

iDareU....The challenges of Diversity, Inclusion & Disabilit...

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SPEAKERS

Lia Zalums, Sue Dymond

Lia Zalums

Hello, and welcome everybody to today's session on ZedAxis TV where we talk with thought leaders and women who are making a positive difference in the world taking on big challenges and doing great things to make things better. And today I have the absolute pleasure of, of introducing you to Sue Dymond. And let me give you a little bit of background. But Hello, Sue.

Sue Dymond

Hi, how are you? Thank you for having me on.

Lia Zalums

I'm really looking forward to to our conversation today. And of course, if you're joining us live on LinkedIn or Facebook, then do let us know in the comments. And if you have questions, do pop them in and we'll do our best to either answer them live or come back afterwards and make sure that you're taken care of. And my name is Lia Zalums. And, and I'm the host of ZedAxis TV where, as I said, we we talk about important things in success skills, business skills, and explore the ways that different business leaders and and women in community are making a difference. And today we have Sue Dymond who is committed to making a difference and enhancing lives. And she is the founder and CEO of iDareU, which is a business that is passionate about community inclusion and people with disability and empowering them to live a life, a big life and a loving life and with dignity and respect. So we're going to hear a little bit of Sue's story today. She's the mum of two amazing women, Chloe, her youngest is 30 years old and has Down Syndrome. And Sue you have never settled for mediocrity. And the same has been true for your daughter. And you've also overcome your own challenges in life with having a stroke, a severe stroke in 2003, learning to walk again and managing ongoing pain and fatigue. And you've also written a fabulous book. So we'll dive into that - Removing the fear of raising a child with a disability - Waising Miss Chloe. Welcome Sue.

Sue Dymond

Thank you so much for your and again, thank you for inviting me to come along and talk to everybody out there in cyberland.

Lia Zalums

Let's get started. So with that, Sue, in your own words, tell us a little bit about what iDareU is about, how it came about and what and how you serve people through iDareU.

Sue Dymond

iDareU is a very much a grassroots organization, although we actually created it to be company limited by guarantee rather than incorporated association because I'm a bit of a big dreaming person. So I'd like to see iDareU go international, not just within the state. I expected that within the first year but reality kicked in. iDareU actually stands for INSPIRING people with a DISABILITY through AWARENESS, RESOURCES, EMPOWERMENT and UNITY. As as you mentioned, Lia, I have a daughter who has a disability. And as we were talking offline, I was saying that when I realized that my daughter was born, Lynn clovers, when I found out how he had Down syndrome, I made a promise and a vow to myself and to her that she she was not going to live with me for the rest of my life. And she was going to have to be the best person she can possibly be. And that was became I guess, my journey. I had done a lot of volunteer work for 20 years actually even after Chloe was born, with troubled teens because I was a troubled teen and I learned to give back and that was about the same - teaching people how to become their best to live their best lives and that to me is that's what drives me. That's what gets me out of bed in the morning. iDareU came about because originally it came about because I was a person with teaching, helping Chloe to have her best life. I also come from Outback Queensland and I was bought up In the Bush were we all whether we liked each other or not, we had to support each other. And through that I've got this really strong ethic that a village raises a child, not an individual raises as a child. I do not come from Victoria, which is where I live now, so I had to get natural, natural supports myself. I had a mix right from early days of having Chloe incorporated into the people in our local environment. She's fortunate as her sister's 10 years older, so Chloe was just seeing always as Chloe, Shannon's little sister, not as Chloe the person who has Down Syndrome. And we also use services. Now I had spent many years fighting the services because I felt that the standard was not high and their expectations set with the standards are very low. There's an expectation of what an individual can do, depending on what disability they had. And I didn't agree with that. I decided that it would be great because I realized what was happening and where I felt different was I enjoyed Chloe, Chloe is not a burden. Chloe is not my lot in life. And I do not want in any way shape or form feel guilty about having a child with a disability. Many people, my ex-husband used to say, you know, I'm really worried about Chloe going out in the world. No, what I'm really worried about the world when Chloe is out in it! So I, I had to I wanted people to learn how to have a good life and have the life they need to live and see their loved one as, as not an equal but just as a person to love. Not because of their disability. And I don't know if that makes sense. Therefore, we got together and I decided I was going to have a For Profit, because then it would be something for Chloe, after I'm gone because of the disability, because my fear has always been that she needs to be government proofed for after I'm gone. She needs to live the life, the quality of life she's living now has to happen after I'm gone. Sadly, this was seven years ago, it was just at the inception of the NDIS. And one of the things that before the NDIS that was happening was you could not be a For Profit and be working in the disability sector. Councils ignore you, governments ignore you. For Profits weren't in the disability sector. So therefore

very begrudgingly and very, look, I'll even say to this day, I wish we weren't a Not For Profit, but at that stage, we had no choice going into the sector we're going into. So you're

Lia Zalums

So iDare U is a For Profit, not a Not For Profit.

Sue Dymond

No, we I wanted to be a For Profit,

Lia Zalums

Ah, but if you did that NDIS wouldn't support you

Sue Dymond

NDIS was not around then. NDIS changed that. That was one of the massive changes happened with the NDIS. If we'd waited a few years, we could have come in as a For Profit. Right. But at that time before the NDIS Disability Services, you had to be Not For Profit. There were no For Profits in the sector. And we were right on that edge. And because of the way we set ourselves up because we're a Not for Profit Charity limited by guarantee and we have DGR status to try to undo that is just convoluted so we do the best with what we have the structure we have. I had to get my head around the fact that Not for Profit is not about not making profit that it's about having the money going back into the business because I had the mindset well if we're not for profit we've got to be for free.

Lia Zalums

So what what is your biggest challenge in getting your message and your teachings out to the people who need it. Does iDareU provide education? Does it provide services? What what does it provide? Who does it actually serve directly?

Sue Dymond

iDareU provides education provides training and provides information and one to one support with people who either have a disability, or have family members or nominees with people disability, we do, because we came out at that same stage as the NDIS. And of course, we had to go on, my daughter had to go on to the NDIS. And I found a massive gap there. And that was called communication. In the disability sector, I'm sure it's in others as well, the service providers and the government have their language. The problem is, so do the carers and the people with disabilities, and you might as well be talking French, to a German person, because they don't actually talk the same language. So therefore, and most people who have kids who are carers, or who are unpaid carers, or family members, or people with disabilities, we're not going to sit there and go, "Listen, I know I sound dumb, but I've got no idea what you're talking about," We normally just sit there and nod, and then walk away going, but no one knew what that was about. So therefore, we saw the gap that we needed to inform people and interpret, we do a lot of that today. And we do a lot of work, supporting people to understand what the NDIS is really telling them not the words that have been used, understand how to use anything about NDIS, how to use their portal, how to become self managed, how to look after some of their stuff themselves have arrived goals, instead of mission statements. There's a difference there one's passion.

Lia Zalums

The passion has to drive the goal, doesn't it? And this is a lot of the work that I do with leadership development and articulation of specifically, where you want to go, how you're going to get there, and why it matters to you. And I think you're absolutely right, that the goal is not the mission. The goal is the outcome. The goal is really the vision, isn't it? What is going to be made possible when you feel this gap, when that person is educated and embodies that knowledge? Because knowledge is power, when you know how to use it knowledge is not power if you don't know how to use it. So that's what I'm hearing. So do people pay you for the services? Or how does your business get funded?

Sue Dymond

Blood, Sweat and Tears. So yes, we are a fee for service organization with doing the support in that way purely because we made a conscious decision. And this is not wise, just for all out there. This is not a wise decision. But sadly, it's where my ethics stand from my journey. We made a decision that we're not going to be funded by the government or the NDIS to keep the lights on.

Lia Zalums

What what caused you to make that decision?

Sue Dymond

Two things. One is we don't want to be accountable and be tied up in red tape, the thing we've found in my journey, one of the biggest issues with organizations that are funded to exist, they're accountable to the funder, not to the client. And that was always an issue. It means that the client really does not get that work. They don't get cared for in the way they're meant to. We are there for the person that we're working for. And that's it.

Lia Zalums

So the client gets funding from NDIS in order to use your services.

Sue Dymond

They can they can get funding through the NDIS to use our services. The other reason let me just say before I move on, the other reason that we did not want to get government funding is it makes you a very vulnerable organization. Because when that government pulls the plug on those funds, if that's what you've been relying on to keep the lights on, your lights turn off. And I think as you know, it's great at the time, it's easy, but boy, you know, every day you're thinking, oh, what is a change of government going to do or what if the budget stops? You know, you're relying on outside sources for the ongoing of your organization, and I think it's a risky place for anybody to be. That's what my experience has been. But in saying that getting back to what we were talking about. We do get some funding from grants or from local state or local government to do particular projects. We have a with what you're asking one of our other things that we sell or that we offer, we offer information sessions for unpaid carers and just for those who are not sure what I'm talking about here, a carer is generally the person that doesn't get paid to look after a person with disability. A support worker is a person who's paid.

Lia Zalums

Okay, so a carer is often a member of family, so there's no line item in the NDIS for a carer

Sue Dymond

I might add, that's been this case even before the NDIS but a lot of people get confused and call carers all sorts of things. But technically a carer is a family member or sibling or a partner or whatever, that's not being paid to care for somebody. And the unpaid carers can get stuck on a real hamster wheel style thing so that it's very hard for them to separate themselves from the person they're caring for.

Lia Zalums

I want to dig into that a bit because when we were talking offline, I think there was a really pertinent point you made about your own experience of how how you decided to raise or to waise Miss Chloe. And so talk about that distinction from your perspective of, I think you called it the rescuing attitude, the feeling that you are the rescuer of the person with the disability and how that impacts your behavior. And just what was that decision point that you made in those early days?

Sue Dymond

Very early days. I made a decision and as I mentioned to you earlier before, and this might be hard for people to hear so versus fine if you don't want to hear it shut your ears, but it's my journey. I never wanted to keep a baby who had Down Syndrome. I wasn't a very nice person. And I'm very comfortable admitting that. Chloe has made me a decent human being if there's one gift she's given me is the gift of being a decent human being. But in saying that, when my doctor had to tell me, after me telling him every month I wasn't going to take home someone who had Down syndrome.

Lia Zalums

Did you know in your pregnancy?

Sue Dymond

No, no, if I'd known in my pregnancy, I would have been fear driven. And I would not be talking to you today, I can promise you that. I promise you that. And I actually work hard in that area now to say, when we know before pregnancy, all these tests, we need to get equity around the information, so an informed decision can be made, not a decision on fear. But that's different than my situation. Getting back to this one. When I got informed that my daughter that Chloe was suspected of Down syndrome, I look skyward and I'm not religious, but I looked skyward and said "alright, you so and so, if you give me a challenge I'm going to take it on, but she's not going to live with me for the rest of my life." That was where it started. From there I have spent every day of our lives teaching Chloe how to be not only an independent adult, but also teaching her to be separate to me. We don't have which happens a lot with unpaid carers. We don't have that enmeshment. I have my own identity that is not around Chloe. Chloe's identity is not around me, although sometimes I'm sad to say, people do say to me "oh you are Chloe' mother." I say "no I 'm Sue Thank you." But yes, and I didn't have the guilt. And that's... it's very complicated. It's very messy and "enmeshy", particularly when you're a parent or a person with a disability, because there is so much that happens and and unless you get real help with it, it doesn't go anywhere. You know, it doesn't go anywhere. It stays. And sometimes it just gets bigger and bigger and bigger within until we don't know where we are we lose ourselves completely.

Lia Zalums

What this plays into your Awareness piece here. It's only with Awareness that we can make different decisions, conscious decisions, sometimes scary decisions, when we have awareness and when we have support. So something that was clear to you lead you to make very different decisions than someone who is not aware of the implications of being enmeshed, of that absolute codependence, that rescuing behavior. And often, it's not just women, is it, but often the mother takes the the primary role here. Is that true in your experience?

Sue Dymond

Absolutely correct. The parent. And this is not always, obviously, but I find that yet the mums are the primary carers and not just with children. Parents, we seem to be a primary carer for whoever has a disability. It's interesting because some mums get into protection. And the dads get into fixing.... the practical. And that's not in every case. But it's a real commonality that dads are solving problems, the mums trying to not rescue but to protect. So yeah, you're right, you have to have acceptance, you have to acknowledge first and a lot of people don't even acknowledge there are shame issues, there are all sorts of things. It's very complex. But you need to recognize what you're feeling. You need to get help for that, then you need to accept. And they are all big, big things, and then you are able to action. But you need to trust. You need to actually go against maternal instinct. I was talking about this before, you know, my maternal instinct is to answer Chloe's questions and make life easy for her. But my reality if I want to make her an independent woman, or as independent she can be is that she needs to learn to figure things out for herself. She needs to be comfortable with failing, and know that it's okay to fail. She needs to when she at one stage, she wanted to learn to drive and I thought, oh, God help all of us now. Because people Down syndrome don't have the fastest reflexes on Earth. And that's a pretty common thing. But not only that, she couldn't read or write. And I said only before you learn to drive, you better learn to read, because you're going to have to read all the signs. We went and got to the learners manual. She spent two years writing. Her writing improved enormously just writing out the manual, I will say there was about 45 exercise books. Her writing improved to a point where she can recognize things and she's semi competent,

Lia Zalums

The power of a goal. She wanted something. And if this was the way, this is what needs to be done.

Sue Dymond

And I said that to people all the time. If you want your child to learn anything, find out what their passion is, because it's not about reaching their passion. It's about that journey. Because after two years, she came to me and said, "I don't want to learn to drive anymore because I can't see properly." The thing she learned in that two years is still with her. And I say to anyone, "no goal is too big, because it's not about technically reaching the goal. It's about what you're learning and gaining towards the goal. " And that includes my eyesight, me wanting to go overseas and my business. Who knows it might not be in my lifetime, but I'm still working towards.

Lia Zalums

So on that note, so how do people know about you? So how do carers know that you are there with programs and support to make their lives and their loved ones lives better?

Sue Dymond

We have a really, really good reputation and because what we do is very different to any other service because we're filling a gap. So we do do a lot of gap filling and language for example. Mainly the way that people find out about us is, dare I say word of mouth. It's really, word of mouth.

Lia Zalums

Word of mouth has just taking on like life on steroids now. With with the impacts of the pandemic we've just gone through, and everyone going online for everything. So like the mass production of different courses and programs. The question then becomes who do you trust? You're going to trust someone who refers you. It's like how we came about with Katrina, being a common friend and she was so passionate about us connecting and I'm so glad that she persisted. We found time now to come together. Word of mouth is one way that people get to know about you. What would be your your top two biggest challenges in your business?

Sue Dymond

Can I jump back a little bit because as well as word of mouth, and that is massive word of mouth with us was professionals as well as the people with disability and their families that we have got a really good reputation. It's also through social media. There's a lot of forums out there on social media. And we are mentioned a lot in those forums. We do have our website, we've only just relaunched it. Please go and have a look at it. It's www.idareu.org.au. We just relaunched it last week, and I'm pretty proud of it. There's a fair bit of blood, sweat and tears in www.idareu.org.au. And we also do our own social media and my LinkedIn. But it's a good question, what is one of our biggest difficulties? As I mentioned offline, I'll be honest, and say, being a company limited by guarantee, and having a Board, even though we are 7 years old, we are still startup. We're tiny. Because we don't actually have the funding to keep the lights on, therefore any revenue we are getting associates costs with it. But we are at a point right now we're needing to move up. We are a size 20 but still wearing size 14 pants, and we're feeling it. Oh my god, but we've got that chicken and egg, well, we don't have the funds, but we don't have duh duh duh. And we're also looking at creating new programs. So for us, it's that getting ourselves the right people on the Board that are going to be passionate as well, and be able to open doors or bring in or help with skills and understand that when you're in a Startup, a Board needs to be a little bit more hands on than when you're fully established. And we're going from that Startup into growth now. That's been one of our biggest challenges. And even though our Boards have changed over time, from a group of passionate with no skills, and then developed into a Board that has people that have got amazing skills, but maybe not as much capacity. So it's finding that balance, that's probably our most challenging thing.

Lia Zalums

Yes, so there are challenges with people resources, and then what about the money it takes to hire in the resources that can actually build the courses and make that happen faster and do more on social media. I do a lot of work with with female founders, and the ones who have managed to get, like a big whack of money, either through corporate donations, or grant monies grow faster because of the scale and speed to action. If you've got more money up front, then you can get the material out and get the launch done on a much bigger scale, to get bums on seats. Without money, you are relying on goodwill and volunteers. Do you do think the change of government now is going to help you?

Sue Dymond

Change of government is definitely going to be helpful for us, particularly in the area that we're working in, and we're noticing changes already. I agree with what you're saying there and it is that matter of finding the funds and what is a challenge to anyone who's looking at starting up I'll warn you of this. Governments and people who give away funds like to give away funds to people that they know. So they normally give away funds to organizations that are very, very well established, and may not quite need as much funds as what they're receiving. There is very low risk capacity, when it comes to giving grants to do that tip over, which I think is a bit sad, because they're keeping a lot of the big organizations ticking along, but they're not giving small ones a chance to come in, in a way. But that's just an observation and where we're at, we're getting little grants, and that's fantastic. But with what you were saying, can you just repeat it was about?

Lia Zalums

It's about the conditions that the funding is given. If a corporate gives you gives you money, because they want to support you, it shows their corporate social responsibility to support you. And so I guess, that's the balance that you were talking about, before about not wanting to be beholden, whether it be to our government or to people providing you with, with funding support unless you've got very deep pockets yourself. The work that you do is so fundamental to basic human dignity and the quality of life at a really fundamental level. And so I really hope that there is going to be more support to relieve some of that pressure you have to make your services available to more people in need. Growing a business takes time and resources and skills. You're either trying to pitch to get to get money to support you, or figure out what your content plan should be, so that more people see you on on social media. And then how can you attract the right Board members and work with the Board members to make things happen.

Sue Dymond

So I'm getting on too... I'm in the six zeros now I'm thinking, goodness gracious, I've got to keep going here, I've got to get this done and sorted before I go.

Lia Zalums

This is why I love connecting, particularly with women like yourself who have got so much phenomenal lived experience, and you're an amazing communicator. And so that translates then into this material that actually is understandable by the people who need to be able to understand it, to know what government resources are available to them, how to access them and how to make the most of their own life and enable their loved ones who have the disability to live a full life and a life of dignity.

Sue Dymond

Once we get people with disability or communities, in closer for people with disabilities, that automatically means that those communities are very inclusive for people who are aged, they're very inclusive for people who may be immigrants or coming from another country. Because when we actually stop having our expectations and our standards high because that's what makes disability, not the actual person. The person doesn't make a disability. It is the barrier, it's the height that we expect people to come to, that makes disability. And I think that's something that we need to change the

mindset on. And the other thing too that I get a lot and I'm always trying to educate people and businesses and services that are not in disability sector. Disabled people are not over there. They're not over there. They might be next door to you. I'm here all the time. " oh, we don't go there. We don't go there." Where is there? There and we are here. And they are a part of our community. And lots of people with disabilities don't need lots of support. But every human being on Earth needs to be a part of our community, and not missing just because we're not where people expect or comfortable with us being.

Lia Zalums

Yes, that human need for belonging. And if we see inclusivity, and we invite belonging, then we are less influenced by our judgments.

Sue Dymond

Yeah.

Lia Zalums

And that's the big thing that that needs to change is how we see people who are not like us.

Sue Dymond

And that's my dream. People with disability live bigger and better lives when I teach all of you out there how to see people with disabilities as just people.

Lia Zalums

That's such a powerful note to close our session on today. You've really hit on the key message here. It is about all of us being inclusive, and seeing sameness not difference. And now how is the best way for people to, to connect with you?

Sue Dymond

I would say the easiest way would be the website www.idareu.org.au And if you go into the website, you can also if you if you feel you'd like to volunteer on any level, even if it's helping at a sausage sizzle, we're looking for volunteers. We are a little bit light on when it comes to the people that are actually work. There's a few people doing a lot, and I want it to be a lot doing a few things. Please don't ever think something's too hard, too easy, too this too whatever. Give us a yell if you think that you'd like to volunteer in any way shape, or form from being a Board member, completely through to coming and putting stickers on our homemade jams that we make to sell as a fundraiser, as well as helping us with funding and all sorts of things. It was interesting, just I know this is the end, but just what you said before, we actually know that we can stand alone, but we need seed funding to jump us into that next level. We're not looking for a lights on funding, but we need seed funding to be able to go to that next level.

Lia Zalums

I really want to thank you for your time today and the amazing work and the amazing perspective that you have and you share and you teach and the difference that you are making to to your daughter and

your community and show us your your first book again. Removing the fear of raising a child with a disability - Waising Miss Chloe

Sue Dymond

This is Chloe here. Yes. Now she is a jewelry maker and has her own website so she actually has her own business now. And just for you out there.....Chloe doesn't have Down syndrome if you ask her. She comes from Down syndrome. So she's just from a different country.

Lia Zalums

I love that perspective. What an amazing journey you have had so far and your vision and mission to change how we all define disability and become much more inculsive as one community and remove the "us vs them" barriers so everyone can live a big loving lofe with dignity, community and opportunity.