

Day 2

Consumer Led Award

Introduced via video by Dr John Wakefield, Deputy Director General, Clinical Excellence Division

Dr John Wakefield: CED's additional sponsorship funding has allowed for the first ever Consumer Awards. These awards are an opportunity to celebrate examples of excellence in consumer engagement. Firstly, let me congratulate yesterday's winners of the Partnership Award. Carolyn Wharton, and Suzanne Michaels from Caboolture and Kilcoy Hospitals for their great partnership to collaborate and great change that's led to much better health outcomes. Well done. It's now my pleasure to announce the winner of consumer-led award category. This category recognises health consumers and carers who demonstrate drive, growth and commitment to partnering with a health service to really improve health outcomes for Queenslanders.

So this award goes to... and I want to recognise the contribution of Sue Swinburne, mother of a transgender daughter, for her great advocacy and participation in engagement activities which has really led to much greater access to consumers for gender diverse and questioning children and their families. As a parent, Sue's provided support to other parents on-line, over the phone and setting up a peer support group. She's spoken publicly at health and education conferences and in the media and been an active advocate to politicians, and government departments around the issues and the need for improved education and health for gender diverse and questioning kids and their families. Sue has co-designed, publicised and participated in these engagement activities with young people, with other parents and staff within the Lady Cilento Children's Hospital Gender Clinic and the Statewide service. She's a member of the Queensland Health's inclusion and working committee. I would now like to invite Sue to the stage to share her family's journey, and her work that has gained her this award and recognition. By integrating families into the improved design and delivery and evaluation of those services, co-design has led to greater access and better health well-being outcomes for young people. Sue will be joined during her presentation

by Dallas Pitt, psychologist with the Gender Clinic to describe the co-design activities and impact. Please welcome, Sue. (APPLAUSE).

Melissa: As Sue and Dallas come to the stage I'd like to acknowledge Sue's family who are here in the audience, Paul, Noah and Annabelle herself and I'd like to acknowledge staff from within the Gender Clinic, and also I believe Fiona Dooguian, the chief executive. (APPLAUSE).

Sue Swinburne: Golly... (APPLAUSE) Oh, hi. That's all right I've just been focused on getting this far, but of course there's all of you here as well. That's super awkward. I have to give you a little heads up. I'm a crier and in fact I cry so much - you know the safety video when you get on to Qantas planes and they're all like, this beautiful land, don't forget to buckle up, I cry at safety videos, so that's just, if I cry today it's not because our life in any way is difficult or sad in any way, it's just I'm a crier. So, yeah, heads up on that. It's not without a degree of embarrassment that I ... oops, wow, how did we get there? There's good. It's not without a degree of embarrassment that I'd like to thank Health Consumers Queensland for this amazing award. There's lots and lots and lots of families and many of them here who are working for our community's well-being and it's great this award exists now to honour and to recognise all of that passion and hard work and positive change. Before I start, I'd like to acknowledge the traditional custodians of this land the Turrbal and Jagera people and pay my respects to Elders past, present and emerging. I'd also like to pay my respects more widely to transgender Indigenous people, brother boys and sister girls and extend that respect and gratitude to all trans and gender diverse people living their truth. Oh, this is a little crying bit. And, I'm back. The advocacy of people make it possible for my family to enjoy the privileges of safety, security and access to health services we have today so I'm super grateful. I'd also like to say hi to my family. My God, there's another crying bit.

This is my husband Paul who is an ace dad. As a British ex-pat he's more polite than I am and an excellent role model in that regard which is balanced by my son Noah who shows a difference to others, which is also super handy at times. So

I'd like to start - today I'm talking about the vital role that I think allies have played in our family's life in helping to create positive change. But to give you a sense of how our family got to where we are today I'll start back at the beginning. This is our daughter 11 and a half years ago. She's a standard baby, very curious about the world. Quiet and easy-going. She was assigned male at birth which is a way of saying we thought this child was our second son. Green button works. So we continued to think that this child was our son, even though when she was able to dress herself she'd raid any wardrobe for the kinds of clothes she enjoyed wearing. Anything that she could make kind of like a dress. Her play and the characters from stories that she would role model in her play were stereotypical feminine, but we were happy for her to dress and play how she wanted. Oops, green button.

As she got older however she became increasingly aware that more broadly society frowned on how she wanted to live in the world. She would ask me how we could stop people staring at her while we were out wanting to know why some people laughed at her. She started to get sad. She was an introverted kid. She kind of still is, but her personality at that point became more and more anxious. When she began kindergarten she gradually began to express her gender in ways that I guess were more stereotypically masculine. Alongside that though, other things started to happen. Little things like she found it really difficult to answer the question "What do you want for your birthday?" She found it very difficult to make eye contact with people outside of her immediate family and she became less talkative and much less confident. (Phone rings) there's the phone... hopefully not mine. She became increasingly conscious of how she presented outside the house, and checking with me when we were going anywhere, who would be there and if she couldn't feel kind of reassured that she wouldn't encounter any negativity she would choose to wear "boy clothes". By the time primary school started she'd pretty much given up wearing her old clothes, but at the same time she withdrew into herself. She became acutely shy, but would have bouts of sometimes violent rage at home, as her brother and dad and I can attest. She suffered from social anxiety and started refusing to go to school.

So this all happened gradually over a number of years. When it got really hard to get her to go to school, my husband Paul and I took her to see a child

psychologist and ostensibly at that time it was to work on school refusal, because she had stopped expressing her gender in nonconforming ways and it was not an issue she ever spoke of. But after two years of work with the psychologist Annabelle was eventually able to talk to us about her sense of self and that she is in fact, a transgender girl. So we, Paul and I started to look for information about what this meant for our daughter. In our initial research we discovered that being transgender carries with it some statistically dire outcomes. So this is an Australian study conducted last year. It surveyed 859 young people between the ages of 14 and 25 as well as 194 parents of gender diverse young people. And so this is what the researchers found and this is the kind of information that we first encountered. We found that as a trans child our daughter had a nearly 50 per cent chance of taking her own life, that she had an almost 80 per cent chance of harming herself and that she would experience discrimination at school, at university and that she was at greater risk of homelessness.

So as parents, this was the question that we asked except with a lot more WTF and very frightened exclamation marks around this question and I guess this became the focus of our research. Obviously, you read those kinds of predictions for your child, you want to do something about it. So what we quickly discovered was that our daughter's well-being as is the case for transgender people generally was actually pretty straightforward. First and foremost, what she needed was for her whole community to understand her, to respect her and to acknowledge her as who she is. And I guess it's an unusual health scenario. Mostly, you need to find care for your child that's specialist clinical care and we did need that. But actually what we needed for her first and foremost was for her to feel validated so that she didn't kind of become one of those horrendous statistics that we'd read. The well-being of transgender children and young people relies on great clinicians, but it also relies as I said on a whole community. What I've compiled for you on the next slide is a list of people I've dealt with directly or indirectly since our daughter came out to us, either for her welfare or as we started to then work to improve the well-being of trans children more generally. And so this is a weird list for how you ensure somebody stays healthy, but these are all of the people upon whom our daughter's well-being relied. I put "parents" on there first, because Paul and I are the most significant protector for Annabelle, but Paul and I had to do quite a lot of

work ourselves so that we had the knowledge, we had confidence and the capacity to care and advocate for our child. And it took actual work. It took emotional work, intellectual work, psychology work on ourselves to make sure that we could care for Annabelle as she needed us to. But that work that we did was to prepare us to encourage and help other people to do almost exactly the same work, to help each of the people on this list to process their own feelings, to learn, to grow and to be their best selves when it came to supporting and caring for transgender children.

As well as the folk that I've dealt with, some of the people on this list are also from peer support that I've done in secret Facebook groups and some of these people also come from my own workplace where I'm part of a working group to improve how my employer provides a safe understanding and respectful space for trans people. But the list goes on. I'm going to quickly run through a couple of the people on this list to give you a sense of how each of these people also impact my daughter's health and well-being. For example, the mayor in our former local council Scenic Rim raised the rainbow flag outside council chambers in Beaudesert, known as a hotbed of liberalism for international day against homophobia and transphobia. So this is a really simple and very powerful way to tell LGBTIQ people that they are seen, respected in their community... oh, Qantas moment. Respected in their community by people in positions of authority.

Conversely in our former State electorate Scenic Rim, not so representing, the local MP wrote an alarmist article for the local paper during the Safe Schools debate contributing to the spread of misinformation fearmongering about gender diverse children, particularly in the school system. Paul and I subsequently spent 90 minutes with Paul being super-polite explaining to our local MP how and why this was not only misleading, but it put our daughter at risk. So the list goes on and each person or institution on this list has the means to make a transgender person's life better or worse, to improve their well-being or to undermine it. As parents and as advocates we need to look for our allies in each of these places and to work with them to create positive change. So what does it look like when things go well? The primary school where Annabelle transitioned Tamborine Mountain State School is a great example of that.

When we first met with them about Annabelle being transgender the school listened to us, and they made it clear they would support us and our daughter and they, like us, had at that point in our lives had very little knowledge about what all of this meant, but they made arrangements for Safe Schools which existed at the time to deliver professional development to the whole school from the teachers to the librarian, to the tuckshop volunteers and the groundskeeper, the staff then worked with our family to help plan for Annabelle's transition at school, to make sure that her peers were able to respond to her transition with respect, warmth and understanding. The school became a genuine partners in the well-being for our daughter. They did this by growing, by learning and by leading the school and the school community in a strengthened commitment to diversity and inclusivity. This commitment was formalised in this policy, which explicitly frames for the school community how gender diverse children are welcome and are safe at Tamborine Mountain State School. This is a wonderful document and painfully rare and has been shared around the State and the country as an example for others to draw from.

Another place that understands how to partner with families is the Gender Clinic at the lady Cilento children's hospital. Annabelle needs expert clinical care as she approaches adolescent. Dallas Pitt and the whole team have worked with a genuine heart-felt and unwavering commitment to genuinely and authentically engage with kids, parents and the community. They're an absolute godsend not just because they exist which is also something of a miracle at Stephen's hand to be fair, but because of how they live the shared values of inclusivity in their work. Gosh, this is what a transgender kid looks like when they have a loving and supportive family and excellent cake. And, a respectful and caring community, a great school and now that the Gender Clinic at the lady Cilento has been formally funded by the Queensland Government, where they have access to appropriate, expert and timely health care. (APPLAUSE).

Whoo. Also, that cake was my crowning glory as a parent. I peaked early. But this support for her was relatively easy to provide. I have a loving and supportive spouse, we're heterosexual, middle class, we live close to a metropolitan area, we're white. English is our first language, **WAOUR** neurotypical and have

access to education and resources. We have won the privilege lottery, but what happens to those kids whose parents don't have the same privileges, capacities or resources that we have? So this quote that I've got up there today is from an article published recently by some Canadian clinicians, that is not easy to say and bless you to whoever that person was. So young people need the support of their parents first and foremost, otherwise that's the point at which they become at great risk. So the parents' group that we run with the lady Cilento children's hospital is one way to help improve the lives of transgender children and young people by supporting their parents to do well, to access the services they need, and to be their best selves in the care and the support of their kids. As I've discovered and the Gender Clinic also knows, schools and government bureaucracies don't always understand gender diversity, nor do they always understand their obligations under the antidiscrimination legislation.

So it's important that we have the parents' group to share information, to model strategic and well-informed advocacy for one another and to give support and advice to navigate the complexities of the current landscape we find ourselves in. So in this environment, this is what parents need according to Canadian clinicians, parents need education, they need support from peers and the organisations they encounter. They need their schools to step up and to show leadership, courage and vision and for those parents of prepubescent kids services should be designed to meet the support and care needs of parents. But what about kids whose parents don't support them? Transgender kids are put at risk when they don't have supportive family around them. It's absolutely vital, therefore, we urgently consider the rights and well-being of trans children whose parents do not support them as well as how they are supported and cared for in the child safety system. Just to finish up, there's one more person I need to acknowledge... this is going to be a massive Qantas moment. Gosh, this person is... oh, golly, I may not get through this. This is Paul and my greatest ally, our daughter Annabelle is a patient, thoughtful, compassionate and hilarious companion. She teaches us daily about resilience, generosity, wisdom and good humour in the face of ignorance, adversity and challenge. I'm very grateful for the opportunity she's given us to understand the world and ourselves. Oh, gosh. It's Qantas, so happening right now. She's given us the opportunity to understand the world and

ourselves in a new more thoughtful and much kinder way. I thank her for giving us the motivation and the clarity to do the work that we do to support the well-being of transgender children in our communities. I'm sorry to pass over to you like crying, that's a terrible segue, but I am going to now hand over to Dallas, who's going to describe the development of the Gender Clinic, the recent co-design that we've been involved in and how the clinic works for kids and families. Thank you very much. (APPLAUSE).

Dallas Pitt, Psychologist, Children's Health Queensland: As you can see I guess from Sue's speech why we wanted her so involved within the Gender Clinic, and the Gender Clinic has very much from the foundations been consumer and carer-led and then we also have an ongoing commitment to be involving consumers and carers. So as Sue was saying this current financial year was the first time that we actually received funding for the clinic and we were able to build a team which is made up of child and adolescent psychiatrists, paediatric endocrinologist and a bunch of mental health workers. So the lady Cilento Children's Hospital Gender Clinic - I'll just say "Gender Clinic" that's too much of a mouthful - is based on a gender affirmative model of care. The goals are about listening to the child and with the help of their parents being able to understand what the child is trying to communicate about their gender identity and also, their gender expression and to help and support them to feel comfortable and confident within this identity.

We also like to explore what gender means to them and to the world around them and also to help reduce the extent of preoccupation with their gender. Based on clear information, clinical guidelines and research literature from around the world we do this and we also treat or collaborate with primary mental health treatment teams to address difficulties and monitor risk. For those of the children and young people who meet clinical guidelines we can provide medical assessment and treatment for stages one and two, which is your puberty suppression and gender affirming hormones. So right back prior to the establishment of the clinic actually being under way there was a 3-month consumer and carer consultation process that occurred. So we were lucky enough to have leadership that really saw the importance of having consumers and carers involved in this. So for three

months which was led by a trans community development worker we ran three different focus groups which involved 20 parents and 14 young people. So with this it was really the aim of it was to get their perspectives of the future model of service, to determine what key resources were required and to directly influence the development of content for future consumers and carers.

So from these focus groups, it helped inform the model of service for the clinic, the need for a parent support group was identified. It also identified the need for on-line resources, it highlighted consumer anxiety about what to expect when first attending the clinic. It highlighted the need for facts sheets around gender dysphoria and also the information was decided upon by consumers. So this is the parents' group that we run. So it's actually run by Paul, Sue's husband. He leads the group and it's supported by key NGOs within this field and also ourselves at the clinic. It's been running since September last year and runs bimonthly and it's been having great attendance and it's also I guess the parents have decided to build a Facebook group as well so they could connect outside of the group. We also, because it's run here in Brisbane we didn't just want to help and support the carers of Brisbane trans young people so we've been able to develop video and phone-in options, because it is a Statewide service and so we're able to have carers from around the State link into this groups. We also have a website. It can be found Googling. It will be our hub for any fact sheets we develop.

There's a couple up there already and it features a video we developed to help with consumer anxiety about what to expect when first attending. We decided on a video format basically because there's a high proportion of young people with ASD and speech and speech and language difficulties and we thought it was the best medium to communicate with them. We really needed with the video to balance between managing consumer visibility and also involvement given the context of threats to personal and emotional safety. Other health clinics have received hateful targeting of gender diverse children and young people. So within this video and also another project that I'll talk about later on, it doesn't contain images or the vocals of our consumers, however, it does directly contain the words from consumers. So the cartoons that you see, the voices, they are direct words

from the focus groups right back at the beginning of the clinic. So just because of time we'll just show a small segment from the video.

Sue Swinburne: So when our daughter started talking to us about being trans, my first response actually was relief because I had seen for so many years that there was something that she was struggling with and it was never really clear to me what that was and so my husband and I were trying to work out for a really long time how it was we could help her come to some place of peace with what it was that was troubling her. So when she talked to us about her sense of self and her gender identity, it was actually such a relief to go "Oh gosh, is that it? Oh, that's fine."

>>: Being able to have the friends and family use the correct name and also the correct pronouns, that can play a major part in just affirming someone's identity.

>>: The support from friends and family that means the most is when they are understanding and have respect for my pronouns and name.

>>: They don't necessarily have to understand, but just to accept.

>>: Young people whose families are really affirming of their identity are growing up to have full and wonderful lives with the same or better outcomes in terms of mental health or educational attainment or jobs or whatever the case may be. So we really are confident that working really in a connected joined up way with families and local care systems is the right pathway in terms of ensuring the best possible outcomes or optimum development for that young person.

>>: So these are little snippets from the facts sheets we've developed and are currently in the process of finalising around the medication fact sheets. So these images were again decided upon from our consumers at the very beginning of our focus groups. So they'll contain information about the medication risks and I guess all of that sort of information and they will be available on the website, as well. So we also have the Your Story Project. This is about an opportunity for our

consumers to be able to share their stories with other consumers. We currently have a handful of them at the moment and we're wanting a few more before we actually place them on to our website. Again, they will be deidentified to help protect the safety of our consumers. We also have the consumer quarterly forum that's under way. This is about an ongoing opportunity to get direct feedback from our consumers. They will be leading and driving community events such as Wear Purple Day and Pride and were directly involved in creating the material for these community events. And I guess we're not just about having this consumer and carer involvement right back from the beginning, we want it ongoing throughout the life of the clinic.

As was mentioned in the beginning, Sue is a carer representative for the Child Health Queensland diversity and inclusion working group. She was asked recently to present to the board. We also have the annual experiences survey done for both carers and consumers. We also had consumers contribute interview questions for all of the current staff in the clinic and whenever possible we also had them involved in the interview panel for the staff. Consumers will also be contributing to resource development that's under way shortly for training that we'll be doing by the Gender Clinic. We also have the family fun day that's being organised and this is going to be an opportunity for families, their carers, consumers and also their siblings to be able to get together and help normalise their experiences. We also have the Heroes Project. So this will be developed with the help of the consumer quarterly forum and it's all about aiming to promote the health and well-being of adult trans people. We hear from carers around anxiety around their child's future and opportunities in life. Hopefully from today's presentation you can see how much we value consumers and carers like Sue and her daughter and hearing their voices and being able to feed that into our clinic on an ongoing basis. Thank you. (APPLAUSE).

Melissa Fox: All right, well thanks Sue and thanks Dallas. We've got time for two questions from the floor and we've got staff with roving mics and I'm sure that you'll both be happy to hang around during morning tea. Do you have to take off? Morning tea is fine. If you don't get the chance to ask your question... yes, we have Helen down here and one more after Helen. See how we go. Oh, two questions.

Go, Helen.

Audience member: Look, the first one is, Sue if you'd like to comment on what sort of grief and how you dealt with it around the loss of the son you thought you had?

Sue: Oh you see, ironically... well not ironically, I know that's an experience that a lot of parents have and I know that possibly to an extent that's possibly something Paul experienced slightly more than me. I didn't experience it at all. I was super happy as I said in the video from Lady Cilento that I understood what had been distressing my child and I was actually just really happy to have my child back, because I felt like she'd kind of been... yeah, become submerged in feeling really unhappy and so no. It's difficult for me actually when I do peer support, because people speak about that grief quite a lot and it's not something I can connect to at all. But yeah, no, I like her, she's good. She's at least as good if not better than she was before, so result.

Melissa: No other questions? Thank you for the wonderful presentation and a very well-earned award. I've got a question about how the experience for you of moving from being in that situation yourself to supporting others and just a comment about that journey, because it's very inspiring as well.

Sue: Anyone in my family will tell you I'm super bossy and probably have one or two control issues, so when I go "oh look, that's the solution for a problem" I'm like "Oh, hey, everyone, I've found..." not "the solution", but yeah, I'm a bit of a doer and so I guess it was pretty natural and I guess when you're advocating to lots of different people in lots of different environments whether they're clinical or educational, social and whatever, it just kind of felt like a progression of that, because I guess a lot of the role that you're doing already is already kind of educating people or helping them to come to a deeper awareness about what's going on and with gender diversity, because it is something that a lot of people who have no experience of it really struggle to understand that just the gift of being able to talk under wet cement and being able to explain to people what it is, what's that like as a parent, what the concerns are for me as a parent and how I invite, Paul and

I invite people in to kind of help fix stuff. I guess that's probably what I do, but really just my resting state is just being super bossy, so yeah, that helps.

Melissa: All right, thank you. (APPLAUSE)

>>: I think we need to reframe that bossiness to "leadership potential", at least that's what I say to my daughters. Thanks Sue and thanks Dallas.