed area. And I guess with your experience, you know helping young people transitioning into adult care, can you tell us about what makes a good transition, particularly for young people with complex needs?

Rachael

Sure. And I think a good transition I guess involves both having the clinical teams on board, as well as the young person and the family members as needed or as appropriate.

I think we have these key principles for transition. So I would say a good transition involves, using some of those key principles, but acknowledging that sometimes those key principles are hard to enact if there aren't services available. So I think a good transition involves clear communication between the health care teams and the young person and the family and also including the GP in that communication. Or finding a GP. Sometimes we find that young people are so well managed by their paediatricians that perhaps they don't have a local GP to go to.

So I think a good transition involves, you know, letting the young person know that they will have to transition out of this service. So it's not a shock to say, I'm sorry. you're too old for our service now and you need to leave. So being really clear around at some point, yes, you will have to transition out of our service. Providing your reassurance that you know you'll be well supported during this time, this time of change. And, you know, we will find a new, we will work with you to find a new team or a new provider to take on your care.

Pramudie

So it sounds like this is quite a complicated process and can be a big change for the young person. Is there a sort of time frame when you start having those discussions around transition?

Rachael

I think it really does depend on each service and when they like to transition the young person out. But we generally say from the age of between 14 to 16, just to start talking about transition, making it just part of each interaction.

So it's not it's not a big surprise at last appointments or things like that. I think the team themselves needs to be really clear about what their processes are, and when they will plan to transfer care to a new team. And to start that planning as early as possible. So like I said, about between 14 to 16 years of age, again, every service is different. So you have to be flexible to what the needs are there.

Pramudie

And in terms of mental health, are there specific things that mental health staff should be doing to facilitate transitions?

Rachael

I don’t think there’s probably anything specific for mental health staff to do. I think the principles and some of the resources that we have through our network are applicable to any specialty.

I think it's around just, acknowledging the different health care providers involved, whether it's just the mental health team or there are other specialists involved, whether they need, making that clear decision as to whether an adult mental health team needs to be involved or a psychiatrist, or finding a private psychiatrist, or whether care can be transferred back to the GP.

So just the team understanding those different nuances, I guess, with the young person in front of them. And again, there's some checklists that can be done around transition readiness to try and identify the young person's goals for transition or, identify self-management, I guess, skills or anything that they could that the team could do to help the young person improve in those areas and help in, I guess set them up for taking on more responsibility for their care in the adult teams.

Pramudie

And I guess for most young people with intellectual disability, their mental health might be managed by a paediatrician or a developmental paediatrician. But when they're transitioning into adult services, I guess there's not that equivalent kind of holistic, across the board doctor, and often that mental health aspect of it care will need to get transitioned to a psychiatrist. Do you have any tips for how young people and their families might be able to find a psychiatrist?

Rachael

That’s a really tricky question. It is hard to find a psychiatrist that, there aren't many public psychiatrists available in through their local health districts. So, I think most of the psychiatrists that our team are aware of are in the private space. So we use various websites that can help pinpoint based on the person's location, where they live to say these are the various mental health services available to them.

Often we will say to people, go back to your GP because they might have a good idea about what's locally available and they have a better understanding, I guess, holistically, of what the young person needs.

And maybe we would know what psychiatrist, maybe psychiatrists that are better suited than others. It is a tricky question. And so there are various websites that our team uses like Health Direct or Head to Health as well. There's I think there's a mental health line through New South Wales Health. So they’re some of the resources that we use and that people can easily access to find services available to them.

Pramudie

And I guess when we're thinking about private psychiatrists, there's often a really long wait time. And so planning early, in anticipation that you'll have to move to a different service and getting on the waitlist.

Rachael

Absolutely. That's why we talk a lot about early preparation. So, you know, you can, plan ahead and say, you know, if the wait list is, you know, a year or nine months or even longer, then you can work backwards and know that by the time you need to transition out of your paediatric team, that you've waited that time, I guess, on the waitlist. So that's why talking about transition early is really important.

Pramudie

And do you have, any examples of a transition that you think was handled really well and what that meant for the young person?

Rachael

We've done some consumer surveys recently and some yarns with young people and their families and what they've, the key things that have come up about a transition that's handled well or has gone smoothly is coming back to those key elements around communication.

And being able to have, being able to know who they can go and talk to about their transition. So there is a lead person. So if they've got any questions or they're feeling a little anxious about what's coming up ahead, because usually at these times perhaps it's around 17 or 18 there are lots of other things happening on.

It's not just your health care. So it's, you know, it could be a really busy time, whether it be through school or work or just life in general. So consumers have said to us, by having a lead person or someone that they can pick up the phone and ask questions to about what's next is really important and that's a key element to having the transition handled well and having a clear plan, and knowing last appointments, and new appointments with their new teams. And ideally having the opportunity, I guess, to have a joint appointment with your paediatric team or specialist with your new team.

And virtual care is a great way of being able to bring people in different locations together, but it just gives, you know, an opportunity before you perhaps see them face to face that you've either met them online, heard their voice. Maybe they ask some questions of the young person themselves. They get an opportunity to ask the paediatric team perhaps a couple of questions.

The young person and the family, if they're, you know, in the room, they get to hear all of those things as well. So, I think that's a key part in transitions that are handled well - that everyone's kind of on the same page. Communication lines are really open. There's a clear plan. And we know that things change and then things, so even if you did have a transition plan and things change, knowing that you have someone to go back and ask questions to, or appointments need to be changed, who those key people are I think is a great way of helping settle, I guess some of the stress and anxiety that can be associated at this time.

Because you are perhaps leaving a team that you've seen for quite a number of years, you've built a really good rapport with. And so, yeah, a lot of people say it feels like you're starting from scratch and you have to, almost like a relationship breakup, you know, you've left one and you're starting again and you have to retell, you know, retell your story again and to hopefully try and build that rapport, that same kind of rapport and relationship with a new team.

So I think, giving people an opportunity to meet those new teams before they actually leave their paediatric teams is a is a great way of, of kind of setting them up for a smoother transition.

Pramudie

So it sounds like having that lead person, so that there's a point of call for the patient in the family is really helpful. And then that real, I guess a warm handover, rather than sort of abruptly stopping one and starting the next one. I mean, that makes a lot of sense in terms of, you know, in the ideal situation, what that would look like. And are there any other, I guess, key principles of transition?

Rachael

So our network developed seven key principles for transition care back in 2014. And we updated them in 2022 to be a web resource and to try, and the key principles themselves didn't change, they were based on evidence and clinician input. But what we did was make the seven key principles applicable to any clinician working with any young person with a chronic or complex condition across any setting.

So, they, I guess walk it through from having a, you know, number one being like a formal process and understanding what your local processes are working through that early preparation and clear communication, empowering the young person, and their carer to maybe improve health literacy or, or around self-management. Then identifying that key person who's going to lead that transition, whether it be someone within that service or a specialist transition support person. Then actually documenting transition plan.

And then the last one is around follow-up and evaluating your processes. And what we found with those key principles is, people use pockets of them, which is fine. We're really keen to embed that into usual clinical process. So that's going to be our

focus for the network moving forward. But I think the principles have a lot of great templates and examples about how people are doing it in real life.

And really keen, as you know, if there are any CAMHS services or CYMHS services out there or any other mental health services that are doing work in this space, really keen. I'm happy to highlight the work that's been done there through the key principles as well. So there's plenty of templates to say how you could perhaps start a transition plan, some ideas around and you know writing a good referral or good handover letter. It talks about the various roles, that, you know, paediatric clinician would play versus an adult clinician versus perhaps a, someone in primary care or general practice.

So there's a lot of great information in there, I think, for the key principles that you can take and I guess adapt, and adapt and adopt to what your local service needs and what you know, what that service delivers.

Pramudie

That sounds like a really useful resource, Rachael. In terms of people being able to access it, is that through the website?

Rachael

So that’s through our ACI Transition Care Network website. It's publicly available. Even though the key principles do talk to a, a health staff audience, we do have one pages for both young people and carers that kind of talk, talk about the, the seven key principles and what that could mean for them. So if they're wanting to perhaps introduce that to their own clinicians, if they haven't had a good talk about transition, then kind of give them a little bit of information, some of the language to use perhaps. So, there is a lot of great resources out there that anyone can access through our web page.

Pramudie

Wonderful. We'll put a link to that in our factsheet as well.

So I know Rachael, your team helps young people transition across the board in terms of, a range of physical and mental health issues and whether they have ID or not. I'm just wondering, are there specific challenges that people with intellectual disability or autism might face when they're embarking on this transition journey?

Rachael

Absolutely. I think sometimes it can be harder to find the appropriate services or providers for someone with an ID or autism. Sometimes the services feel like they're

not equipped to take on a patient with an intellectual disability, or perhaps their physical space or their waiting rooms is not conducive, I guess, to someone with maybe sensory needs or additional needs as well.

So I think you need to allow for that extra time to find those suitable options. Exploring whether telehealth or virtual care might be a better modality rather than sitting, you know, in a waiting room or face to face. So those things need to be taken into consideration, I guess, as well as a long wait times.

And I think it's important for the adult teams receiving the young person to just remember that, whilst they might be your new patient, they have been living with this chronic or complex condition for perhaps all of their life or most of their life.

So they have a wealth of knowledge and lived experience to share. So allowing ample time for perhaps the first few appointments to build that rapport and checking in with the young person and their families about their transition goals and giving them time to ask as many questions around perhaps this new way of seeking health care in the adult space.

I think that continuity of care is really important, especially for those young people that might be on strict treatment regimens or have regular, you know, prescriptions for medications. If those, if that early preparation, those wait times perhaps don't align, then it might mean a gap in those treatments or medication that can be provided.

And as we know, there are, some medications can only be prescribed by a specialist. The GP can't help out. So I think it's really important to take that into consideration as well as your, as your planning, planning out the transition. And those timings and I guess highlighting perhaps that this could be a, you know, an escalation point, I guess for those adult teams when you're writing those referrals or hand over letters.

Pramudie

Great. That's really important. We know that there are a few services that can help young people with transitions, such as Trapeze for young people transitioning from Sydney Children's Hospitals Network and the Transition Care Service as well. Are there other services that might be helpful during the transition to adult services?

Rachael

So there are several specialist transition support services, like you mentioned, Trapeze through the Sydney Children's Hospitals Network. There's also Petaway, paediatric to adult service at Southwestern Sydney LHD. There's transition care coordinators based at Hunter New England. And there are two transition care coordinators based within the ACI who cover multiple LHDs.

So each of these services have their own referral criteria. But they're a good place to check for local advice. And perhaps specific to the mental health space, they might

have some idea. I'm not aware of any specific transition support for mental health services.

There is a policy directive around transitions from CAMHS or CYMHS into adult mental health services that might, that will provide some direction. So I think it's around within that mental health team understanding what's available. And perhaps if there's somebody that is appropriate to take on this transition lead. There are some other services, that I know of, through diabetes perhaps and other specialties where someone within that service, whether it be the medical, nursing or allied health, they take on that transition support lead.

And so I guess it's important just to ask within your LHD or specialty health network about what's available within your service there for transition support. But there are a stack of general transition care resources on our website, including a fact sheet for transition if you do have an intellectual disability.

There's also some videos about finding a GP and getting a specialist referral. The videos were created with the input from young people as well. So they're really short animations that are available on our website. And there are plenty of resources on the web page that cover a few of the different aspects of transition that we've chatted about today.

Pramudie

Great. This is a really important element of care, because we know that a lot of young people, as they move into adult care, can fall through the cracks. So it's really sounds like it's very important work, that you and your team are doing. Was there anything else you'd like to say about transitions to adult care?

Rachael

I think transition is, you know, a key milestone in someone's long term health care journey. And people are really keen to work with our network in improving transition care across the board throughout New South Wales. We're very, very happy to work with people who are passionate in this space.

And we do have, we're lucky to have some key clinical leaders in our network as well. So always looking for new people to join and see how we can improve things for young people and their families through this time.

Pramudie

Thanks Rachael. That's a great note to end on, and I hope that listening to this podcast will inspire more people to think more about transitions in their services as well. It was lovely to have you on. Thank you again.

Rachael

Thanks for having me. I really appreciate the opportunity to be able to talk about this important transitional in care. Thanks.

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.

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