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| Webinar 1 - Working with parents with intellectual disability |
| Video transcript |

**Q: Welcome to the Working with Parents with Intellectual Disability in the NDIS webinar. This webinar is part of the Child and Family Services NDIS Learning and Development Program developed by the Parenting Research Centre of the Victorian Government Department of Health and Human Services. My name's Nicole Telfer. I'm a disability specialist at the Parenting Research Centre and national manager of MyTime, a program of facilitated peer support for parents of kids with disability. Today I'll be speaking with Dr Catherine Wade, principal research specialist at the Parenting Research Centre and internationally recognised expert on parenting with intellectual disability. She's the founding member of HealthyStart, the national strategy to support parents with learning difficulty and their children.**

**But before I begin the webinar I'd like to acknowledge the Wurundjeri people of the Kulin nation, traditional custodians upon whose ancestral lands we are 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 across Australia. So welcome Catherine.**

A: Thank you Nicole.

**Q: During the webinar today we'll be looking at the experiences of family with disability where a parent has an intellectual disability. We'll look at some of the challenges for families in navigating the NDIS and explore some strategies you can use to support them through the access, planning and implementation processes. So over to you Catherine.**

A: Thanks Nicole. Hi everyone. So I thought I'd just introduce you to start off with to a few basic facts and some things that we know about parents with an intellectual disability in Australia. We did some research not long ago looking at how many people there were in the Australian population who had an intellectual disability who were parents and basically we identified that it's a very small proportion of the population who have a diagnosed intellectual disability who are also parents, around about 17,000 people in Australia fit that bill. So that's a very small proportion, it's less than one per cent of our population who fit that bill but we need to keep in mind that that's a very narrow definition of intellectual disability.

We know that there are far more people out there in the community who are parents who have cognitive limitations that affect their ability to take on new information so we refer to those sorts of people as people with learning difficulties. When I talk about people with intellectual disabilities I really am including people with learning difficulties because they often fall into that same group of people who need additional supports to take on new information to support their parenting. The other thing it's important to keep in mind is that we know that with support and education that's matched to the learning needs of people with learning difficulties people with learning difficulties can be effective parents to their children and that's a really fundamental premise upon with everything else that I'm going to say is based.

We need to accept that parents with intellectual disability and learning difficulties can be loving and meet the needs of their children and do all of the other things that other parents can do. One thing we know about parents with intellectual disability though is that they often face many other challenges that other parents don't so there's this added layer of complexity that often exists for parents with intellectual disability and we need to keep that in mind when we're working with parents to support them. So some of the things that we know about parents with an intellectual disability and learning difficulties is that as a group they're much more likely to experience the sorts of things you're seeing on the screen now so adverse mental health outcomes. We know that people with intellectual disability in general are much more likely to experience stress, anxiety and depression and the same goes for parents with intellectual disabilities.

We know that intellectual disability is also really strongly correlated and related to poverty. It's a bit of a chicken and the egg. People with intellectual disability are far less likely to have higher income jobs but we also know that people from poorer backgrounds are much less likely to be exposed to the sorts of opportunities that get them into higher paid positions or give them financial stability. So parents with intellectual disabilities are much more likely to be exposed to living in poverty and also along with that comes social isolation and one of the things we know from our own research is that parents with intellectual disability in Australia were much more likely than the general population to be living in rural and regional areas. So many of them live in urban areas and major cities but many of them are living outside of those urban centres so they're much more likely to be exposed to social isolation.

They have fewer friends, fewer neighbours that they can turn to for help. When we ask them the question "do you have someone you can turn to for help and support" they're more likely to say "no." Some other complications or complexities that parents with intellectual disability are typically exposed to are unemployment of course. I've mentioned poverty before so that's related to that. But also communication difficulties so there's often some challenges that parents with intellectual disability will face in taking on new information but in also communicating information to people so we need to bear that in mind and we'll talk a little bit more about the implications of that for NDIS in a little while. Another vulnerability of these parents is that they haven't had particularly good exposure to good parenting role models themselves.

So often they will be more likely to have experienced exposure to out-of-home care themselves so they might have come from an out-of-home care situation, foster care situation themselves but have been through lots of changes to their living arrangements as themselves as children. They're often not surrounded by other good examples of positive parenting role models. Finally we know from research here in Australia but also research across other countries in the world, the U.S., the UK, Sweden, Japan, we know that these parents are much more likely to be represented in the child protection and court system. So for a variety of reasons they're much more likely to be the subject of child protection involvement, much more likely to have their children removed from them than other parents and much more likely to have their children removed into non-kinship care situations. So they're less likely to have access to their children in an ongoing way after their children are removed from their care.

**Q: Often really, really complex family systems you're talking about there Catherine.**

A: Absolutely. Yeah. Often it's not just one of these complexities but a lot of them are in place for one particular family. So there's lots of challenges that crop up for these families that I think we need to keep in mind when we're working to support them through things like the NDIS.

**Q: Accessing the NDIS can be a really difficult time for families. So with the additional complexities that you've just spoken about for a lot of these families where a parent has an intellectual disability what might it mean for parents when navigating the NDIS? What sorts of things do we need to consider?**

A: Yeah. Well I think importantly you need to keep in mind the multiple complexities. I mean essentially focusing on the fact that this is a family who's probably got a lot going on for them, they've got a lot to keep in mind. They perhaps don't read and write so well so challenges associated with dealing with the forms and dealing with the professionals who they need to make phone calls to, the appointments that they need to make. This is all going to be an added challenge for them, particularly if they've got multiple stresses associated with mental health difficulties, living in poverty and financial stress in addition to their child's obviously developmental needs. So it's important that you think about that when you're working with a family through that sort of assessment phase of the NDIS.

Also consider too that parents with intellectual disabilities commonly have had very poor experiences with the system, with the service system. So they might have had interactions with service providers that haven't necessarily gone well. They haven't been necessarily - where workers haven't been aware of the challenges that these parents might have faced in their life and haven't necessarily given the information to them in the right way so that they could take it on. So their learning experience was probably quite difficult in the past and they might be bringing that to their interaction with you. They're remembering that. They're remembering that they didn't get a positive result last time or that they felt blamed or they felt stigmatised. So there might be some early work that you need to do to engage the family. A bit more work at that point.

**Q: So really that relationship building sounds like it's really important, especially if you're not aware ...**

A: Absolutely.

**Q: ... of people's previous experience with the system.**

A: Yeah and the other thing I'd say is that it's important that you're a bit more active in reaching out to the family. That they may - family engagement particularly for parents with intellectual difficulties that period of time when you're first engaging with families is a really critical time and it might just take longer than what you're used to when you're working with a family with learning difficulties because there's a bit of trust and rapport building that needs to happen given previous experiences of being involved in the system. So allow a bit of time and be more active in reaching out to the parent.

**Q: So there are three main phases to accessing the NDIS and there's the access phase, there's planning and then there's implementation and each of those requires something different for parents. Different skills and different approaches to what they need to do. So maybe we could start by looking at each of those in a little bit of detail and have a think about what might be helpful for parents along the way. So firstly we know that accessing the NDIS is a really complex process. There are forms to complete. There's evidence to provide. There's processes that need to be followed and there's also a language used that might not mean a lot to a lot of people. So what practical strategies can people use to support families and support parents through this access process?**

A: Yeah. Very good. It's important that communication from you to the parent is clear and as simple as possible and jargon free. That can be a real challenge with NDIS.

**Q: It could be.**

A: Yeah. So giving information in ways that the parent understands and usually if you ask a parent how they learn best they're able to tell you. They'll tell you that they don't read and write so well. They'll tell you that they like to hear someone talk about it or they like to see it or watch a video or practice it themselves. So they will be able to tell you how they want information to come to them. The other thing is to check for parent's understanding. This is vital. So we know a lot about parents with intellectual disability as a group, not everyone, but as a group. They're much more likely to do something that we refer to as acquiescence, terrible word. It basically means you say yes to everything that somebody asks you when they ask you a question.

"Have you done your homework today?" "Yes." "Have you brushed your teeth today?" "Yes." Even complex questions like "have you completed the NDIS form?" "Yes." So parents with learning difficulties do this for a number of reasons but one of the reasons is because they don't want to disappoint. They don't want to fail. So they don't want to let you down by saying no. So one of the ways to combat acquiescence and this tendency to say yes is to check for parent's understanding. One of the really practical ways that we do check for understanding is by asking the parent to show me so rather than just saying "tell me" saying "show me." So "show me how you checked for lice in your child's hair the other day. Show me how you make up a formula bottle. Show me how you filled in the NDIS form." There are other ways that we can check for parent's understanding but essentially it's about showing and giving the parent an opportunity to practice that skill.

Another practical strategy that we can use to support parents through that sort of process of accessing the NDIS is to think about the sorts of communication strategies that we're using and matching how we're communicating to parents to that individual's learning style. So if they learn best through pictures we use pictures as prompts. If they learn best through practicing it themselves then we help them to role play and we coach them to use that skill. The other thing is to maintain a present orientation. Again a bit of jargon. What that means is thinking about the here and now, thinking about concrete things rather than thinking about abstract concepts. So asking the parent to visualise what their life is going to be like in 10 years' time is quite an abstract thing to do. By helping them to think about what's happening for them now and what they might like to change is a good way to make something turn from abstract to more concrete.

Allow the parent plenty of time to respond as well. So often we don't like awkward silences as human beings and often if we ask a question and we don't get an immediate response we want to jump in with the answer or jump in with another way of asking the question. We like to talk a lot. But parents with intellectual disabilities sometimes need a little bit more processing time so it's okay to feel comfortable with silence. Ask the question, pause, wait a few seconds and then prompt if you don't get a response so being comfortable with allowing time.

**Q: Great. So once a person has been granted access to the NDIS the next stage is moving to a planning meeting. So at that point a person needs to identify and be able to talk about their goals. We know the importance of pre-planning meetings in helping parents to be prepared and to think about what they might want to achieve but what strategies might you suggest or how else might we consider the support needs for parents with intellectual disability around goals?**

A: Goal setting, yeah. I think the first thing to think about is whether you've got all the right people involved in that conversation. So sometimes it can be very helpful to allow the parent to invite someone else into that conversation. It might be a support person, an official, formal professional support person that they have, an advocate that they use sometimes or maybe it's their spouse or their partner. Maybe it's their mother or their father or a friend who plays that sort of advocate kind of role, advocates for them. So think about including a support person in the conversations where you're having that goal planning session with a family. Also think about the language that you use so think about the way that you ask questions and again this comes back to that idea of not using too many words and complex words and jargon and also being really concrete in the questions that you ask.

So for example if you're asking a parent to think about what goals they'd like to set for their child asking them about what's happening for them now that's a challenge that they might like to change and then following that up with a question about if it was different how would life be better? So getting them to think about what's happening for them now that's a problem and how life would be better if they could get rid of that problem. Because I think the concept of a goal is by its very nature quite an abstract concept so sometimes it is challenging to get parents with learning difficulties to identify goals. They'll often come up with very broad goals that are sometimes unrealistic and unachievable.

So when I work with parents quite a lot they'll say they want their child to be happy. They want their child to have a good education. They're worthy goals but they're very broad, very long term, very much in the distant future. So if you can get them to identify goals that are small, realistic and achievable in the next three months that's the way to go.

**Q: So the implementation stage is often really difficult for parents. It can be hard to interpret what's been included in a plan. The documents can be quite challenging to read. It can be hard to find support coordination or to look at what services you might need to actually deliver on the plan and supporting parents with that implementation of the day-to-day activities like getting to appointments or making follow-up calls it can be really challenging. So tell us what strategies we might be able to use to support parents with that real active kind of implementation stage of the NDIS.**

A: Yeah. Good. Well I think first of all relating your activities and what you're doing with the family back to their goals so continuously going back to encouraging the parents to think about how this relates to what they want to achieve for their child so that's the first starting point. Again being active in engaging with parents and providing that support so you might need to attend more of those meetings with other services in the initial stages just to help the parent to feel comfortable in communicating about their needs and to take on information. So think about yourself as being a bit of an ongoing support person for that parent. I think again things like allowing the parent time to take on new information, allowing them time to answer your questions.

Learning happens with people with learning difficulties and intellectual disabilities but it can sometimes take longer for learning to take place. Provide information in a variety of ways so we know that when we're under stress as professionals the teaching strategies we tend to fall back on are the ones that don't work so well so you talk a lot, you talk at people and we talk more and we talk louder. But we know that for anyone but particularly for people with intellectual disability the teaching strategies that work best are things like role play and coaching and repeated practice, opportunities for repeated practice. So it's thinking about how you're teaching. Is this matched to the style of learning that this parent needs? Use visual aids. Use text message reminders. Lots of prompts. Prompts are good. Prompts aren't annoying. Prompts are helpful. So think about creative ways that you can use to sort of prompt the parent to implement the plan.

The other thing I'll say is that you really need to attend to how services are working together, really ensuring that you've got a good care plan coordination process in place so that everyone is aware of what everyone else is doing. So all of the different services involved in the life of this family are working towards the same goal so the parent knows exactly who each of the people are in the room and what their purpose is so really working on service coordination and collaboration.

**Q: So those care team meetings and using support coordinators and those sorts of functions and roles to really bring everybody together ...**

A: Absolutely.

**Q: ... and make sure that everyone's got a clear understanding of what's happening.**

A: That's right.

**Q: So there are a number of families who have additional complexities and it's worth us looking at a couple of scenarios now. We know that there are families who experience multiple disabilities where they might have a parent with a disability but also have a child with a disability. So what would you think needs to be considered in those situations where there's more than one person with a disability in a family?**

A: Well essentially the way you work doesn't need to change. I mean you need to adapt the information that you give, the way that you give information to the learning needs of the parent if the parent has a learning difficulty. But the sorts of things you do with the family won't change. Essentially they're the same. But I think it does mean that you need to pay attention to the need to involve all family members and potentially more than just the immediate family in that care plan development process. So you need to think about have I got the right people in the room? Are the parent and the child sufficient for this interaction and for this meeting and for these conversations or are there other support people that could be involved in this conversation?

I think the other thing to think about is again going back to what we talked about a minute ago in relation to that coordination between services. Really important that you're all on the same page and that you're all giving clear and consistent information about what's going to happen for this family and what the intentions are with the NDIS plan and the NDIS work so that everyone's on the same page and that the parent is getting consistent information about what they need to do.

**Q: So really that clear and consistent kind of approach, looking at support coordination across both family members?**

A: That's right. Yes.

**Q: Also making sure that there's clarity around their roles and responsibilities so there's no confusion for the parent or for the child in that situation.**

A: Exactly. Yeah.

**Q: So what about situations where you think a parent might have a disability but they haven't disclosed it and you're not really sure? How might you approach that?**

A: I think about whether it's important for it to come up to the surface. Is it important that people know? Is it important that there is a label or a diagnosis that the parent is identified as having a learning difficulty or intellectual disability? In many cases the answer will be no. For what reason would you want to have a parent assessed or for what reason would you want to have that label? If it helps as in if it helps for getting access to other services or if it helps for others to understand that this person perhaps needs a different way of working in order to take on information then, yes, you might explore it. But I'd really encourage you to think about whether the positives of having that label and giving it a name, giving the intellectual disability or the learning difficulty a name, is that going to be helpful ultimately for this family?

If it's not there's no need to bring it to the surface. There's often a bit of stigma and negativity attached to parental learning difficulty. These are people who have often gone through schooling situations themselves that have been quite negative so often talking about the person as having a disability or impairment is not particularly helpful, can be stigmatising and it can be a negative experience for the parent themselves. So just think about whether it's important.

**Q: In those situations how would you actually approach the work with the family if you weren't sure?**

A: The first thing I would do would be to ask them. Ask them how they learn best. So ask the parent if they like to read things or if they like to watch things or if they like to talk about things and the parent should be able to tell you how they like to take on new information. But if you suspect that there might be intellectual disability or a learning difficulty that's getting in the way of the parent taking on new information then there are definitely things that you could do and some of those things we've already talked about today. But using clear and simple language, using less words, less talk, falling back on the strategies we know work with parents with learning difficulties. That's showing them rather than telling them how to do things. Things like that.

**Q: So really going back to looking at how you're communicating and what you can do to make the communication simpler for them.**

A: That's right. Yeah.

**Q: So as we come to the end of this webinar in terms of the NDIS and parents with intellectual disability if you have any further questions about working with families within the NDIS you could refer to the NDIS Child and Family Sector Interface Good Practice Guide or you could speak to your team leader or contact your local DHHS NDIS transition team. Catherine where would you suggest people go for disability specific resources?**

A: Well I think raisingchildren.net.au is always a good resource for information about parenting. They also have a really useful tool on that website which is parenting in pictures which is something that I often refer workers to and parents too for information about how to learn important parenting skills but in a really pictorial way so a low language way. The other resource opportunity for you to access is the HealthyStart strategy so the HealthyStart strategy is Australia's national strategy for supporting those who work with parents with learning difficulties and you can jump online. If you type in healthystart.net.au it will direct you to a really information rich website about how to use best practices in working with parents with learning difficulties.

**Q: Fabulous. Thank you so much Catherine for your time today. It's been really valuable and I really hope that people out there have got a lot of useful information and great strategies from you so thank you so much for your time today.**

A: Thank you Nicole.

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