TESSA DE VRIES – Welcome to One in Five, a podcast created by the Melbourne Disability Institute, at the University of Melbourne. I’m Tessa de Vries. In this series we will be looking at how research can tackle some of the biggest issues facing people with disability and their families. Join us as we talk to a range of people about new research findings, possible solutions and policy ideas.

Early Intervention is something we talk about often when children are first diagnosed or acquire a disability. But it’s a broad term, which includes a lot of different things

In this episode we’ll unpack what is meant by early intervention, why it’s so important, –

CASSIE - It's interesting, it's probably the worst but best day of my life at the time. We wanted to stick our head in the sand and not know anything about it. But knowing what we know about early intervention and the positive outcomes, I'm so fortunate that we received that news and that information so early.

TESS DE VRIES - We’ll ask about the best way to approach early intervention.

KAREN DIMMOCK - The family is the primary source of support for a child. It is the child’s first teacher, it is where they learn and grow, so family centered practice is absolutely acknowledged as the best practice in terms of early childhood intervention. “

TESSA DE VRIES - We’ll check out new tools designed to work in a range of different cultures

ANITA D’APRANO - There is evidence that tells us that if we use tools that are designed for one population, in a completely different population, there are real risks that we either over or under identify issues, and the population is disadvantaged. So we really need to make sure that we are providing culturally safe and competent care by using a culturally adapted or appropriate tool to pick up developmental difficulties

TESSA DE VRIES – And we’ll find out what impact the NDIS is having in this space

TIM MOORE – The NDIS is really an adult model, it is based on the notion that person with a disability knows what their needs are and how they might best be met and is able to choose services and service providers to do that.

And the question is, is was it reasonable to expect that parents of young children with disability should be able to make informed choices about their children and about their families when they are fresh to the task?

TESSA DE VRIES - That was Tim Moore

I'm a senior research fellow at the Centre for Community and Child Health, which is part of the Murdoch Children's Research Institute, and also a member of the Department of Pediatrics at the Melbourne University.

TESSA DE VRIES - We asked Tim to explain what the term early intervention actually means

TIM MOORE - Early childhood intervention refers to a process for helping families of young children who have developmental disabilities or delays. So this occurs during the earliest years, from the point of diagnosis until they go to school, and it consists of services, agencies that can provide support to families, and the fundamental aim of early childhood intervention is to help the caregivers, parents and other people who are spending time with the children, to be able to provide the children with the kind of experiences and opportunities they need to develop, and so the job is to work with caregivers and parents.

KAREN DIMMOCK

If you are a parent of a child with a disability, and you enter the world of early intervention, there is a whole new language to learn.

TESSA DE VRIES - That’s Karen Dimmock - she is the CEO of the association for Children with a Disability

There are therapists in terms of speech therapists, occupational therapists, physiotherapists, psychologists, this starts to dominate your life. So what we do is help people navigate those first few years and finding out what actually is available, how to access it for their child. And what is best practice in this area.

We also then I guess, speak up to decision makers around well what's working and what's not. Right now is a huge time of change, because the funding model has changed. And that has benefits as well as unforeseen consequences. And, and the things that we're talking about right now.

KAREN DIMMOCK - So it does begin with a diagnosis journey. Now a really key thing to remember is that you don't need a diagnosis to get early intervention. But you do need evidence that your child is not meeting developmental milestones. It is different for all families, for some it may begin in utero. For some it's apparent there's a disability very soon after birth. For others it as their child perhaps reaches toddlerhood, they're not meeting developmental milestones, the parents might notice that themselves or a child care worker or a kinder teacher or the maternal child health nurse notices. Once people are having these types of conversations, it is then about getting some funding for early intervention and then finding the services.

Now with the NDIS the way to get the funding is through the early childhood component of the NDIS, which is called early childhood early intervention. Part of all of it is about collecting evidence, paperwork is an enormous part of the NDIS and families need to gather evidence from all of those early childhood people that are associated with their child around where their child is at in terms of developmental milestones, or if they do, in fact, already have a diagnosis. And then from once you have funding, you have a plan, you're able to select services and effectively purchase early intervention services for your child.

TESSA DE VRIES – Evidence shows the best way to get good outcomes is when health professionals work closely with the child and their family in all interventions.

TIM MOORE - Yes, the idea is to use a family centered approach. And that involves a partnership between the professionals and the parents. It means attending to the issues that have greatest importance to the families and focusing on those, it means helping the parents make choices, which are fully informed choices about what to work on, it means building family capacity to be able to help the children, it means paying attention to the needs of all members of the family, not just the child with a disability. And it's a it is a holistic way of thinking about families, families are on a journey. And you're helping them at the beginning stages of that journey.

**AMBIENT SOUNDS OF PHYSIOTHERAPY**

CASSIE – Hi, I’m Cassie, mother of Audrey who has cerebral palsy

TESSA DE VRIES - We visited Cassie and Audrey in their home to see how they go about doing their therapy, and talk to them about their experience.

CASSIE - In terms of Audrey's journey, it started quite early in terms of early intervention and disability. We found out she had a stroke in utero, roughly when I was 36 weeks pregnant. So the terms disability, early intervention. cerebral palsy were thrown at me when I was still l pregnant. So it was a lot to take on at the time. But in terms of best outcomes, I think because we hit the ground running in terms of early intervention, literally from day dot, we probably had the best opportunities we could have, you know, given that we knew so early.

CASSIE – So the type of cerebral palsy that Audrey has affects her left side, so things like fine motor movement, grasping even gross motor movements can be quite challenging. And that sort of then moves on to coordination and balance as well. So for the first couple of years was pretty busy. So we saw the OT privately every two weeks, the Occupational Therapist predominantly did a lot of hand therapy, and then incorporating active activities of daily living as well.

We did do a couple of intensive six week blocks, one of which included constraint therapy, so it's where you sort of in effect, hideaway, the good limb so her right hand, because her left hand is affected, and you force her to do things with her left. And it was quite challenging, a way to sort of keep tabs on us and the OT created a diary that we had to fill out, which was great, so made us accountable for our time. And I was quite conscientious that I love doing homework and having things done and ticked so this worked really well for me, and at the time, I only had one child, which was good. So fortunately I had the time to do it. And I've personally found that quite motivating. If I have a period of time where I don't sort of engage with the therapist, I do feel as though my foot does come off the gas a little bit in terms of home therapy. So seeing them regularly does keep me motivated and keep me on track which I found personally for me, quite important.

As she gets older and that strong personality and fierce independence that she has comes through it can be a bit challenging, if she doesn’t want to do something at the age of five it’s hard to make them, but when they’re six months, eighteen months, it’s a little bit easier. I think as she gets older trying to sit her down and do you know, the therapy can be hard and that's when we talk about trying to incorporate it into our activities of daily living making it enjoyable, making it fun, making it play based as much as we can.

How do we do that? So we have a really big room over there with many, many toys, a lot of which were purchased with hand therapy in mind and physiotherapy in mind - changing it up keeping it new and exciting. We used to be able to sit her down for long periods of time when she was young, which was easy and it worked. Not so much when she's older. So it's obviously looking at the child responding to them, once their attention starts to go try something different or finish it at the time and coming back to it. Make it fun, make it a part of everyday life if you can.

TESSA DE VRIES - We’ll return to this idea of family centered practice shortly, but first to Alicia Spittle

ALICIA SPITTLE - I'm a research fellow here at the University of Melbourne.

TESSA DE VRIES - To find out what research says about *why* early intervention is so important.

ALICIA SPITTLE – So it’s really important that we start early so that the babies get opportunity to experience things. So we want to harness that neuroplasticity, so particularly the first two years of life we see the most motor development occurring so we want to harness that plasticity but we also want to prevent waste. So we know that famous term, you gotta use it or lose it, if these babies don’t use it they’re going to lose it.

So what we want to do is getting early to change the way that their brain develops, we want to help them learn to a physiotherapist, so we want to help them learn to move to learn to roll learn to crawl, learn to sit, and not only thinking about their motor development, but then also thinking about their social cognitive, so their thinking, and early language development.

So what we want to do is try and help children to reach their maximum potential, whilst that brain and the rest of their musculoskeletal system is still developing, rather than waiting to problems to really manifest and then intervening once the problem has occurred.

It has been traditionally a problem with the wait and see approach and I think with many children with disabilities, parents know a lot earlier than they actually get the diagnosis. If we wait too long, parents are getting frustrated having to fight the systems to get support. If we can help parents early on, we can again change their trajectories, enable parents to positively interact with their children, rather than having to be seeking support all the time.

Well, interestingly, to date, the research is a bit inconclusive. Because most of the research studies to date have started with babies at 12 months, or 18 months. So at the moment we’re doing a research study. It's the largest randomised control trial in the world early intervention for young infants with cerebral palsy. And we're actually recruiting 300 infants from Victoria, New South Wales, and Queensland, who were diagnosed or at high risk of cerebral palsy prior to six months of age. So we're really trying to get in there early, change the way the brains are shaped, we're harnessing neuroplasticity, what we hope, is by getting in their early we can actually improve the trajectories of these babies so that we're actually improving their muscle strength. Children with cerebral palsy often have problems with weakness, and also spasticity, and we’re hoping that by intervening early we can actually overcome some of those problems.

What we're trying to do is our early intervention studies is give children frequent intervention, where they're actually practicing a lot with their parents at home. So rather than just having physio once a week, or once a fortnight, that they're actually doing exercises at home through play, to improve their development. And we think with that repetition, and fun, and hopefully that we can improve their strength, their coordination, which will then have ongoing effects on to their language and their cognitive development, that will change, hopefully, improve outcomes for these children. But we need to await the results of our randomised control trial.

TESSA DE VRIES – Research has shown this home based therapy, led by the family, otherwise known as family centred practice, to be the most effective approach.

TIM MOORE - Yes there are a number of reasons for that. One of which, building positive relationships, train parents and children is a fundamental difference for all children, and of particular importance for children have developmental disabilities because they may interfere with the ability of parents to connect with them.

Secondly, parents have far more time with children then professionals do. So, if we think about the amount of time that early childhood interventionalists could offer to families, then it might be off the order of you know, a visit, couple of visits a week, that might constitute 5%, of children's waking hours. And children learn from all the environments that they're in. So what we need to be concerned about is the time when the professionals are not there. Because children learn from having multiple opportunities to practice skills in everyday environments. That's what the evidence supports. That is more effective, then, with very young children, with a professional therapist or educator, working separately with the child and trying to build their skills, because there's no guarantee that the skills you build there will be transferable to the real life situations.

TESSA DE VRIES - That’s Tim Moore again who was recently commissioned by the Department of Education in Victoria to review the evidence in best practice in early childhood intervention.

TIM MOORE- So we looked at the major issue of is early, is the underlying aim of early childhood intervention to build the capacity of the caregivers, has that been altered? And the answer is no. And the other part, we looked at what had to do with inclusion, and the fact that that if that if every environment is important for the development of children, then they need to experience a range of environments, and therefore, being in attending an early childhood program is in fact a form of early intervention. And yes, that's still holds up. Then we also looked at the eight principles of best practice that have been identified and which the NDIA has endorsed as being the basis on which early child intervention should be delivered under the NDIS, so we looked at each of those, and they include Family Centered practice, and all of them still hold up, there's no significant change in the evidence that says Family Centered practice is still the in regarded as the way to deliver services, accepting, however, that there is a gap between the rhetoric and the reality - never been easy to consistently deliver services that are family centered, it’s a challenging way for professionals to operate.

But it remains the key underlying philosophy and practice for early childhood intervention services, and that's across the world. So it is endorsed widely.

KAREN DIMMOCK - The importance of a family centered approach, I think, can be perhaps illustrated through two analogies.

TESSA DE VRIES - That’s Karen Dimmock again

One is that you need to fit your own oxygen mask before assisting others. We hear this every time as we fly. But it doesn't matter how good a therapy session is with a child that's addressing perhaps their specific needs if the family itself is not coping for whatever reason, then none of those things are going to be reinforced on a daily basis in the family setting. So looking at the context of the family as a whole, building their capacity and the support available to them is really integral part of getting the best outcomes for the child.

The other analogy is how regularly we do exercises that are set by our physios. So I'm in my 40s, I, you know, injure my back or do my knee, I go to the physio, and I'm quite committed to doing the exercises for the first few days. And then to be honest, it really drops off. I feel like this is a fairly shared lived experience. And it is absolutely the same for children with disability and the homework you get set by therapists. So if it's not integrated into just your everyday activities into the natural play that children do, then it's just not going to happen.

My son has given me permission to share this story. When he was having early intervention. He has hypotonia, that he's very low muscle tone. So he was very, very floppy. The early intervention with the Occupational Therapist was to build all of his muscle groups. So the jaw so he could chew food, the fingers so he could hold a pencil, the core so he could sit up and supported. But it really started to work when the OT said to me, wrestling is the best form of therapy, because I had two sons under the age of four. And wrestling was a family pastime. And that's when it went from being something you've got to try and remember and do, to something that just was incorporated into our family life. I'm not saying that wrestling is the therapy for hypotonia. It was for my son in the context of our family.

TESSA DE VRIES - The second part in Tim’s review in best practice in early childhood intervention asked whether

TIM MOORE - the introduction of the NDIS had impacted in some way upon Family Centered practice and upon best practice, they had heard that anecdotal evidence that the kinds of choices that parents were making, and the kind of services that were being offered were not consistent with best practice. So we reviewed the literature on the NDIS, which certainly indicated that there were quite a number of concerns and problems around the whole issue of parental choice.

The NDIS is based on the notion of choice and control. And the question is, is was it reasonable to expect that parents of young children with disability should be able to make informed choices about their children and about their families when they are fresh to the task?

The whole NDIS model is, in fact, an adult model. It's based upon the notion that the person with a disability knows what their needs and how they might best be met, and able to choose services and service providers to do that. And there's no, there's no question about that, that that remains a, an admirable goal. It's endorsed by all disability groups, and so on.

However, in the case of families of young children, that's not an assumption you can safely make. So whether the model applies parents are not able to make informed choices in the first instance, by and large, they don't know what the system is, they’re still getting to, coming to grips with what their child's needs are, they're still uncertain what they can actually do in this space.

And the whole experience can be overwhelming.

And the evidence indicates and under those circumstances, parents are likely to make choices that are not necessarily in their best interest. Parents also tend to make choices based upon kind of default ways of thinking, cognitive biases, including the notion that obviously, the experts know better than they do, and that the experts are the ones who should be doing the job. Or that what someone else does for you is better than what you can do for yourself. Or what you pay for is better than what you can do for yourself, these are common cognitive biases.

So that parents in the first instance, without appropriate support for decision making, and without being fully informed about what early child intervention can do for you, and what it should look like opt to buy therapy, they think that’s what their child needs.

And indeed, that's what the evidence is indicating. So the evidence of our survey, certainly bore out the fact that a lot of parents coming to the decision making process without being fully informed about best practice and early childhood intervention, without an understanding of what their family night need or what they might be able to learn to do.

KAREN DIMMOCK - I think the NDIS and the way that funding is structured is also having a bigger impact on family centered practice, because of the way the funding structured and how it drives the market, to perhaps explain that I need to perhaps explain how it was previously funded.

So it was previously funded by the Department of Education and Training directly to early childhood intervention organisations. And they worked in interdisciplinary teams. But they also had what was called a key worker or a family coordinator, who would be a real liaison point for the family and doing that. I guess that checking of how the family was going and had a very clear focus on building that family's capacity, as well as a focus on all the things that needed to happen to get the child ready for school.

What happens now is that the funding is for that specific child and it is in the child's name and even though the NDIS acknowledges Family Centered practice as best practice, and things like key workers are mentioned in the press guide, parents are focused on therapy. And I think this is human nature. So at this point in time when you're finding out that your child either has a disability or a range of developmental delays, you've been given this money and you feel like you will do everything to pursue therapies that will hopefully address that. For some families, they're in a, perhaps a stage of understanding their child of hoping that it might lead to a treatment or cure. For others, it is wanting to make sure that their child reaches absolutely their best potential. And families will always prioritise therapy for their child over, perhaps support for them as a family or even for coordination between therapists.

The change in terms of the funding has also meant a lot of new providers have entered the market. Many of these are solo practitioners, as well as organisations that just have one specialty, such as speech therapy.

The NDIS does mean that more people are getting funding to access these types of services but we don’t necessarily have the work force to meet that need. There certainly are areas in Victoria, where it is incredibly difficult to access therapists. Thin markets is the sort of formal term to refer to that. For families, it's just, you know, desperate and kind of devastating that you might have the funding but can't actually access the service.

So what all of this can result in is a lack of coordination between therapists not prioritising a family centered approach and building the capacity of families. And also not prioritising all of the paperwork and reports and evidence that needs to go towards supporting a child starting school. One of the concerns we have also is that perhaps as a family might start to go right, actually, I do want to change how I'm spending the money and maybe I'll do it a little differently, that the person they've got the closest relationship with is the therapist and they have a vested interest in the family continuing to spend the child's package with them. All of this puts a huge amount of stress on families, it can mean stress of just getting to multiple appointments. It's the stress of am I making the best choices for my child? And it is the stress of finding a balance between therapy and time just to play.

And that's certainly the feedback that we get from families.

TESSA DE VRIES - So what kinds of things might help to fix these issues?

KAREN DIMMOCK - The change we would like to see is the change in the structure of plans. So plans currently have three components, core support, capacity building that is largely where therapy is funded. And that's largely what early childhood intervention plans focus on and capital which funds changes to home modifications, vehicle modifications, as well as assistive technology. We would like to add a fourth C, perhaps call it coordination, but that part of the funding is there and it is dedicated towards building family capacity, that it is dedicated towards coordination between therapists and that for a child who is entering school the following year, it is dedicated towards supporting that process of school readiness.

I think this would mean that families didn't feel like they were using their child's funding for these other aspects that had a broader family centered approach.

TIM MOORE - We can either regard the problems that we're seeing as being teething problems that are inevitable in such a massive, ambitious program in the introduction of the NDIS - hugely to be applauded in many ways for - extraordinary thing, no other countries done anything like this. So they're going to be teething problems introducing this model, they’re worse in early childhood intervention because of the clash between the fundamental model.

And the other way of thinking about it, well, these are not just teething problems, there actually is a problem, a fundamental problem in applying the NDIS model to the early childhood intervention model. And what we need is in fact to reconceptualise the early part of the NDIS as a journey in which we support, the job is to support parents, we need to redesign the support that families need in the early stages.

My initial sense was to say, well, we don't know that this is a teething problem, or whether it's a fundamental problem. My colleagues and I would now think, now we're looking at more a system problem here. There are teething problems. But if we could fix the teething problems, I think we'd still be left with some fundamental issues, that we need to think, again, how we can better design this early stage to support parental decision making.

LIZZIE CALLINAN **–** For me, those early days and weeks and months were very inward looking. And I think sometimes that sort of focus on early intervention can be like that, can be a bit isolating, you know, you're driving, you're on your computer, researching, you're driving around to whoever the best speech therapist is, whether it's in your suburb of or further afield. But I guess the more I moved into it, the further down the road. I got, I guess, the more kind of outward looking I've become and looked at all looking at how can we be trying to make some changes in the world so that it's more accommodating of our beautiful kids?

So my name is Lizzie and I'm mum to three children have nine year old Jasper, seven year old Rory, and my youngest is Greta, who is four years old. Greta, just before her second birthday, she was diagnosed with a rare form of Down syndrome called Mosaic Down syndrome, which means that some of her cells have the additional 21st chromosome and some of her cells have the typical number.

So I'm very much a researcher and so as soon as her diagnosis was confirmed, I was on the phone to Down Syndrome Victoria and had this wonderful support worker who had a great conversation with and sort of, you know, said you can ask, ask me anything and, and I always remember her one of the things that she said that day was, you know, sometimes the diagnosis of Down Syndrome is everything, and sometimes it's nothing. And I think that's really sort of holds true. You know, sometimes you completely forget that, that Greta has down syndrome, it seems silly to say, but and then other times it sort of is comes to the forefront and you're quite aware of it and conscious of it, and it feels very important.

And I felt a real pressure to, I felt like we had had the sense of having missed this opportunity for.. to sort of have an impact on those early couple of years. I remember really vividly that a sense of urgency to find out what she needed, and to be able to provide that to her very quickly.

One of the main ways that we helped her with her speech was through introducing key word sign. So it really simple form of sign language which is used in conjunction with speech. So, one of our early learnings from all my research was that people with Down Syndrome tend to be strong visual learners. And certainly Greta’s no exception to that. So it was really powerful early on. So for example, at the time of her diagnosis, we were working on her learning her colors, it just didn't really seem, she just didn't seem to be retaining, retaining it. So soon after her diagnosis, we learned the colors of the rainbow song with the key word signs, and it was incredible saying how quickly with that addition of that visual cue, how quickly she, she learned them, it was it was really amazing. Actually, my husband, I think was a bit skeptical about this key word business, but seeing that he was like, All right, I'm on board. Yeah, and the boys, that was a beautiful thing to do together as a family, it became a bit of a competitive sport, we'd be sitting at the dinner table saying, now what's, what do you think the key word sign for whatever is, everyone would have a guess. And then we go to the online dictionary, and, you know, whoever was the closest was the winner, and the other one would run to the room crying!

Immediately after Greta’s diagnosis, my thoughts went to you know, what have we missed, you know how can we kind of catch up or, what do we need to be doing and you know how - hindsight is a wonderful thing - how might we have you know supported her differently had we had the diagnosis.

So there was a lot of anxiety and worry and feeling like we could have done better I guess, for her had we known earlier. But it quite quickly I sort of probably rethought that and realised it wasn't as if we locked her in a dark cupboard for the first two years of her life. You know, she was part of our family, she was being stimulated every day. She had her big brothers helping her, you know, reading to her, you know, coming to school, hanging out with her. So she was, she was getting what she needed. And we were able to parent intuitively, you know, I knew that she was developing differently to her brothers. So, you know, I guess I would parent her accordingly.

And I feel, not that not that we're very sort of far in you know, we're all you know, I'm all very much sort of new to all of this, but a couple of years down the road. I guess I've had the ability to speak to parents who are newer or who are sort of earlier in the journey. And each time they come with the questions are, you know, what should we be doing? What did you do you know, is it you know, how often should we be going to physio and what sort of speech and, you know, what, what, what should we be doing? And I just, you know, I answer all of those questions.

But I also try to say in a really kind way that you just need to, at that, that young age, they just need your love and they just need to be part of your family and, you know, you really don't need to treat them any differently, kind of just love them and try not to worry. But I didn’t do that! I worried!

Yeah, look, it's difficult. It's difficult.

And I guess too that idea of trying, you know, there's that fine line between you know, really trying to get the best support for your child. But then how much of that is about kind of trying to change them to fit into this ablest world that we live in? And I, you know, I feel that kind of… I feel that tension. And I think we'll probably always will….. and certainly I know it’s not just me.

But I’d hate to think people sort of losing those precious, kind of early weeks and months, with worry and with sort of seeking, you know, seeking out the next best thing and just, you know, every child’s needs are you know, very simple really.

TESSA DE VRIES - One of the challenges faced by the NDIS is equity of access. Finding a way to make the scheme accessible and easy to navigate, so that everyone who needs it has equal access regardless of their language, literacy or support network.

TIM MOORE - The current delivery of services in early childhood intervention is in equitable. It's inequitable, because some people find the NDIS portal difficult to navigate. And there is insufficient support at this stage to help them do it. And the groups that are disadvantaged are families from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, anyone who is not used to negotiating a bureaucratic system. And the other people who are disadvantaged people living in rural remote areas where they simply aren't enough services.

TESSA DE VRIES -Another project at the Department of Pediatrics and the Graduate School of Education is tackling this issue directly. We talked to Anita D’Aprano,

ANITA D’APRANO - I’m a developmental pediatrician, specifically in Indigenous child health research

TESSA DE VRIES - to find out more.

ANITA D’APRANO – So a developmental screening tool is sort of the first step in picking up children who might have to might go on to have a developmental disorder, or might have a delay that, you know, the late talkers and they will catch up. And we know from lots of evidence now that if we use standardised tools, so instruments, we can more accurately identify children who are at risk of developmental difficulties earlier. So if we rely on our judgment alone, then we often miss kids, and they are not detected early, which means we can't provide that early intervention.

And one of the gaps has been that these tools that exist for mainstream society, they haven't been any that are culturally appropriate for Australian Aboriginal children. So one of the goals of my research has been to adapt a mainstream tool that is used in Australia for use in Aboriginal communities. And so that work has been done in collaboration with Aboriginal communities in the Northern Territory, to adapt a tool that is very commonly used called the ages and stages questionnaire.

TESSA DE VRIES - The ages and stage questionnaire asks parent or caregivers to answer questions about their child’s development.

ANITA D’APRANO – And we've adapted it so that it is more culturally relevant for Aboriginal families. And we've developed this tool, it's now called the ASQ Trak. So talking about raising Aboriginal kids, that's the acronym.

So it picks up where children might be at risk of developmental delay or developmental disorders. And then it really helps families linking with the people who will help them navigate their way through assessment and finding out, you know, is there a diagnosis and also accessing appropriate intervention,

TESSA DE VRIES - and so how did you go about adapting the ASQ questionnaire?

So we’ve just tried to make simple alterations or modifications that make it more relevant for the experience that some children and families might have.

So an example might be that there is one question asking about whether a child can start cruising around furniture, so holding on to finished walking around. And that was an item that we removed the reference to furniture and asked if the child can cruise by holding on to people who might be sitting on the ground, because in some, in some contexts, there may not be a lot of furniture in a home. Or where there was a reference to drawing. Rather than suggesting that you only draw by using a crayon and paper, we've asked the question about drawing in the sand with a stick. So that's an example where we try to make it more relevant.

Anita 18:56

So there is evidence that if we use tools for one population in a completely different population there are real risks that we over or under identify issues. So it can look like the child has fewer skills, or is struggling, but it may be that they haven’t engaged with it because it isn’t relevant, or the families don’t understand what we’re trying to get at. The reverse can also be true that if we ask families, simply ask them a question, can your child perform the task, the families may feel that they should give us the socially desirable answer. So they may say that the child can do it, because there's a fear that if they say they can't, that that may have a negative consequence. So there's a risk that we then under identify, it can be it can go either way. So if the tool hasn't been adapted, there's a real risk, that the families don't engage with the process because they feel it's not for them and the population is disadvantaged.

So we really need to make sure that we are providing culturally safe and competent care by using a culturally adapted or appropriate tool to pick up developmental delays in Aboriginal kids. And why do we need to do this? Because if we don’t pick up these kids early they miss out on services that are available. So we need to be working with families to pick up developmental difficulties early enough so we can offer early intervention.

TESS DE VRIES - And how is the adapted questionnaire being received?

ANITA D’APRANO - So now it's being used in remote, regional and urban communities. Practitioners have told us that the culturally appropriate version is much preferred for them, they feel that families are more engaged, they find it fun, they learn from it. So this is a huge achievement in terms of equity because these are kids who were not having any screening unlike the rest of the Australian population.

And as a result, so one service has identified that by being able to use a structured tool and identify children who are at risk of developmental difficulty, they have been able to argue for funding for early intervention. So they've been able to go to the National Disability Insurance Agency and argue for funding to provide services in this remote area of Australia. So prior to this, we didn't have a way of quantifying it. So this is really helped services to say, well, this is the extent of the problem. We need to be providing services, and it actually has resulted in a direct allocation of funds for services.

TESSA DE VRIES -Another project trying to improve access to services in rural and remote areas is Baby Moves. Alicia spittle, who we talked to before, and her team have developed an app to improve access

ALICIA SPITTLE - So one of the biggest barriers is, is actually getting a diagnosis and then referral to early intervention particularly in rural areas, or areas where there's not clinicians who are expert in scoring the general movements assessment.

So our team has developed an app called Baby Moves. And the app utilises an assessment called the General Movements assessment. And that's an assessment has been shown to be the most predictive of cerebral palsy between 12 to 20 weeks of age. What we've done with this app is we've actually enabling parents to take videos of their baby’s movements, and then they’re sent in to a clinician to score the baby's movements and give the parents some idea of the baby's level of risk of cerebral palsy. If we're concerned about the baby's movements we'll get the baby to come in for further assessment, and then we can involve a workup process to make that diagnosis based upon a number of things.

But what we've been able to do with that app is make the general movement assessment more accessible to people, particularly in rural areas, or areas where there's not clinicians who are expert in scoring the general movements assessment.

OUTRO MUSIC

CASSIE – I mean, it sounds so cliche, but it's a marathon, not a sprint. That's one little thing that I would probably tell myself if I could go back five years. Again, just trusting your instincts and your gut. You know, you want the best for your child. So, if you think something isn't quite right keep finding people to give you the right answers. Don’t settle for something that doesn't feel right just keep finding asking questions and seeking the best people to keep you know, to have around you for the best outcomes for your child.

ALICIA SPITTLE - I think also, it's really important for parents to make sure they have some support for themselves. It's a really challenging time for families having a baby who's diagnosed with a developmental disability. It's hard being a parent of a baby with or without a diagnosis and it can be challenging, and when you're comparing your baby to others, or people are asking me lots of questions. And it's really important to acknowledge that it's a difficult time. And to get some support for themselves. Parents plays such an important role in their babies lives that they really have to prioritise looking after themselves as well. It's very easy for parents to more than happily look after their babies, and not focus so much on getting care for themselves. But it's really important if to give your baby the best care. Parents need to look after themselves as well.

LIZZIE CALLINAN - Look, I remember at the at the time just desperately wanting a cleaner to saying could we, if they're not I just want to clean up and that would free up my time… and I still think that! Like it wouldn’t, it wouldn't be a massive cost and then it frees up the person who actually has that, you know their mom to do some really important work rather than cleaning the toilet.

TESSA DE VRIES - Thanks for listening to One in Five. You can find links to the research featured in this episode on our website disability.unimelb.edu.au . We’d love to hear your thoughts, and we hope you join us next time on One in Five.