**SERPIL:** What's best about going to school?

**WILLIAM:** Seeing your friends and meeting new people.

**SERPIL:** What do you get to do with your people?

**WILLIAM:** Learn about new things and cooperate with them.

**MUSIC**

**SERPIL: That’s William. He’s 10 years old and he loves school. In fact, he’s especially interested in lessons from history - and he likes to play sport. But he finds reading and writing a challenge.**

**William has needed additional support at school after being imputed with a disability. That’s when the school flags an undiagnosed disability and puts adjustments in place to enable the student to learn alongside their classmates.**

**This is Disability Conversations. The second season of the NCCD Portal series.**

**Hi there – I’m Serpil Senelmis.**

**In this episode, we’ll step into the shoes of parents to explore what it’s like to navigate imputed disability.**

**And we’ll find out how parents and schools can work collaboratively so the student is as successful a learner as possible.**

**Ok, let’s meet William’s mum.**

**RENEE:** I'm Renee, I'm 40. I have two children who both have additional needs. I have my own physical and other types of disabilities.

It was clear to us even from playgroup, when he was a baby that he was quite different to other children. Knowing how difficult life had been at school for my husband, particularly, to be understood and to be catered for, we didn't want that to occur for William, because he seemed to be quite similar to his dad.

Andwe realised that he couldn't read properly around about the age of kindergarten. So, we were trying to do intervention type activities for him and with him at home ourselves. And the teachers or support staff even then would say, “it's okay, he'll catch up, you don't have to worry about it. You're putting too much stress on him or yourselves.”

We didn't want him to get left behind, and being a dyslexic myself, but not understanding that when William was three and a half, I didn't get my diagnosis till I was in my late 30s. I had an understanding, an uncomfortable feeling about what it was like, not to know how to read until I was much older.

**SERPIL: Like Renee, William was diagnosed with dyslexia – but in his case it was identified in year three.**

**Renee says while schools are experts in education, no-one knows her child better than her.**

**RENEE:** They're the experts at schooling –the teachers. I'm the expert on my child. But my understanding of behaviours has always been, a behaviour is a function of something. It's a form of communication. So, even if a child is acting out aggressively or crying, it's usually because they need something. They just can’t say it. They can't advocate for themselves. And this is at school, especially when things are getting hard, and he doesn't like writing or reading.

So, he would often act out, and then get in trouble. The difficulty in that is people don't see the lead up to all of that. What transpired in the day, perhaps the teacher was away, but nobody advised us so that I could forewarn him. And then you get a relief teacher who doesn't know that he needs help with X, Y, Z, especially the reading and the writing and expects that he would just go on with it by himself, instead of having the scaffolding around expectations or the visual reminders, that will help him with his writing.

**SERPIL: That sort of unique insight that Renee has as a parent can unlock the key to classroom participation and ongoing learning and engagement according to inclusion expert and former teacher Sam Pollack.**

**MUSIC**

**SAM:** Parents have a wealth of knowledge and experience that can help explain or give perspective on where their child is at or why they might be performing one way in the home or community versus, what is being seen in the school environment.

Hi, my name's Sam Pollack

**MUSIC**

**SERPIL: And Sam’s an inclusion specialist who works with families and schools to help young people with disability.**

**SAM:** So, by sharing that information, it really does start to give that school alternative perspectives around what adjustments and modifications can we put in place to allow that child to succeed.

So, quite often the home environment is very different to a busy classroom setting and looking at where adjustments in the classroom could occur to simulate what was successful at home, whether it's environmental, looking at lighting, whether it's looking at noise, whether it's looking at position, whether it's looking at more cognitive approaches or considerations, such as timeframes, how long a child has to maintain focus, how many breaks they're getting, what the expectation of the task is actually asking them, how much time they've had to process the expectation, how much scaffolding has happened beforehand.

Also, something that's really important is what the motivator has been for that child in the first place. So, what is it that's hooked that child into the learning experience that's made it successful?

**SERPIL:** So, can you give us some examples of the types of observations or information families could share with the school team so that it would assist schools to better understand a child's needs and provide those appropriate adjustments?

**SAM:** Many of the children that I work with respond better when information is presented through multiple means, including not just auditory, but visual.

Also thinking about where families can share what the interests are. And how a topic or a task can be shaped to link into something that the child can connect with or has an interest in. Thinking about the child's concentration span and working within that. So, if a child can concentrate for 20 minutes, then really focus on hard concentration for 15 and then give them a break before their attention span is reached.

Looking at the child as an individual learner and what they need to be able to be successful and being able to shape it for them rather than for the majority of children that may be in a class.

**SERPIL: To ensure that each individual learner can be successful in the classroom, Sam recommends that families and schools work closely together.**

**She says the first step is to identify the students’ strengths and challenges – whether that’s related to learning difficulties, social or behavioural issues, communication difficulties or making transitions.**

**SAM:** So, there is a young person that I've worked with that has a history of difficulty making friendships. The parents were aware of the concern, but they didn't know what to do about it. I went into the school and did some observations, and we were able to work out that the additional processing time required for that child totransition between activities, to move from one environment to the other, was a major barrier that was presenting itself for that child, to limit her social opportunities and interactions. However, when we then talked to friends outside of the school, they didn't know the child was presenting with limitations on a range of activities or social topics that they could engage with their peers.

So, working with the school to identify the barriers is always the first step. And then from there, it's looking at well what can be done to address that? So, is it that the teachers need some further information? Is it that some strategies are needed? Is it that some advice from the team maybe that's working with the child outside of the school can contribute?

Quite often, parents may have a concern or a feeling that their child may be struggling, but they may not know where to go to have that affirmed without the risk of labelling their child or their child becoming labelled. Often the first place to start is to work with and to talk tothosefriends or family or whether it is existing therapists or treatment providers, GP, or paediatrician that’s already engaged with the child around their concerns and why they might be feeling that way and starting to see if there is a trend or a consistent concern in many different environments.

So, what may be triggering that, or what may be making that more obvious or pronounced, or perhaps where that's not been seen and exploring around that as to what is happening in that environment where that's not being noticed. And then from there looking at the feedback that comes from that.

**SERPIL: And there are some successful strategies parents can action in trying to communicate the needs of their child to the school – such as this suggestion from Children and Young People with Disability Australia or CYDA.**

**MUSIC**

**SUE:** One of the approaches to be considered first is to ask more open questions about how you can come together to meet on that particular issue.What would be an appropriate way to discuss the issue or to discuss the child's experience?

**MUSIC**

**SUE:** Hello, my name is Sue Tape. I work for CYDA and I'm a project coordinator in inclusive education.

Some families use photo boards. So, they will show photos of their child being successful. The sorts of environments that work for them, to the school, in a series of photos. And then that's a great prompt in a meeting or from an email where you might need to convey some more specific information.And it's about what the child likes, what they enjoy, the sorts of places where they are successful.

So, if say you have a child who has sensory needs, you can talk about the sort of environment that they enjoy and are successful in. So, whether it be about light, shade, noise, temperature, et cetera.

**SERPIL: Sue’s experience with imputed disability goes beyond her work with CYDA. Her own child has an imputed intellectual disability as well as a diagnosed physical disability.**

**As a parent, she’s found having a vision statement for her child to be helpful. Along with a Princess Leila shaped Lego figurine.**

**SUE:** Having a vision statement with the key information about the student, can be very helpful for parties. I also find the vision statement for my own child as a very helpful prompt when I'm in meetings – because it keeps me centred.

So, I also take with me a Lego mini figure. I sit it on the desk, and it reminds me what I'm there for. I'm not there for me as a parent and to prove my point or to win a strategy or something like that. I'm there to ensure the success of my child.

**SERPIL: These conversations are not without their challenges.**

**So, what are some difficulties parents are likely to face when discussing their child’s additional needs?**

**Sue Tape.**

**SUE:** I think one of the main challenges that families may face is that they'll be asked questions, which will feel like you are being asked questions about your parenting. So, I remember very clearly being asked about eat, sleep, and toilet productions. Andwondering to myself, how is this relevant to my child's experience at school? It takes a little bit to learn that school is aware that what goes on at home has an influence on the child's experience at school. And that the questions that they're asking are really to understand what they can do in the school situation.

And while it feels invasive, it feels like you're questioning my parenting skills about what time my child went to bed. It's really to dig into what other things might be going on so that they can understand that and then pull together an approach for school. Be prepared for some questions that will feel like they're digging into your parenting.

**SERPIL: During this time, parents may find it difficult to communicate to the school exactly what their own child’s needs are.**

**And this can lead to miscommunication between families and schools.**

**But according to Sue, there’s effective ways to avoid or resolve misunderstandings.**

**SUE:** The ideal scenario for communication between families and schools is clear, calm, and polite. It doesn't have to be lengthy. It doesn't have to be overly emotive. You want to convey the sentiment that you feel about the situation. You want to convey your aspirations, your goals, for the situation.

I think asking for clarification is a key to breaking down any miscommunication. So, just checking in that you understand what has been said or what has been communicated. Because when someone has to read back over their email or repeat what they've just said, you may find that they slightly adjust the approach that they're taking to how they communicate, and they might even adjust their approach to what they're communicating as well.

Check in that you understand the situation and it might be that you do understand the situation. But by asking them to essentially repeat themselves, you might get some more information, or, some insight into what's happening behind the scenes.

Many advocates will recommend following up by email and saying something along the lines of, ‘thank you for the discussion today. I think what we've agreed is this, could you please confirm via reply email, whether I'm on the right track.’

One major suggestion I would have for both schools and families to foster the best connection is to recognise that it will take extra meetings. It will take extra time. But, you will save time in the end because you will both be on the same page, and you'll be working towards the same goals. So, make the time upfront to agree what the approach is, and also agree how you're going to check in with each other.

So how will you communicate over the course of the term or the semester as to how things are traveling and how will you check back in as to what to do next and what's next for the student?

**SERPIL: That means, it’s important to consider how families prefer to communicate with the school.**

**For instance, for Renee, emails works best.**

**And she’s got some other tips on how to approach conversations around imputing disability.**

**RENEE:** Email works best for me. Other people like phone, some like written word. But when we've been able to set that up effectively, it's made it much easier.

Andin terms of imputing disability with William, we had an excellent teacher before we had diagnosis A or B, who made a spreadsheet, but she just drew it out, a timeline for the day, over a week.And she would colour in herself where she noticed that he might need help. So, we could identify if there was a pattern. And that was really creative approach to not seeing the person as the problem but seeing if there was a pattern that we could help the person with.

I truly believe that we're our child's advocate. So, you might find in a meeting about their abilities and areas of improvement that the school perceives that they can't do X. And you know that they can with supports at home, or they might just be able to do it without supports at home.But because of the situation at school and additional pressures they are unable to achieve that. So, I like to ask the school ‘what are you doing to stretch them to the next level of learning’ or whatever that looks like. Please talk to me about how you're going to support them to achieve that, and then let them talk.

**SERPIL: Maintaining such an open dialogue between home and school is vital.**

**After all, it’s an ongoing partnership from the time the child sets foot into a classroom – to the time they graduate.**

**And, if there’s an imputed disability, working in silos can lead to problems for the student.**

**As Sam Pollock explains.**

**SAM:** Often valuable information and perspective about that child's learning and development is missed, or inconsistent. And that leads to further challenges. It can lead to limited access. It can lead to disengagement and withdrawal and school refusalas the child gets older, and learning becomes more challenging.

I think that the key part is that the process of imputed disability is going to benefit the child. And it's going to make sure that the school has the supports in place. It's going to make sure that the parents have the support in place for their child to be supported in their learning and to keep them engaged with their learning.

**SERPIL: The fact remains, there are some misconceptions around imputing disability.**

**And for some parents or families the suggestion that their child has a disability – although not diagnosed – can be somewhat difficult to hear.**

**It can bring up all sorts of feelings and thoughts.**

**Sue Tape.**

**SUE:** Adults with disability will tell you themselves that many of them have great pride in their disability because it's part of who they are. We do understand that as families follow along a pathway where they end up with the diagnosis of a disability for their child there are lots of different feelings along the way.How do I give this child the best chance in life to be successful?

And all those feelings are obviously quite natural, but people with disability speak about wanting families to let that go and get on with being a parent, raising their child, embracing their children's differences, embracing their child's strengths.

**SERPIL: When an imputed disability is discussed for the first time with parents, Renee says the experience can be like grieving.**

**RENEE:** I think there's a whole grieving process that people go through thinking that there might be something wrong with their child or themselves. And a particular family that I'm supporting where they've said, ‘that's not how I was brought up. I never did those things. I don't understand why that's happening.And this is really new to me. And I grieve for the future.’ Thinking that perhaps their child won't be perceived as normal. Whatever that means. Normals just a setting on a clothes dryer, I tell people.

When we can heal our own expectations about what a person's life should look like, we embrace difference now.We enjoy that about ourselves. We add colour. And I try to help the people that I help to see that. Being different is okay. It's actually what the world needs, the diversity.

It's not to take away from the fact that life for people with disabilities is hard – because it is. There are many challenges that we face just to have a seat at the table.

Butonce we have those adjustments and understand ourselves better, it makes it much easier to achieve whatever it is that makes us happy.

**SERPIL: With the fear of the unknown, it’s understandable that parents can feel stressed and anxious about their child when a disability is first imputed.**

**So, what advice is there for parents in that situation?**

**SAM:** One of the most common concerns that the parents that I work with have is becoming ‘that parent’, to the school in terms of needy or demanding or unreasonable. And quite often what I've found is that's very rarely the way that the school sees that parent. It’s actually quite a strength-based view that they have in terms of parents are motivated and they're engaged, and they're committed.

Another option that parents can do to sort of relieve some of their anxiety is to remind themselves and to ground themselves with where their child's strengths lie and that the areas that are of concern or current worry are not defining who their child is and that their child is made up of strengths.

It really can be quite challenging and overwhelming.And there's a lot of questions which amplify the anxiety and concern that they're feeling.And I think it's around trying to build up an understanding of, where can we go and who can help us? So, trying to revisit those pathways of support around them, whether it's the GP or the paediatrician, whether it's family, whether it's a support network of friends or other parents that have been through a similar situation.

And it's also that the school will be an ongoing partner in that journey. Whether it does end up being a diagnosis or not, the school will be a major player in making sure that that child continues to be supported and have access to their learning and trying to remain in a frame of mind whereit's still a journey. And as the child grows, they'll continue to find ways of learning.

By imputing a disability, from a school perspective, it does allow them to capture the additional supports that are required for a child.So that if there is a diagnosis or there becomes a diagnosis known later on, they have the supports in place, or they have the resources in place to be able to support that child.

**SERPIL: And with the right adjustments, students like William can find the confidence to tackle school head on.**

**Renee says his year three teacher made all the difference.**

**RENEE:** I can think of his year three teacher who made changes for the whole class to accommodate people like William. But because he knew innately that it would help everybody, not just William.

The thing that he did was not to make them all sit on the carpet for a half an hour to hear instructions. He knew it wouldn't work for William. William's concentration back then was probably five to 10 minutes on the mat.

So, he broke down his teaching into five-to-10-minute chunks. And then they would get up and do movement things around the class. He understood the link of what motivated William, which was the ball games and the team thing and engaging with peers. And that particular year, before we left that state, he was awarded the Chief Minister's award for literacy for most improved in the year.

So, hereally did get the best out of William. And he encouraged William to believe in himself. And he also didn't make William feel different to other students. He showed them that making these changes to the way that they taught and learned, helped everyone, not just the person who needed the help.

**MUSIC**

**SERPIL: Since William has been able to get the learning adjustments he needs, particularly for reading, he’s been thriving.**

**RENEE:** He’s more and more like other children and happy to be with them. Loud noises don't bother him,because it's all about giving those extra bits of help as they become necessary, and then allowing the child to be a child after that.

**MUSIC**

**SERPIL: You’ve been listening to Disability Conversations – the second season of the NCCD portal series.**

**Disability Conversations was produced by Written & Recorded.**

**This is an Education Services Australia podcast. And I’m Serpil Senelmis.**

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