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| Webinar 2 - Carer breakdown |
| Video transcript |

**Q: Welcome to a webinar looking at families with children with complex disability and family breakdown with a focus on the role of principal disability practice advisors. This webinar's part of the Child and Family Services NDIS Learning and Development program developed by the Parenting Research Centre for the Victorian Government Department of Health and Human Services. My name's Nicole Telfer. I'm a disability specialist the Parenting Research Centre and national manager of MyTime, a program of facilitated peer support for parents of children with disability and developmental delay.**

**Today I'll be speaking with Kara Parnis who is a DHHS principal disability practice advisor in the west division. Kara's worked at DHHS for 11 years in disability client services, health and education for people in out-of-home care and placement coordination for children on statutory audits. Kara's been a principal disability practice advisor since April this year so welcome Kara.**

A: Thank you.

**Q: Before I begin the webinar I'd like to acknowledge the Wurundjeri people of the Kulin nation, traditional custodians upon whose ancestral lands we're recording this webinar today and pay our respects to the elders past, present and emerging. We acknowledge the deep feelings of attachment and relationship of Aboriginal people to country. We also pay respects to the cultural authority of Aboriginal people viewing this webinar from other areas of Victoria and Australia. Kara, can you tell me a bit about why the role of the principal disability practice advisors were commenced?**

A: So the role of the principal disability practice advisor was created in recognition of the service systems gap that was left when the NDIS was created and traditional case management I guess is exiting the department to a service coordination model through the scheme and for children and young people who are on voluntary child care agreements predominantly. I guess the role was established because traditionally disability client services case management would hold the role of having oversight of children and young people on voluntary child care agreements which is no longer the case. So in that transition principal disability practice advisors were established and our role predominantly is to have oversight, placement monitoring and case coordination of children and young people who are on voluntary child care agreements.

We do that through ensuring there's establishment of a care team, that the child or young person's NDIA plan is adequate to meet their disability needs so we might undertake advocacy with NDIA and that's not only for children and young people who are on voluntary child care agreements but could also be for people who are involved with the statutory system or people who are involved with family services. So we do provide advocacy and consultation to the sector more broadly but our primary focus is for placement planning and progression and transition planning for children and young people who are on a voluntary child care agreement.

**Q: What are some of the signs that a family with a child with a disability might not be coping and is at risk of breakdown or potential relinquishment?**

A: Yeah. So I guess there are quite a few and some of them are fairly common across all of our service sectors and systems. But ageing carers is one that's fairly common as well as carer illness. I guess more commonly is an increase in behaviours of concern when a child or young person hits that puberty age because they're obviously getting bigger, behaviours become more aggressive and more difficult to manage. Another factor is the impacts for siblings that that might be having for the family so siblings retreating to their bedroom and spending all their time in their bedroom. The child or young person needing that 24/7 support so carers feeling that burden of limited formal supports in place in the home or not being known to disability services or the NDIA is another one.

It would also be I would say a huge one is education or decreased attendance in education for whatever reason. But that would mean that the [4.25] that breaks the carers between 9:00 and 3:00pm that they would normally get and so I guess the level of care that needs to be provided has again increased. It could be health or medical needs or an underlying need that we don't know about and the young person's trying to communicate that with us. So we're seeing an increase or an escalation in behaviours from that. Another factor would be mental health of carers and where they're travelling at a certain point in time. We often see where a carer is not doing well in terms of their mental health. That has an impact on their ability to care for their child or young person so an increased need for supports at that time so that they're able to recover and take back on their carer role.

**Q: So really lots around change so where there's been a change in situations or circumstances ...**

A: Yeah.

**Q: ... or a period of change for a young person such as puberty, all those types of things really are those things that you'd look out for.**

A: Definitely, yeah. We see that is the common factor also where we often have children come in in a crisis and we haven't known about them prior so a family has battled through and done the care provision for maybe 13 or 14 years without ever having accessed any disability supports or only had a school as a support network and that's certainly a common thing that we see as well. May not have ever come to Child Protection's attention so no child first or family services have engaged with that family so brand new to the department or to the NDIA or any of the supports out there.

**Q: What happens when an urgent response is required such as a child not being picked up from school?**

A: I guess when a child's not collected from school schools would generally go through their normal processes of making a report to Child Protection to inform them that there's a child or young person who's in the school grounds without a parent. Child Protection would then try and make contact with the parent to assess what is going on and if there is a risk to the child from the parent. Where there is no risk to the child from the parent that's where our role does play a key role in trying to understand and better support these families around what's their needs at that time and what are they needing to care for their child? Why are they in that situation? That's where we'd then go into planning.

If it does take a statutory pathway of support because there is an assessed risk to that child from the parent we would then work in collaboration with Child Protection and provide consultation and advice around what they can access. So we might still in those cases provide advocacy with the NDIA through our NDIS transition team to see where they're at or support them to directly make contact with NDIA.

**Q: So is that process a different process to the way it used to be or is it pretty much the same despite the changed NDIS environment?**

A: It's pretty much the same. Where a child or young person is requiring an urgent response the mechanisms for that support haven't changed. What has changed is I guess because the supports used to sit within the department and you used to be able to walk up or down stairs and say "this is the situation, can you check what supports are there" that's the shift and it is a big shift in how we operate because it is an insurance scheme working or considering the child or young person's disability support needs not necessarily the parental support that's required. So where we might have put in supports in the home for increased periods of time if that's outside of the child or young person's disability support needs or what's assessed as parental responsibility that then wouldn't come from the NDIA support. So we'd look at how we can still continue to support the family in those instances.

**Q: Are there any strategies to get everyone around the table quickly to address an urgent need for a family?**

A: Yeah. So can speak specifically to the west division. We have a rapid response process so where a family does enter crisis and there isn't a need for statutory involvement we would call something called a rapid response meeting where we get key people from the department around the table in an authorising environment to talk about what a plan could possibly be for this family. Where Child Protection are involved in an investigation capacity or Child and Family Services are involved we might liaise with them to provide that information, support and advice for them to relay to the family. We wouldn't necessarily in the principal disability practice advisor role make direct contact with families because it's introducing a third party at a time that's not potentially required.

But I guess where a child or young person does then enter a voluntary child care agreement space the principal disability practice advisors would make contact with families and we also have a position, disability practice advisor, that reports through to us who take on more of the client focused work and do placement planning and progression for these young people. So they definitely have a lot of interface with families and care teams.

**Q: Can you tell me how respite has changed under the NDIS?**

A: Yes. Respite is now called short term assisted accommodation and it has to be in a person's plan for them to be able to access it. So a person might get 14 days annually overnight respite in their plan but might have a larger amount of money for community access and that's for core support and capacity building so it's about inclusion in the community. Where a family used to enter crisis we used to go to our respite coordinator and say "this has happened, can we have a block of respite for a month to support a family to settle back down?" That's not how it operates anymore I guess. We can still purchase things at a fee for service but it is a business model essentially given it is an insurance scheme.

In saying that where I have had someone contact me saying "this young person's mother has gone into hospital, needs an emergency response in terms of emergency respite" I have been able to contact the NDIA and they've said "of course. I know it's not in their plan but this will be endorsed so please go ahead and organise that." So it's a shift in how we work but NDIS do recognise where there is an urgent and critical need. Again where it comes to parenting responsibility or risk of caregiver breakdown that is different.

**Q: So respite still exists.**

A: Yes.

**Q: But it's just a different way of approaching it and a different way of accessing it ...**

A: That's right.

**Q: ... and a different way of paying for it I suppose.**

A: That's right. Exactly. Yes.

**Q: So Kara, what other supports can be included in an NDIS plan that might assist with family functioning or preventing family breakdown?**

A: So there are many things that can be included in a young person's or a person's NDIS plan. As I mentioned earlier the scheme is about capacity building so often what we will see in a person's first plan is provision of OT assessment, sensory assessment, speech and language assessment, behaviour support. So these things I guess are things that are put in place in the first plan and the people who are providing those assessments are expected to provide a report with recommendations and the NDIS would consider funding those recommendations where it's reasonable and necessary to support the person's disability. So we do see aids and equipment going into home, assistive technology is one that can be looked at.

But definitely that need for assessment and recommendation is definitely considered because it is around capacity building for the person within their plan or over the life of their plan. So the expectation is that as we build capacity the supports will potentially reduce and they're more independent in their community and a participant of their community.

**Q: So often that first plan is developing all of the information, gathering that clinical information about an individual to be able to try and then guide future plans I suppose.**

A: That's right. That's right. Yes. Definitely. It's something that I've seen with metro just being rolled out and a few of our areas. The other thing to add is that local area coordinators have been established for people or services to contact and they're the people who act as your NDIA liaison or information source. So they can tell you what's out there in terms of support coordination and services that you might want to access, how to navigate your NDIA plan, how to implement your NDIA plan. So there are things that are available for people to build on their knowledge. The NDIA website has heaps and heaps and heaps of information and tools to assess with planning and there's price guides on there and there are categories of support that are available through the website so it's not limited to the things that I've mentioned. They're only a small amount of what is available to NDIA or can be considered for NDIA funding.

**Q: I know that the idea of collaboration and how services are working together and how people within the Department of Health and Human Services are able to engage support coordinators and other NDIS funded services is a really important part of how they're able to implement plans and things like that.**

A: Yeah. So support coordination plays a key role in implementing the person's plan. Where a support coordination is not involved in it or hasn't been funded through a person's plan that's where the local area coordinator can provide support. So it is new and it is a changing scheme because it is a once in a generation change and we all have heard that before and it's still very much in its infancy.

**Q: Kara, can you tell us a bit about the support the advisors can offer young people transitioning from care?**

A: Yeah. So where a young person is on a voluntary child care agreement the advisor's role is to plan for that transition from care into adult world and so that's the oversight that we would have in that and we would work with support coordinators and care teams around what is the best fit and that includes gathering evidence around assessments and needs or what would be the best accommodation model for that person post-18. In a statutory case we would provide advice and consultation to Child Protection practitioners. Leaving care responsibility obviously still sits with the statutory system in those cases and we would support them to gather informed evidence around what might be available to that person through the NDIS beyond 18 in terms of accommodation in that transition planning.

So not everybody would go into a supported accommodation model, it's how we can support people to be independent but also how do we get informed assessments to support what we are seeking for that person in care?

**Q: Kara, thank you so much for your time today. It's been really valuable to gain some insight into the role of the principal disability practice advisor and how it interfaces with the NDIS. There's a range of places people can go to to get more information. There's the NDIS Child and Family Sector Interface Good Practice Guide. People can go to their local DHHS NDIS transition teams. They can also speak to their team leaders and as you mentioned there's local area coordinators that are available for people to have those conversations. How can workers go about getting in touch with the principal disability practice advisor within their local department?**

A: There are four of us so there's one principal disability practice advisor in each of the divisions. Probably an easier way is to get in touch through your community based Child Protection worker but you're always more than welcome to contact any of us directly if there's a need.

**Q: Great. Thank you so much for your time again Kara. It's been really valuable.**

A: You're welcome. Thanks for having me.

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