

Paul Thies:

First observed in 2006, World Down Syndrome Day is celebrated annually to raise public awareness and insight into the lives of people who have Down syndrome. Recognizing the need for global support in this endeavor, the United Nations General Assembly passed a resolution in December 2011 to officially codify March 21st as World Down Syndrome Day.

Paul Thies:

Hello. I'm your host, Paul Thies. In this episode of If/When, it was my privilege to speak with three women who each have children who happen to have Down syndrome and were kind enough to share their experiences and what they have learned as they have made this journey. Joining me today are Nicola Enoch, chief executive officer of Positive About Down Syndrome, a UK-based advocacy organization, Steph Bywater, Jacobs divisional director, and Lara Jumagdao, Jacobs senior architect, fire and life safety specialist.

Paul Thies:

Well, Steph, Lara, and Nicola, thank you all very much for joining me. I'm really excited about talking about this topic and talking about people who have Down syndrome as part of their life experience. It's an honor to talk with the three of you. You all have people in your families who have Down syndrome, and so you'll be able to speak from first-person experience of what that's like, and hopefully dispel some myths and help people better appreciate the unique talents and capabilities that community brings to all of us, and help awareness. Starting off, just thank you all so much for joining me.

Steph Bywater:

Thank you.

Nicola Enoch:

Thanks.

Paul Thies:

All right. Steph, let's start off with you. To start us off, can you share with our audience the importance of terminology and language when talking about Down syndrome? What are the appropriate, conscientious, and loving ways to engage in this discussion.

Steph Bywater:

Sure. Obviously, it varies with different people. My perspective as a parent, I feel as if I'm still very much a newbie in the DS community, as we like to refer to it. I know what grates me, rubs me up the wrong way, so to speak, if someone approaches me and talks about my son Jared in this particular way, but it's probably worth saying that that doesn't translate to everyone. For example, I don't like the terminology Down's child, for a number of reasons. I don't like the shortened version of Down's. But then my personal friend, her son's a little bit older, she does refer to her son as having Down's.

Steph Bywater:

So that can change depending on the individual. It's always worth checking in the first instance. I always take it that someone's terminology is not necessarily coming with any malice, unless it's an obvious term that we don't use now, and we should definitely correct that. But it tends to come from a lack of

awareness. So I don't necessarily correct people on the first time they've said it, and certainly not in a wider audience.

Steph Bywater:

Like with any disability, it's good practice, and I'd say that this is very important, that we always recognize the person first. So we'd never talk about a Down syndrome kid. It would always be a child with Down syndrome, as we would people with vision impairments. And that translates to a lot of circumstances, not just disability. So those are the two big ones for me.

Steph Bywater:

The third one is when someone comes up to me and talks about, "Oh, they're always happy." That really winds me up, because then ... And by saying they, you're putting them in a pot of people, and it doesn't personalize it. So yeah, I'm happy for you to tell me if my individual child has got certain traits, but to put them in that pot together, that's something that I do take up with people. But obviously, I try to do it in a respectful way so it doesn't come across as confrontational, because that's something that ... I don't think it would help with awareness with that individual.

Paul Thies:

No, that's beautifully said. It's important to remember, every individual that we meet is irreplaceable and non-repeatable, right? Everybody comes with a million aspects to their life that go to make up who they are. So children to happen to have Down syndrome, this is just one aspect of a million things that go to make up who they are. So it's important to remember that they are individuals first, and they're people deserving of our love and respect and being treated with dignity.

Paul Thies:

Now, Steph and Lara, I'm going to ask each of you to share your family experiences. You're both parents of children who happen to have Down syndrome as part of their life journey. Steph, your son, I believe, is four years old.

Steph Bywater:

That's right.

Paul Thies:

So like I said, you're a newbie here on this journey. Can you tell us a little bit about what life is like with him?

Steph Bywater:

Yeah. Our family unit, there's four of us. Jared's got an older sister. She's just turned seven, [Mila 00:05:51]. They both go to the same mainstream school together. Jared's just started reception in the local community school. He does a normal school day. He has one-to-one support all of the time he's there. That's just to assist him, because he learns in different ways. Children with Down syndrome are known to be more visual learners, and it takes longer for him to pick up parts of his education, so the curriculum's slightly different for him. So we've got support in terms of the local authority.

Steph Bywater:

We have an educational healthcare plan, which covers the extra measures that need to be put in place to help Jared learn, and enjoy school, obviously, as an important part of it. And he does. He really enjoys school. I mean, he's wiped out by Friday. Lunchtime, they go into assembly, and more often than not he's coming out and they're having to carry him, because he's fast asleep. So he really gets the most out of school.

Steph Bywater:

And he is a mini-celebrity on the playground. Even the older children know Jared's name, or high-five him, which sometimes makes me conscious of Mila's feelings, because wherever we go he tends to ... he goes and seeks out the attention. If we go to a pub, he'll make friends with complete strangers. Mila's just more shy, and so she tends to step in the background anyway. But I'm always that mom that says, "Well, actually, this is Jared's sister." I'm really conscious of that all the time. I don't know whether that will change. But she's also his second mom. She's very caring. And my husband as well. So yeah, the four of us, we're busy ourselves. We've got a smallholding here, so yeah, we're busy with animals. And I work full-time for Jacobs as a project manager. But that's life, and hectic like any other family, I would've thought.

Steph Bywater:

In terms of medical requirements, touch wood, early years with Jared we had quite a few issues medically. We feel as if we've got through that phase now. Generally, he's a fit and healthy boy.

Paul Thies:

Oh, that's awesome. Yeah, and that really struck me, thinking about Mila's experiences, right? Because Jared, it sounds like, like you said, he's a bit of a celebrity, and probably draws attention naturally to himself. So your daughter being a little more shy probably needs a little bit of that extra attention or just making sure that she doesn't ... Not that she would feel resentful for him, but you know what I mean. It's just balancing that dynamic and stuff. The fact that you franchise her to help mother him or ... You know what I mean? She helps give him care. I think that's wonderful.

Paul Thies:

Now, Lara, your daughter just turned 16. What has life with a teenager been like?

Lara Jumagdao:

I was listening to Steph earlier, and actually can relate to what she was saying, that Jared is sort of a celebrity on his own. Jasmine is sort of the same way, because she is courageous, and she's not really shy at all. I'm a mother of three in Qatar, with a 10-year-old, Jasmine is 16, and a 13-year-old. So with the three kids, I sort of feel that sometimes the two other kids gets really jealous as well. It's not because we play favorites, but Jasmine is friendly with everyone. When we go home to the Philippines on vacations, she gets away with almost everything. It's not because they favor her a lot, but because she knows how to ask for things. And part of being away, probably they're trying to make up for the time they haven't spent with Jasmine.

Lara Jumagdao:

But basically, on a day-to-day basis, we're really focusing quite a lot on teaching Jasmine life skills right now, because we're hoping that someday soon that she'll be able to look after herself. We're trying to

start with small basics, like setting the table and fixing herself as soon as she wakes up in the morning, brushes her teeth, and fixes her hair. I think because we've started with her at a very early age, she's already picked that up as she grows, and that already became a habit for her. As soon as she wakes up, she goes on her own, fixes herself. You don't even need to remind her to change her clothes or anything, because she's learned that from a very early age.

Lara Jumagdao:

Actually, comparing to my other two kids, you really have to nag at them and remind them constantly, "Hey, you haven't changed your clothes. I've seen that clothes the other day. I don't think you've taken a shower." But for Jasmine, because she has her routine and she sticks to it ... And I don't think there's any challenges with raising a teenager with Down syndrome. It's probably the same as the experience that I've had with my older other daughter. But it's less challenging now, because my other daughter helps with Jasmine quite a lot, just like a second mom to Jasmine. I actually can't put the two of them apart from the other room.

Lara Jumagdao:

And they fight. They fight a lot. Earlier this morning, I was startled because one of them was screaming, and they were fighting. Yeah, but it's the normal things. They argue, they fight. But at the end of the day, they make up. And Monique, my other daughter, she actually cannot sleep without Jasmine by her side. So she's the one that surrenders most of the time.

Paul Thies:

Aww. Now, Lara, what are some of the biggest misconceptions people have about having a family member who has Down syndrome, and what are the realities?

Lara Jumagdao:

When you tell someone that you have a daughter with Down syndrome or you have a child with Down syndrome, quite a lot of the response that I receive is that, "Oh, I'm sorry to hear that." Almost instantly I try to correct them. I tell them there's nothing to be sorry about, really. We're okay. We're doing fine. Jasmine has brought some changes in my life that I would have never expected.

Lara Jumagdao:

As Steph mentioned earlier, she's not always happy. I think that's one of the misconceptions. She has mood swings. She gets mad. She gets sad, really sad sometimes. It's just that she's sweet, and she gets over it really quickly.

Paul Thies:

Well, you know, and the beautiful thing about all children is they bring changes to our lives that we may not have planned for. But it's the greatest adventure we'll ever be on, in my opinion, is parenthood. Now, Steph, let me ask you. You have connected with Nicola Enoch and her organization, Positive About Down Syndrome. And she's joining us today, and Nicola, I've got some questions for you here in a minute. But let me ask you, Steph, what led you to connect with Nicola? And why does the organization resonate with you?

Steph Bywater:

Jared was a postnatal diagnosis. What that means, we went through the normal scan procedure, 12 weeks, 20 weeks, and as standard in the UK, they test for Down syndrome as well as other genetic conditions. We were told we ... The terminology used, which is another one that we're trying to get changed, they talk about it as a risk. So you've got a 1 in 250, in our case, risk of this child having Down syndrome. In the community we like to call it chance, because risk, just the nature of that word, it's to expect something terrible, and we know that it's not. So yeah, we went through 1 in 250, which is outside the parameters for further testing, so nothing out of the normal pregnancy. It was actually fine.

Steph Bywater:

And it was day one or two, I think, that a couple of doctors came into the room. That day will never leave me, the feelings in that room. I'm trying not to get emotional talking about it, because it was as if a family member had died at that moment that that news was delivered. It doesn't matter what words were said, because I don't remember the specific words. It was how it was delivered which had such an impact, and that nothing good can come of this. We were expecting the worst because of how our doctor told us. And after blood tests, it took another seven days before it was confirmed. We went away, we had a leaflet given to us, and then it was a week limbo of trying not to Google it, because it's human nature to. And then you're just thinking of those preconceptions of a person with Down syndrome, because yes, we had contact with a couple people, we weren't in the community. So didn't reach out many people at that time. Just wanted to shut myself off.

Steph Bywater:

We were due to have the official news confirmed on a telephone call the day after. My husband had arranged to take that day off so we were together to receive the news. They actually phoned me the day before. We were just getting ready to go to my husband's close friend's funeral, so we were in a heightened state of emotion. He was a coffin bearer of his good friend. So I got the phone call, and I didn't feel capable of letting my husband know the news. So I rang an employee assistance help line, which ... Fantastic. I can't sing their praises enough. At that time, they articulated it so well to me that you need to grieve now for the child that you thought you were going to have.

Steph Bywater:

And that's what I did. I had to take the time to adjust. And I really, at that moment, was reaching out. And I don't think I connected with Positive About Down Syndrome until later, but it was really trying to focus on the here and now and not thinking about the scary future that got me back to where I needed to be. It didn't affect my bonding with Jared, because my wider family unit, my various in-laws, were actually amazing in terms of making sure that we celebrated the new baby in our new family as the most important thing, as opposed to the diagnosis. So that's what we did.

Steph Bywater:

Positive About Down Syndrome, it's all about how it's delivered by the medical professions, and how to support those new parents, not just mothers, parents, prenatal, postnatal diagnosis. I'm sure Nicola will tell us a lot more about it, but it's just fantastic, the work that they do with going in and speaking to midwives and sonographers and doctors just to make sure that ... So many of us got the same story as me, and it needn't be like that, because we're not talking about Down syndrome in the 1980s, when the life expectancy was 25, I think it was. It's very different now. And it's just raising awareness of how much fun a person, a child, can bring with Down syndrome into people's lives. We celebrate the smallest milestones now, which we would never have had if we hadn't have got Jared in our life.

Paul Thies:

That's beautiful. It's so necessary to remove the stigma, I think, of so many of these kinds of conditions that children may enter the world with, right? And it seems to me, and I may be alone in this but I don't think I am, that we tend to focus too much on what people can do, as opposed to who people are or what they can be, or should be, right? We don't focus on the human being, we focus on the human doing. So then you run into those kinds of scenarios where somebody's like, they're so sorry to hear that you have a child with Down syndrome, or they're so sorry to deliver this news. And it's like, you're really not focusing on the right thing at all. You're completely missing the whole story here about new life and a new baby that's coming to the world.

Paul Thies:

Nicola, let me bring into this, what led you to create your nonprofit organization, Positive About Down Syndrome? How does it fill the gaps that other organizations may not be meeting for individuals and families?

Nicola Enoch:

Okay. Thanks, Paul. Well, I think, as Steph says, too many new and expectant parents are receiving these really negative experiences, because as you say, there's so much stigma and outdated attitudes and perceptions around the condition. As Steph said, only in our lifetimes, in the mid-'80s, life expectancy for someone with Down syndrome was in the mid 20s or so. I know certainly when I was born in the mid-'60s, pre-cardiac surgery, life expectancy was something around the age of 15. But I think a lot of people, and certainly in the UK, people in the '60s and '70s ... well, certainly in the '50s and '60s, were still being institutionalized, people with Down syndrome, and very much segregated from mainstream society. I think all of that breeds that ignorance around ... You know, it's genuine ignorance and fear of what is perceived as the unknown.

Nicola Enoch:

What we're finding ... My son, Tom, is now 17, and I had a very similar experience to Steph, and I still get emotional about it to this day, and I've spoken about it a huge amount, because it is a life-changing moment. And for a lot of parents, new parents or expectant parents, it can have very negative consequences. I mean, very briefly, I pretty much rejected my son, because society and certainly the medical narrative led me to believe that babies with Down syndrome are to be avoided. And sadly, in the UK, the vast majority of women, when they discover their baby has Down syndrome, do go on to terminate.

Nicola Enoch:

And I, basically, after several years of running a small local group, was realizing that I wasn't alone. And obviously, social media and so on, I was in touch with hundreds of other parents, and discovering that too many people were just receiving these really outdated attitudes, and the information that we were given at the time of discovering our babies had or may have Down syndrome.

Nicola Enoch:

So I launched Positive About Down Syndrome really to plug that gap, that more often than not, obviously, expectant and new parents are being counseled by medical practitioners, and what parents, from my experience, and most I speak with, really want to know is what's life going to look like? What's

the social model? We're often overwhelmed with a list of potential medical conditions our child with Down syndrome may have, but what does that actually look like? Will we ever go on holiday again? Will my child have to go to a special school? Will we function as a family?

Nicola Enoch:

And I think Lara talking about ... well, both the other families talking about how involved their older children are with their child with Down syndrome. For me, I had a three and a half year old daughter at the time Tom was born, Emily, and I thought, this is it. I've ruined her life by bringing this baby into the world. Not only our lives are going to be negatively impacted, but Emily's too. And my word, how wrong was I? But that was genuine ignorance, and that was the society that talks about the risk, a medical narrative. In the UK, we do screen around Down syndrome, and not providing expectant parents with balanced information. And the whole language. We have this defined medical norm, and anything that deviates, we ... I remember them referring to Tom as a chromosomal abnormality, or a disorder. And those aren't nice phrases to hear when you've just had a newborn baby.

Nicola Enoch:

And like Steph mentioned, the thing about ... I remember when Tom was a bit older and I was starting to become a bit more protective of him, a doctor saying to me, "Oh, this is the Down's baby." And I thought, "No he's not. He's mind. Don't label my child by a condition. Actually, he's Tom." We don't need to keep calling people by their condition.

Nicola Enoch:

But really, PADS came about out of a desperate need to support expectant and new parents better. I feel passionately that parents deserve so much better. And we just [inaudible 00:24:06] so we started off just providing an insight into what we call the lived experience, the social model, just sharing photos and everyday stories about our lives, which really ... Yes, some of us, we have to adapt in certain ways. But as you said, that's parenting. Parenting is a tremendous privilege. But you know, you get the rough with the smooth, and every child ... As I said, I've got two children, Emily and Tom, and both give me sleepless nights. Both make my heart burst with pride. That's the way it goes. And every child has challenges and strengths.

Nicola Enoch:

But yeah, PADS exists, really, initially to support those expectant and new parents. We provide information. But we now have fantastic ongoing support. We have 30 Facebook groups. Because it's really important in so many situations never to feel alone, and I think many of us, as new parents, probably ... I felt desperately alone when Tom was a few weeks old, and struggled to even leave the house, whereas now, 17 years later, we sadly still see that. But we're trying to just fill those gaps where people don't have access to contemporary information and ongoing support. And then when our kids arrive, we do celebrate them. We send all our new parents gorgeous little hand-knitted hats now in our PADS stripey colors, and a copy of our publication, Nobody Told Me the Truth About Down Syndrome, because that's what parents need to know, the truth. What is life going to look like?

Steph Bywater:

I think Nicola put it actually spot-on in her TED Talk, when she ... kind of putting a new image to ... You spoke about, you had an image of a Down syndrome child with a bad haircut. And that's exactly what I thought.

Nicola Enoch:

I know. We all do. These outdated images, don't we?

Steph Bywater:

You know, dressed terribly, with the awful haircut. By putting these images out there of adults with Down syndrome, realized, that's not the case. It was quite a few years ago, but they've now got decent haircuts.

Nicola Enoch:

And I think it's this generalization as well, this sort of, they are always happy, or they may have this condition or that. I used to think, gosh, that makes people sound like a separate breed of dog. It makes ... It does, though. I used to think, what do you mean, they? I can remember a doctor, again, saying, "They tend to be flatfooted," I think it was. I thought, why can't you just say, "Tom has flat feet," you know? Just talk about him as my son, who he is. It just makes people with Down syndrome feel very different and excluded, perhaps, from our society. I think that's something we work really hard to try and just show that people with Down syndrome have the same needs as everyone else. As you said, we all need to be valued and appreciated. Yeah.

Paul Thies:

Right. Well, and I think it's changing the narrative that people, they're not problems to be solved or problems to be fixed, right? [crosstalk 00:27:22] And I will go out on a limb and ... I mean, our medical community, so many of them are heroes, right? And they work in unconscionable conditions and have to deal with so much human suffering. But I do tend to think it's a fairly universal that, at least maybe in Western medicine or whatever, the approach tends to be to focus on the problem. Like, I've got to fix this, you know? As opposed to, I'm encountering Tom, and let's talk about Tom.

Paul Thies:

And you know, they're overworked. At least I know in the United States it's a stressed medical system, right? So they're probably overworked, and they're trying to do the best they can. But it does seem like there's an opportunity to change attitudes, like you're saying, to shift from let's fix this problem, to let's talk about Tom and his quality of life. So let me ask you, Nicola, and Lara, I'm going to ask you to also chime in on this. But what have you found helps dispel some of the fears and anxieties that expectant parents might be feeling when told they're having a baby who has Down syndrome?

Nicola Enoch:

Well, certainly for us, I think that insight into just seeing what lived life really does look like. I think the lesson that I certainly learned, and I think many others have, is this thing that you do ... You love your child no matter what. I think we all have expectations in life, don't we? And expectant parents think that the pregnancy will go well, the birth will go well, and they'll be delivered, this beautiful baby will arrive, and everything's perfect. And actually, as soon as you think there's anything that deviates, we do have this negative slant. I think you alluded to the fact about, we need to look at people's abilities and not disabilities. But I think when you're an expectant or new parent, that's really difficult. I think you're overwhelmed.

Nicola Enoch:



I think what helps is time, and again, I think Steph mentioned it, that someone said to her, in a way you ... Grieve is a strong word, to say you grieve for the baby you expected. But actually, I mean certainly felt I did. But what you're doing is you're adjusting, and you're actually going on to discover what really matters in life, and perhaps your perceptions start to shift, and you start to realize, is getting into the best school and going to the best university and working 60-hour weeks for high salaries the best route for my child? Possibly not. What actually matters for this child, and for me as a parent?

Nicola Enoch:

There's a huge amount. I've digressed slightly from what you asked about, what helps expectant and new parents. Certainly what we try to provide through PADS is just giving them access to what life might look like, and just giving them time, and a community to belong to, and to know that they're not alone. I think that's another huge thing.

Paul Thies:

And then Lara, can you share from your experience what might help dispel some of those fears and anxieties of someone who's welcoming a new baby into their family?

Lara Jumagdao:

I think with the technology world right now, there's always an instinct for us to just Google things. Not everything you read in Google is correct. You have to be really cautious on what you read, which sites you go to, because a lot of them are outdated. I remember the time when we had Jasmine, because I didn't have the prenatal tests, so we knew Jasmine had Down syndrome just after the birth. As soon as I got home from the hospital, the initial reaction was to search the internet and find out what I had to expect. But having read a few articles, it just made me nervous of how I'm going to be able to raise a child with Down syndrome. So I stopped. I closed the computer and I stopped reading, because I don't want to continue reading anymore, because it's all negative writeups about Down syndrome.

Lara Jumagdao:

So what I did was, I went to Amazon, purchased a few inspirational books, and then actually reading about experiences of parents and mothers, about raising a child with Down syndrome, it actually helped me. Then later on, which the social media was a lot better, I joined support groups, which shows at least ... You know, you see pictures from time to time of children growing up and achievements that they've had. It inspires you that this is the path we are probably going to have as we raise Jasmine. But it's not always the same. Not everyone, not even my other two kids. The milestones are all different. Not every child is the same. It just helps that you're surrounded with loving people and the family. It also helps that your family's understanding and is patient, because with Jasmine, it takes some time for Jasmine to reach some of her milestones, and my family has been very supportive.

Paul Thies:

Oh, that's wonderful. Yeah, and I think that support has got to be vitally important. But just having that open heart to looking at the child as a person, as an individual, and not focusing on the negative. Again, I think it comes back to that treating people like they're problems to be fixed. But celebrate their life, right? And every child, regardless of what condition they come to us in, there's no guarantees or certainties how their life's going to turn out. Every child is a gift, right? And our experience being able to live with them is a gift.

Paul Thies:

Nicola, looking at the road ahead, in terms of as a person who has Down syndrome achieves adulthood, can you speak to the capabilities, expectations, potential work opportunities for adults and older children with Down syndrome so that they're able to participate more fully as members of society? And can you dispel some of the myths that might limit how they participate?

Nicola Enoch:

Oh, yeah, that's quite a big one. Tom, as I said, is 17, so he's just started college. He went through mainstream school. In the UK, we have a pretty dire track record, I'm afraid, around employment opportunities for people with learning disabilities, not just Down syndrome. I think it's something around the nature of 6% adults with a learning disability who are actively seeking work or actually in paid employment.

Nicola Enoch:

So for me, some of the barriers, for sure, that prevail in society are around expectations, not just by ... Well, obviously by employers. But I think before that, even, through education. In the UK, we've got a Down syndrome bill just going through Parliament, which will be world-leading once it becomes enacted. That will be actually shining the spotlight on local authorities and bodies to really look at the needs of people, in this instance with Down syndrome, but other learning disabilities, because I think we really need to change ... There needs to be a shift in attitudes and mindsets, again, around what people are able to do.

Nicola Enoch:

And to raise the expectations. As Tom left school, there was no choice for him where to go. It was the local college or the local college, and it was a very generic skill-builder course or the very generic skill-builder course. And yet Tom, he wants to be a fitness coach. But there's no course that he can currently access because he didn't get certain grades. And yet our children and young people are well supported financially by local authorities, so he carries a pot of money with him into education. But it's not being spent, in my view, particularly effectively. He's being looked after and that, but there's no vocational aspiration. It's much more just only generic skills.

Nicola Enoch:

So I think we really need to up our game around looking at what people can do and having higher expectations. I was actually delighted last week to receive an email, it's the first one I've ever received, from a local solicitor saying, "We've got a position that's come up that we think would suit someone with Down syndrome. Can you help?"

Paul Thies:

Wow.

Nicola Enoch:

I thought, how wonderful. They've got an admin role they think would suit someone who enjoys a structured, routine outlook, and it absolutely will. So I've made contact with some people, and I'm sure that will happen. But I think a lot of it, yeah, we've got to change. You know, very bureaucratic. There

are too many barriers, and we've really just got to break down the barriers and have a big shakeup. The situation's pretty dire, so it desperately needs addressing.

Nicola Enoch:

In terms of myths and things, I think it comes back to the same thing, really, as for expectant new parents. There's a lot of fear because of the stigma. Perhaps people are afraid that they might not be able to understand someone with Down syndrome. Often, perhaps, people with Down syndrome might have poor communication, relatively poor speech. Not always, but that might well be something that people are nervous about. And I think people don't like to feel awkward. We don't like to be taken out of our comfort zone. So I think one of the biggest things people can do is actually meet people with Down syndrome and talk to them and find out just what they can do and what they enjoy in life and get to know people, because then that negates all the outdated ... the fears that people might have, and they can start to look at, do you know, this person's got these skills and this personality, and they can really bring something to our organization.

Nicola Enoch:

I remember, it's not the same, I know, but when my son was in his first year at secondary, so he was about age 11, and we had a tutor group. And his tutor said to me, "Your son is a breath of fresh air in our tutor group." I said, "Why's that?" She said, "Well, there's a lad who sits on his own every day who everyone ignores. He's got mental health issues. No one talks to him." She said, "Tom walks in every day and says hello." And she said, "After a couple of weeks, I've noticed the other students starting to question themselves, and the lad who's ignored has started to raise his head and talk to Tom." And I thought, well, there's a skill that we don't measure, that we don't look at, that compassion, the ability to include people and care for people. And I thought, I'll take that over a Latin GCSE any day, thank you very much. [crosstalk 00:38:47]

Nicola Enoch:

And I remember seeing a wonderful documentary about a young woman in Australia working in a care home, a young woman with Down syndrome, who loved to engage with more than and just chat with the elderly residents that other people might perhaps find a bit boring. I don't know. But this woman was doing a fantastic job. I think everybody has skills, and we need to just be a bit more creative and think outside the box more.

Paul Thies:

Yeah, well said.

Steph Bywater:

I think that's really struck me. I've had the opportunity to while I've been pulling together our Jacobs World Down Syndrome Day celebrations ... A couple of members of staff with Down syndrome, one of whom works in the lab, so she very much is data analysis, desktop type work. She wrote me a beautiful email that brought a tear to my eye, to be honest with you, in terms of expectations. I could never imagine to receive that kind of email. So that threw my rule book into the air.

Steph Bywater:

But what struck me is their colleagues and the warmth and the energy they bring to the physical workplace, that now we're in this situation of hybrid working, we're all looking for those people connections. I go back to the office one day a week. It's not the easiest commute for me, but I do that in order to see people, because it really makes a difference to my wellbeing. If I was to turn up and I had someone that would happily come up to talk to me, regardless of what mood I'm in, whether they're aware of it or not, just to have a cup of tea, I think that would be a very good skill to have in any office, to be honest with you.

Paul Thies:

That's beautiful. Steph, I'm going to give you the final word here. When we were preparing for this podcast, you'd mentioned that you focus on the here and now. Can you share with the audience a little, why do you focus on the here and now, and speak to how that's important to you on this journey?

Steph Bywater:

A couple of reasons, really. Because I've got to focus on making it the best of Jared's life ... Well, both my children's lives. So if I start thinking about what ifs ... You know, when they get to 20 years' time, are they going to be able to drive? And I'm not just talking about Jared. That's the one thing that struck me. My husband, the first question he asked when we found out Jared was diagnosed with Down syndrome, "He won't be able to drive." And people with Down syndrome can drive, and better than some other people.

Steph Bywater:

So there's no point in second-guessing, because things can throw up ... You know, we don't know what's around the corner. That's one thing that COVID has taught us all. We definitely don't know what's around the corner. So let's not waste the energy. And yes, we do have to plan for a future. Being all grownup about it, we've got to make sure that there's plans in place, and financial and [inaudible 00:41:56] responsibilities. So that's in the back of the mind. It will never go away.

Steph Bywater:

But let's focus on, what does he need now, and what's he need to get to his next milestone? Because that takes up a lot of energy, to be honest with you. As a wider family, we've got very close grandparents that are very much part of his day-to-day life as well. So clubbed together, we can get there quicker. I'm not saying it's all rosy and we all agree, because it does cause confrontations sometimes. But for me, that's the most important, of what we can achieve now, not in the future.

Paul Thies:

Well, and you described is, I think, a universal family experience. Nothing's ever perfectly rosy or smooth. But as long as there's love anchors it at the end of the day, then you know you'll get through. Well, Steph, Lara, Nicola, I really appreciate this conversation, these beautiful words of advice and insights. I think it's a lesson for all of us just to always remember that when we encounter people, every person we enterprise is a gift and is an individual who's irrepeatable and should be celebrated. I really thank you so much for sharing all your insights with me today.

Steph Bywater:

Thank you for the opportunity.

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Nicola Enoch:

[crosstalk 00:43:23] the opportunity.

Lara Jumagdao:

Thank you.