Understanding physical and hidden disabilities for health professionals and consumer representatives

Sharon Boyce, Consumer Representative- Discovering DisAbility and Diversity

Breakout Room 2- 14/06 1430-1630

Steve: Bear in mind there's no right or wrong way to participate. It's all a learning experience for us to understand the difficulties or the encumbrances that those with an impairment might suffer in everyday life. Without any further ado, I'll hand it over to Sharon. We will stop to have a break for questions at the end. I'll hand it over to Sharon.

Sharon: Thank you so much, Steve. I want to check that everybody can hear. I don't usually talk to the PowerPoint but I particularly thought that today we could focus on that to start with and then link that with some activities. We'll arrange the room as we go through, if that's okay with you all. So you'll be able to help me with a bit of room rearranging too. I'm going to sit back here.

Righteo. I'll hold the mic but I won't be able to turn and face you all the time. Thank you everyone for coming along and being a part of this process which really is an education, understanding and exploration of how we feel, what questions we have in our hands, what we think about disability, how we believe health and disability can over lay and we know that they do. I guess the process for me, and a little bit about my life as a starting point from where we're going this afternoon, started when I was 11 and I was diagnosed with juvenile chronic arthritis. After probably about a year of investigations, where my parents took me to every doctor under the sun where I went from eight stone to five stone in the old version of events, where I went from a kid that had ADD, ADHD, never stayed still for a second, sport was my life and that was what I did, you know. I was the head of the swimming. I was the person who did the basketball, the netball, the softball and my parents weren't around for the rest of the time every weekend. I went from that to a kid who couldn't get off the floor within probably four or five weeks. That was the start of my parents' journey into health and exploring every option that they possibly could for how do we, I guess, support health, life and doing things differently.

From that perspective, that was a physical disability. I then had to think about what I was going to do with my life and I started to think about higher education, where would I study, what would I do, things like that and from that process I then went into look at teaching and education, special needs teaching and all of those areas of, I guess, hidden disabilities and that became my area of passion, looking at things like dyslexia, autism, Asperger's syndrome, what we can understand about all of those differences that people lived every day. Things that we were taught as teachers as to what we should be looking for, what we should put in place, how people would react, what they would do and they were very different to what we were told in a textbook about how people would react.

When I went into a school with all of the activities that I'd set up for kids to understand about disability, my learnings were that I needed to be doing them for the teachers. I needed to be running these things for the policy-makers. They had the questions in their head and they were hungry for information and the kids that I was going in to workshop with, with voluntary mutism, with an inability to speak, engage, were the ones that were coming up to me and saying, can we show you our tuckshop? Teachers, they shouldn't be chatting to you. This isn't what happens and sometimes we were learning so much from those kids that I felt that we had to actually create an understanding and a change in the way that we actually were doing things and that's how this program evolved.

It was from my understanding of what was inclusion. How do we live inclusion? We've just released the becoming ready for inclusion report. From a Queensland Government perspective we have the all abilities QLD plan which lays out how we need to look at policy, procedure and all of those different areas. But it's the lived lives of those people in front of us that we really need to understand and that's where I'm coming from today. It's about everybody's role within this room is different. Everybody's experience is different. Everybody's way that they actually interact with policy that they're asked to deal with, the people that they're asked to deal with, their family members, themselves, the NDIS as it rolls out, how do we actually go about doing those things effectively? How do we encourage people and know what to ask for, as a consumer? How do we know what to plan for, as a person in charge of one of the many areas within health?

You know, what and how does that person in front of us, what exactly do they need? And sometimes it's knowing, is it okay to ask that question? Who gives us permission to ask that? Is it appropriate? What do you think is my most asked question that I get? Every day within the early years context? I probably go into a preschool, prep room or year 1, 2, 3 classroom at least once a month with this program. What do you think is my most asked question? There's no right or wrong answer but I want you to have a go

Audience Member: Do the children ask what's wrong with you?

Sharon: That's - yes. Yes. But that is not the question. This is a question as I'm going through the front door, I probably haven't even got through the front door. Yep. Over there.

Audience Member: Can I have a ride?

Sharon: Do you know what, that is probably actually second or third but accompanied by that, can I have a ride, they've already worked out how they're going to get me out of that chair, where they're going to put me in the room. It's can I have a ride? I'll just put you over there. They throw me around somewhere in their room and you can just sit there and we'll have a go on your wheelchair. How fast does it go? That is probably like a little bit down the track but it's asked every time too. So you're right.

But what is the question when I go into that early childhood centre that I'm asked?

Audience Member: Do they ask you...

Sharon: No. That's too bad for them. Yes?

Audience Member: Can you get out?

Sharon: No.

Audience Member: What's your name?

Sharon: No. They don't care what my name is.

Audience Member: What happened to you?

Sharon: Very similar. What happened to you. But there's one particular, and no-one has asked it.

Audience Member: What's wrong with you?

Audience Member: What's your disability?

Audience Member: I know the answer but I can't say.

It's cheating because I know the answer. They're asking why:

Sharon: Absolutely. That's the first question that I'm asked. For those down the back but I have very small hands, you probably haven't noticed. That's from arthritis. I used to have very, very long fingers. I used to be able to do an octave and a half on the piano for those that know, my fingers, bones everywhere in my body have crumbled. That's exactly what's happened.

So their question, what happened to your hands? Similar to yours, Helen, how come you have those small hands and if you don't answer them straight away, there's no giving up. They just get more polite but louder, "Excuse me, I said how come you have those funny fingers?" Okay. Okay. I've got very small hands. I know but the bones in my body have broken. Oh, is that why you use a wheelchair? Is that why you've got that thing around your neck?" That's when I've got my neck brace on. So they ask those questions. They all come from that. "Can I use your chair? Can we have a go?" The barriers are broken down and as adults we forget to do that. We think ooh, we shouldn't ask that question. That might not feel confident or comfortable with that. It might be considered rude. How do we know to support the people that we're working alongside every day?

That's what I am really - that's my challenge to you today. We're going to work in groups. We'll trial the different activities. From that, you are going to have an understanding of what difference is about. We are then going to come back and we're going to explore, what's your role? What's your job? What do you do every day? How can you use that knowledge of autism, that five minutes that you've spent trying to, I guess, be part of a group while you're experiencing autism, how can you support somebody that that was their lived life every day? How can you support someone whose challenges of perception, a mirror challenge is one of our hardest, how can you feel when you've had a go at that and how do you bring that knowledge to your role and what you actually do? So that's what today is about.

How many people here are consumers today? Okay. That's a pretty high percentage within this group and if we can educate everyone alongside of us and take them through on that journey of understanding, we are really going to be able to make an impact on - as a state, what QLD can do and show case. How we can actually get people to know that it's fine to ask for access to things like into the NDIS, how do we do that, how do we find out that information ourselves, how do we link that knowledge because knowledge is power and by understanding those key areas, we can progress forward and make a difference.

So what I think I'll do, I know I've got the PowerPoints up now to go, what I think I'll do is we will very soon get up and start moving around and trying all the different activities so we then have something to come back and actually see to progress through to, I guess, have questions in your head about how you'd like to do stuff, what might work, how it might work, things like that. Before we get started, I'd like to ask if you've got any questions first up about what we're doing or anything, anything that you want to ask. There's nothing off limits.

Audience Member: I agree with you. When you're dealing with a person with a disability you have to break the barrier in communication but don't you think that the question varies from a person to another, especially people from different cultures. It has to be holistic. Talking in this area and coming from a CALD background, I wouldn't be able to ask a person from my own culture this question. It is very sensitive and offensive.

Sharon: Yeah. Okay. You can go and sit down. Thank you very much for your help. What was your name?

Audience Member: Odette.

Sharon: She asked a question that is physical in our - if we look at diversity and the CALD background is an area that is absolutely, I guess, so complex in how we actually do - do things and how we do them effectively within health and within the NDIS. I was sitting on a table with a group and exactly that issue came up because often within a lot of communities there's questions that you can't ask and then there's questions that as a woman you can't ask, as a person who is a friend or relative you can't ask. There's so many rules, I don't know if I can work out what they were and you can't and that's where you've got to find out and you've got to make sure it's such a sensitive area that those supports are put in place to actually help, because you don't want to be the person who goes in and instead of helping, you hinder the process.

My advice in that area is be very careful before you make recommendations. Research the area incredibly well. It's the same too, if we're just talking about a general population, it's all very well and very easy for me to say, oh it's fine to ask me questions about disability, how I feel, how I might approach things, but my life, from memory, when I was 11 when I was diagnosed with arthritis and I thought, this isn't going to mean any change to me or my family, never knowing that the changes would actually mean to me and my family and my sisters and all of those supports, if you think about those processes for a person who has had a car accident and one minute they're perfect, the next minute they can't breathe. How do they deal with that anger and resentment and all of those processes? For some people it's absolutely fine. For others it's very difficult.

You overlay all of the layers of culture, language barriers. I'm working a little bit within the Indigenous communities as well and the access points. My friends who have disability in their family in the Indigenous communities, so often their families just look after them and there's a low acknowledgment of disability. It's not seen as a disability. It's just a different way of looking after family. How do you put those things and tell people, you've got to ask for some help and it's like, no, we're not going to ask for help. We do it. We love the person. But it's your entitlement. Yeah, you don't need it. You can have all those arguments and I'm not saying any of them is easy. I'm saying if you acknowledge they're there today, then we often can get to a point where we can put supports in place. We can say oh, that's working for us and give examples from other families where things might be working. I think a lot of families that I work with, where kids have dyslexia or reading perceptual problems in schools and the teachers often have said to the parents, we see that there's a little bit of a problem here with your son, he's having difficulty with reading, but no, he's great. The teacher sees it as a problem. The parents often, because dyslexia is often genetically passed on in families, will often have dyslexia themselves. They've overcome the difficulties. They see the gifts and challenges but the way things are done differently, they don't see the negatives.

So often as educators we've got to look at different ways of supporting difference within families and instead of labelling, seeing it as a disadvantage, we can offer more perhaps a different way of looking at that. I used to be a person that said, we should never use labels. We should never look at that, but I went to a workshop in a conference similar to this and I had someone challenge me and say, if you had a pantry full of bottles full of some sort of white thing that looked like sugar, how do you know what you were going to make if it doesn't have a label on it. If it isn't identified, what you are using or how it is used together.

I haven't really thought about that, I think it is true, but I think it's important to see those things not as negatives but what works together to make our community rich and how we can work together.

Audience Member: It's true there are lots of challenges but you don't want them to turn into barriers. Quite often I'm talking to someone, say a therapist, and it's a teacher who is good at teaching and that's what I want for my child. My child and I are the experts on how they learn and what they might need and the education process. If you don't have mutual respect, the communication breaks down. Language is so powerful and the language thing is really interesting. I was looking at the handouts and there was some stuff on understanding students with autism and most of those strategies, that's what we're talking about, are very appropriate for kids with hearing impairment as well.

Sharon: Absolutely.

Audience Member: Labels are useful for going to the next pantry, for strategies on how to cook with those things that were in the first pantry but bear in mind that different strategies will work for different groups and the same strategies won't always work with people in the same group.

Sharon: And people change and people move forward and we need to look at life long processes and the way that we can -

Audience Member: Talking to someone Indigenous or different, I think the first thing to acknowledge is that's not your area. I don't understand your culture, please help me. That again is respect.

Sharon: Yep. When we're looking at the cultural thing too, respect is the key. You'll notice that both two of my carers, Depa and Mary are both from Nepal. I have learnt so much from them and that link between care and nursing and their study and the way that they work with my Australian staff, we have ma rea as well. The respect, the processes of learning and the differences within those areas because, I mean, Mary is a nurse as well so the whole over lay between health in a different country and health in Australia. There's so much to learn.

One quick question before we get into the activities, if there's anymore

Audience Member: I come from Mount Isa. It's not actually a problem that I personally have but I'm hearing that as our disabled youth reach 17, they can't be treated in Mount Isa any longer. They have to be sent down here and it just seems so unfair that you're not a child anymore, you go to a new level of needs and the parents have to bring the child down here. It just doesn't seem fair.

Sharon: And I have to say, I haven't heard of that but that to me is something - I'm on a charity of a disability council. Can you enlighten me a bit more?

Audience Member: We have some really needy people. It cost them so much to bring their sons down here for treatment. That would be great.

Sharon: I also have to say from that perspective, 17, 18 and you've been living in a community where you've been supported, they would probably feel very scared. Coming to a new community, a big city and also not just the cost, just the whole emotional thing could create major problems. Let me see what I can find out about that.

Okay. Obviously I've been talking for too long but what I'd like to do is all around the room are different activities. I'm going to get another two tables in here because we've got more people than we thought we would have but I want to make sure that everybody tries every challenge and I particularly want to make sure that everybody tries the autism and

Asperger's challenge which is over on that side of the room and that's the tape recorders and the CD players and the gloves, et cetera. Then the mirror challenge which is next to that is all about perception and the way that we see and the way our brains work and the way that we actually see life and I want everyone to have a go at that.

We also have down the front here a canvas. I want today all of you to put a hand print on that canvas. There's heaps of different paint and colours and the toilets are just outside there. You've got no excuse for getting paint on you but I'd like you to also write, there's some permanent markers there, just a statement or a comment or something that you have had come into your head while you've done the activities today about health and disability, anything. If you can't think of something, just sign your name, because your hand print is what's unique and we're going to give that to Health Consumers QLD to hang in there for you to remind them about what you've done for diversity today and the difference about inclusion. Okay. Right.

Now, I'm hoping that everyone can see me and what I am going to do here and Mary, if you can come down here first. We're going to look at this table and tell you what you've got to do here when you come to this table. I'm not going to take a long time to explain what you have to do because I think it's fairly self-explanatory. This one here. Okay. This one here is about vision impairment. Now, I'm sure you've heard about glaucoma, cataracts, myopia, all of those are simulated from these different glasses. What you have to do is put on a pair of the glasses, a pair of the goggles or a set of the cardboard glasses. Probably try them for a maximum of one minute. Try doing a dot to dot. Mary just hold it up. Or pull out your mobile phone and see if you can text somebody while you're wearing the glasses. Don't work out what you're going to do before you put the glasses on. Put the glasses on first or the goggles. The goggles are just another more severe type of the glasses and they're smaller if the glasses are falling off your head. All of those, try one or two of the vision impairments. You will be able to see with them. I don't want to see, I can see perfectly. That's not the challenge. The challenge is when you've got cataracts, can you still do a dot to dot? Can you still use your mobile phone? Can you still play a computer game? That's what it's about.

The next one is around being totally blind. You are versing a partner and both of you put on your blindfolds and stand like Depa and Mary and you'll play connect 4. The yellow counters have a sticker on them, don't they, Mary, can you feel a sticker on that? Okay. So the yellow ones feel different to the red and then the partner puts the red ones in, then the yellow and the red and you have to get four connected in a row. Just like you normally play but you can't see the colour, you can only feel the colour. We usually play naughts and crosses but I thought we'd have a go at connect 4 today and see how you go.

Around the table we have our wire challenge. This is a physical disability challenge. Four of you in your group using your nondominant hand, your hand you don't usually use at all. You need to turn it on like Mary is showing you and then - you don't want to hear that sound (computer game sound). You don't touch the metal. It's all about your coordination and you're using your nondominant hand. So you're making it very difficult to coordinate and pass that through. When you hear that sound you're out (computer game sound). So four people are playing it in a row and see how you go with that. If you really want to have another go, just try and start again and have a go. That is about physical fine motor challenges.

Then our monkey challenge. You choose one coloured monkey using your nondominant hand and link four different coloured monkeys in a row. This one essentially is about patience, whether you can do it and not give up because I have some going, I'm not playing that, chucking them everywhere and other kids who just keep on going. No trouble at all. It really depends on how you approach things as well. How are you feeling, Depa?

Depa: It's hard.

Sharon: It looks very easy but it's one difficult challenge. Okay. You've got the idea. Now, this table here where I am, I think we've just got the - yeah, do that one. Okay. Now, I'm sort of trapped here but I can talk. I'll do it this way because I've got to go around the front then. This one here where Marie is. This is a fun one. Everyone at the end of today, when Steve gets you back over to your chairs, is going to come over with a lolly bracelet on their hands. They will have done that all one handed. They'll cut the string, open the packet of lollies, thread them on with one hand and then tie a knot with only one hand and have that on the hand. Physical disability? Fine motor. Next stage on from the wire challenge.

Okay. Then around the table we've got the jumping frog challenge. What you've got to do is put the frogs out in front of the ponds. That's the yellow and red pots. You're going to use a pencil pointer but you're not using it in your mouth with this one. Using your nondominant hand, use that to jump the frogs into the pond, see how many you can get in your team, going into the pond. It actually is pretty hard on the table cloths, compared to usual.

Then we've got - then our next one is this one here, our play dough challenge. You need to, using your nondominant hand, open a pot of play dough one handed. Nondominant. Marie is waiting to get in to play with the play dough really. Okay. Now you're going to open that up. Take out the play dough and then you have to make a play dough face of someone in your group. A little artistic. You can only use the implements that you've got there on the table and if you like you can take a picture of it and send it through to me. I'll have a prize at the end of today of the best - it can be a group, comment, whatever you want to message through to me on my phone and the prize is my dyslexia book but I have to take your address and send it to you because in the hotel I didn't bring it today. So if you want to, as you're going through, if you think something is really worthwhile send a picture through and I'll put my phone number up on the board a little bit later.

We have our speech language challenge. One of the hardest ones there. If you hold up the board, Marie. In your teams I want you to deal out the cards and play go fish. The difference is you cannot speak at all. If you speak, you're out. The only thing you can use to communicate is the communication board, there's two of them in front of you, and by using this communication board you can play the game. The rules are on the table and see if you can actually manage it. I guess I didn't see the real struggle of not having words because I always had used words and while I couldn't use my body, I could use words and I never felt a fear that there was a time that I wouldn't be able to but two years ago I actually had to have emergency surgery, was in a coma, had a tracheotomy put in and didn't know that it could be reversed and thought that I was never going to be able to speak again. That was probably one of my most fearful times because I couldn't explain to anyone about my body, what was happening, how to do things, why it was happening to me and I remember when they actually put the speaking valve, those of you who know a bit about them. Does anyone here know if you put a speaking valve on you can then speak with a tracheotomy. The OT or speech therapist, I guess she came to my bed after I came out of the coma, she said I've got something you might be interested in trialling today. She put it on and I went, oh, I never knew you could actually do that. She was like yeah, didn't anyone explain it to you? I was like, no. That's one of my real, I guess, agendas in health is to, I guess, give a little bit more explanation about tracheotomy and the scary things that can happen within that and the amazing things of having that speaking valve and being able to do things. Once I knew you could actually get a spare one of those, and I also had the rule you had to take it off at night, well, in my hospital the notes, Sharon refuses to have her tracheotomy valve taken off. Sharon refuses to have it washed. Literally I wouldn't take it off. I was terrified because I had no voice and it was such a scary time of not being able to speak. So try and see if you can do that challenge and really see if you can survive without speaking for five minutes. Scary and hard.

Okay. Let's have a look over this other side. Now, the activities over this side, as I said, are probably and of the most important ones. This one here is quite a fun one. It's a race. We might get - can we get four volunteers here for this one? Do you four just want to step up for this fishing challenge one. What you have to do is put your hand you usually use behind your back and then we're going to have a race. What you've got to do is you've got to - when I say go, pick up the fishing lines and then we're going to go through and you have to pick up all the pieces, flick them out the side and then you have one piece back in the tray with the fishing line off it to be the winner. Okay. So on your marks, get set, go. Flick them out the side there. Come on. Put yourself under pressure. Try and go as fast as you can. Come on, come on, come on. Actually you're all going very well. Remember it's one piece back in the tray with the fishing line off to be the winner.

How are you feeling?

Depa: It's nearly there.

Sharon: Yay. Give her a clap. How did you feel though when you were trying that and - yeah? I noticed you were looking around each other too. How everyone was going, comparing yourselves, all of those sorts of feelings I want you to think about while you're doing them today. Okay. Now, the next one around, you've had a farm accident and you're only allowed to use your amputated arm when you're doing this challenge. You've got to try and put the scissors on to the paper in the right place, either chop out one of our websites, look at using the curvy line with the scissors, however, and whatever piece of paper you want to try but you can only use that one part of your body.

You can hold it with your feet, mouth, however you want to go but give it a go. Okay. Then we have our two hearing impairment challenges around on that left-hand side. You have a lip reading challenge - okay. The shaking boxes challenge. You've got to try and listen to the sound. Don't look at it underneath. Bad girl. The reality of this one is you are trying to match boxes, match sounds. It is really tricky because you think you've just got it right, put it out and it all goes out of control but they do match and Mary was right showing you on the bottom. Put them on the table in pairs what you think and check that you're right. That's about hearing.

The next one too is about lip reading, linking that to hearing impairment. What you've got to do is look at the boards and in pairs, test each other. Mary, give us one of your board, like say it with your lips and not in words. Yeah. Perfect. Depa you do one. Say it again. That's very hard. Do that one again. Did anyone get that?

Audience Member: Tree?

Sharon: Dog. So D. She just said the sound. Okay. So that one, testing each other how you would do something like that. Then we've got our two physical challenges here. Try to get with your nondominant hand, yellow balls, blue balls, a challenge you can do regularly with both hands. Try it with one, see how you go. Don't even think that one is going to be easy because it's not.

Okay. Our mirror challenge. Now, I want - yeah, you can try that one. You've got to try and get that ball into the basketball hoop and you have to then hear the cheering and everything that happens when you make it worthwhile. She won't even be able to show you what the cheering sounds like. It's not that easy.

Okay. Let's look at the mirror challenge. Now, you three girls - or four girls, if you wouldn't mind just standing along the side where Mary is and I'm going to get a new volunteer. Everyone is looking away. Just because I don't know your names. Would someone like to come up and have a go at the mirror challenge? Excellent. What was your name?

Audience Member: Anne.

Sharon: Anne is having a go. Thank you, Anne. Mary, take away one of those mirrors and we'll put them on another table anyway. We're going to make sure we have a couple of the mirrors out. Anne's job, can everyone watch and make sure you can see what Anne is doing because Anne's job is to grab a pen in her regular writing hand. She's going to have a partner and that partner will stop her from looking down at her picture but her eyes have to see it in the mirror. Can you see your picture in your mirror, Anne? Now, you need to trace around the outline of your picture down on the table. Tracing around the outline. Can everyone see what Anne is doing? If you can't, just stand up. How are you feeling, Anne?

Audience Member: Careful.

Sharon: Is she going okay, Depa?

Depa: Yeah.

Sharon: You guys can jump up. Can you see? This is one of our hardest challenges. Feeling a little bit messed up in your head, Anne? We probably chose the one person in the room who can do it. I'm saying that in every group, there's probably two or three people who will be able to do this challenge. They won't feel - very slowly, yes. They won't feel the same as the rest of us who went oh, I tried to do it and it's not because of my arthritis, I can't even get the pen to start on the piece of paper. I look at it and it just - I can't do it. Yeah. How are you feeling, Anne?

Audience Member: Certainly I lost it.

Sharon: Yay. I want everyone to feel like what Anne just felt like because do you know what, the more pressure that you put on yourself, the worse it gets. The goes out of control. The more that we actually think that we are helping people sometimes, the more we go, just do it this way, guiding them. If we took a step back, it often would work so much better. I want everyone to have a go at that.

On the table is a pink piece of paper. I need you to fill this in and some yellow and then put it in your pocket and we'll talk about it at the end. What it actually asks you is how did I feel, one or two words. Try not to put too many bad words because I'll ask you to read them out, what they are. I want you to really put down how you feel. If you felt like it every day, how would you like your day to be changed, supported. This often works with people with cerebral palsy. They're so bright. They know exactly what they want to do in their head, when it comes to people putting pressure on them. My friend gets taxis a lot. When they go, have you got your change ready, she opens up her purse and it goes out of control. If no-one is rushing her, she can do it quickly. She can speak perfectly. It's all about putting pressure and how that affects people as well. That's our mirror challenge for you.

Then on the next table is our autism challenge. We have two of them on either side of the table. Eight people can play at once, four on each game. What you have to do is you have to put your headphones on. You have to put a pair of glasses on. You have to put a pair of gloves on. There's a yucky smell on the table and you have to press play on the CD player and play the game of snakes and ladders. I know there's a lot to think about with that but it's very self-explanatory. What exactly is happening is you're altering your sense of touch, the way you manipulate the space in front of you or the way you feel stuff. We're altering your sense of vision by you wearing either red or purple glasses or something that's going to distort what you've seen. We're using big dice and tiny, tiny little counters. So even the perception of what you're holding and counting.

You're also - you've also got the yucky smell which particularly will hit with autism, often affected by smell. It comes to morning tea and they'll be hyperactive. You think, they've eaten something at the tuckshop or something is weird. Often no, it's the smell of sweat and Vegemite sandwiches and all the stuff that happens in a school. Or adults will go oh, that stinks and you think, I've just put on my favourite perfume but they're so literal and they'll just say it and they won't mind. So how do we understand and how do we think about how we do things better to support and work alongside someone who has autism or Asperger's syndrome.

There's a sheet on the table for that one as well. I want everyone to fill in a yellow sheet and put it in their pocket. Thank you, Steve. I've got my own situation happening here. Marie is holding down the back one of our white canes. Our other vision to loss activity where you have to partner with somebody, put a blind fold on, using the white cane follow the sound of that person's voice to find where they are. I'll work a bit more closely with you with that activity and then we have two wheelchairs, where I'm going to work with you to do a number of challenges in a wheelchair as well.

So what I'd like you to do, without further ado, we've also got a game of darts down here, one handed darts, and a game of one handed ring toss down near my hoist down the other end. If you get time to do those, that's okay. My absolute desire is that you do the mirrors, the autism, the canvas and the different vision issues and the wheelchairs. If we can get through all of those today, I'll be absolutely happy, but if you want to try something else or interlay or over lay a number of the differences, feel free to do that as well. Okay. I want you to get into a team of four and go straight to an activity that you want to focus on and I want you to stay with that team of four for the whole next hour. Okay. Once you're in your team of four, straight to your activity.

(Group activities)

Sharon: How are you feeling? You've got a minute to go.

Steve: Everyone ready to provide some feedback back to Sharon? Take your seats, please.

Sharon: Okay, guys. How's everyone feeling? Now, don't just curl up and go to sleep because that usually happens, that people feel very, very tired because you managed to try all of the different disabilities. You engaged with whatever it was. In most cases could you do it?

Audience Member: Sort of.

Sharon: Sort of and yes. Of course you could but was it a challenge and yes, that usually is how you'll answer that. Am I right?

Audience Member: Yeah.

Sharon: It was hard work. Yep. You didn't want to give up on some of those things. If I think about hidden disability and looking at the outside of somebody, you often are not sure exactly how that person would be acting or reacting in the way they're processing that information and I'll get more specific about that pretty soon, but before we get started, I just wanted to quickly have a look through a couple of these slides.

First of all, I should just give you my mobile number if you do want to message through something before the end of, like, the next 20 minutes. Has someone got a pen that they could write that down? Steve, maybe you can write it on the piece of paper up there. See that big piece of paper up on the lectern. We'll grab a pen. By the way, this canvas is looking fantastic. Look at that. Steve even added a little bit of scribble on to the canvas.

Steve: That was my signature

Sharon: Well, they can make that into a hand print later on. 0417 708 94 5. Now, if you've got a picture and want to send that through, or if you've got a comment about today and what you think disability or health or inclusion, one word, one comment, something that's going to make me think oh, they've won a copy of that book. If I have a few really good ones, I might choose to send a few out but I will just message you back, if you're one of the winners this afternoon. So that's the phone number 0417 708 945 and then I thought I should also look very quickly at some of the PowerPoints, just to let you know, I guess, some of the things that I really look at what is important in life with the people that we're looking at. Looking at who you're supporting. Letting the person know what's happening. Increasing a person's self-worth, breaking down barriers, taking away fear. Who felt a bit scared trying some of those challenges? Yeah. Found it not always easy. They sometimes make you feel a little bit sick, uneasy. You imagine then if you're trying to communicate and take on board stuff that is about life and death and a way forward. We need to think about how we can make a community feel supported and also think about safe clinical practices, the back drop behind what we're doing.

We need to look at real understanding. What actually is happening for people? Look at policy and health. I think really importantly being fair and equitable and giving everybody a fair go at life. It's, first of all, their life and looking at a shared approach to health care and the individual in all areas. We don't need to really look at my stuff but I just put that in as a back drop between the importance of communicating with people. Fear that can happen if barriers and understanding is not clear from all sides of a health journey. So knowing about what's happening for ourselves, the people that we are supporting, the disability that they have, the differences, the diseases. Even how wrong information that's passed on in the process can create such difficult circumstances when hand overs and change overs within hospitals are not done effectively.

I'm not going to worry about that. That is just the background of the work that I do and the roles that we all have and how some people have fear of being treated differently. People not wanting to actually tell and disclose that they have a difference but they're living that every day and I want you to think now about how you felt when you were actually trying the autism challenge. How many people can say that was something that they found very confronting?

Audience Member: Distressed.

Audience Member: Shot down.

Audience Member: Overwhelmed.

Sharon: Who just wanted to take their headphones off and almost like shove them and walk away?

Audience Member: Rock in the corner.

Sharon: Yeah.

Audience Member: It made me aware what I do have and made me more grateful.

Sharon: That's absolutely correct. You know, for so many of us and so many kids that is the everyday that they live. Adults have often overcome those feelings of fear, disempowerment, but when they come to a situation where all of that is happening and it's all closing in on them, it starts all over again. But you often hear about kids that are on the run, they don't want to be part of, they've run away. That is why. Yeah.

Audience Member: I feel like that and the first thing I do in hospitals is I get all cold… in the wards they have the airconditioning on freezing.

Audience Member: I've never forgotten one person telling me the start is start and the staff need it at a certain temperature.

Sharon: It's all very well for them but it's the patient they're supposed to be focusing on in the hospital. I have to say too, how many people reacted to the smell over there, the really sweat air freshener. For some they can't stand it, it makes them feel sick, linked with the sounds coming into their heads, the messages that are wrong. If you felt like that ever again, how do - or what would you like to be done differently?

Audience Member: I also felt when she'd done it, what would you say if a child did that at a certain age, if the kids talk and that, every day if they drew like that, why would you bother drawing.

Sharon: That is absolutely it. If you saw everybody else who could do it and you couldn't get the pen to start on that piece of paper, what self-esteem do you have? How confident do you feel to be able to give your approach and your reactions to things? Who had someone beside them who was very kind and was nice and said, are you doing quite well? That's great. Politely sitting next to someone and they go, oh, that's not very good.

Audience Member: It's like having someone going, hurry up, it's my turn.

Sharon: If you had someone like that every day, what would make it better? Obviously people not saying that. We don't want to have time limits on what we do. We need to take the pressure off a person. If we ask them to do something and tell us something, we need to give them time to actually tell us what those things are. What are the answers? How would it work? How could we feel better being in that icy cold room with the airconditioning up and someone saying, come on, I've got to fill this form in for you. We need to have all these answers on here before we can progress. We're never going to get this stuff up to let them know what's happening for your food tonight.

You might not even feel at all like eating and having any food by the time you've had all that stuff happen to you. So it's a matter of what is going to work for people. How many other people would say if they were trying the headphones, the autism and experiencing that hidden disability, what would make it work better for you? How would your every day work better if that was happening?

Audience Member: Empathy.

Sharon: Absolutely.

Audience Member: And support, understanding.

Sharon: Understanding. In front of you is a person first and foremost. They have a diagnosis probably, if we're looking at it within the health system. They need a pathway forward and you need to put in place certain procedures but if you don't understand that person first, nothing's going to work. So it's so important that if we're looking at anything within our area at the moment, as health consumers and the whole of QLD in that process of the interface between NDIS with health, disability, education, all of our CALD communities, the different processes between all of the ways we are doing stuff, if we don't have an education, if we don't have an understanding of what, first of all, the difference is, we can't progress anything forward to make a difference.

We need people to want to go and support otherwise it will fall apart. If we don't - apart. If we don't look more at mental health. If we don't look at some of those areas of dementia, Alzheimer's, how they are impacting on health earlier and earlier and the areas of autism and Asperger's, where we're just clumping people together and saying, we're unsure about that. They don't look any different to anyone else. Why are they expecting this to be able to support them? Our society will fall apart. So my challenge today is how do we do it better? What did you feel today? How can you then create strategies for - to make solutions, to make those things work, because I was talking up the back to a lady and none of us know how we're going to change, what impacts are going to happen on our lives. Disability comes to all of us in some form, in some way in our lives. Never when I was diagnosed when I was 11 and we searched all across Australia. We tried every strategy. I did all the drug therapies. I did all the natural therapies. I went and saw Lady Cilento when she did all her egg, yolk and orange juice and my mum took me along. She had this teenage daughter who was, I'm not going to listen to anything she says and now I'm hungry for information on new therapy, on new ways of using medicine, on different ways of doing exercise and holistic health as well as every medical drug there is as well.

Audience Member: Do you think that we need to start with education? And education of the parents? I'm just sitting here and thinking at a time when I was on Facebook and there's someone I know that's desperate. She gets on Facebook and says, what do you do with NDIS? Where do you go? There's no-one to help me. Maybe you need to go even further back and somehow put some education into them so these parents don't feel helpless.

Sharon: I'm passionate about it. I see that parents who have kids with so many levels of autism, where people or they've not even got a diagnosis and people don't know where to go and how to go and what we should be doing and I know there's not enough people who know the system but we've got to go back even further to look at why things are happening and I think that people think very simplistically about experiential ways of understanding but I don't believe we can have any other way, apart from a very early starting point because we all jump to conclusions. There's no telling me that when we don't look at the outside of somebody, we automatically come up with ideas of what we think they can and can't do. We put barriers on them. We put a box around them.

When we hear about mental health issues, when we hear about schizophrenia, we really have no idea. We all need to be educated about all of the different types of disabilities. Physical disability is probably one of the easiest that we can, I guess, create answers for because we can put some funding into it. We can put a ramp in. We can access a room. Those of you who use the wheelchairs, thank you for trying that. They were quite challenging because we had a small space. We had things accessible outside but they were still difficult to deal with and it wasn't easy. But when it comes to emotional attitudes and people's reactions to us in the wheelchair, people's reactions to us in every day life, what you may and may not be able to do and people who automatically jump to conclusions.

I love one of my favourite things that I worked with was a young boy with Asperger's syndrome and his principal said, he won't join in. Don't be worried. Just treat him like any of the other kids but don't try and engage him with anything because he's not going to be chatting with you. Well, Michael who was working with me was talking about the fact that, you know, we all have different gifts, talents, things like that. He said, you look at Sharon and you probably think she doesn't know a lot about computers, what might make something fix. He said, also my pHD I had to have everything sent through to my supervisor. The whole computer froze. Sharon came into my office and she pressed one button and the whole lot started again and I sent it through on time. This little boy had not spoken through the whole of the day diversity at his school. He said, excuse me Michael what button did Sharon press? That wasn't what was asked. The principal looked at us. I said, well, it was an Apple computer. He said, I knew it had had to be an Apple computer. It wouldn't have worked on any other type of android device. An Apple one would unlock it and send information. His passion was computers. That gave him the ability to have a voice and he was voluntary mute. He did not choose to speak in school because the environment was too much for everything that was happening inside his mind. That's where we need to not put limits in people. How can we engage kids, support parents, create pathways with the people we are working with every day, whether they are old or young, whether they have a physical disability. I am on the Board of QDM and a lot of that stuff is about different ways of intellectual impairment, different types of psych social. I also work with physical Disability Australia. There's no end to the areas you can work if you are given a chance where people don't put limits on you and where you see there's an actual solution to put things in place.

That's my challenge to you today is think about how we can better educate our networks that we work with as consumers, as advocates, as people in the position of making policy, of putting those things in place through our communities and going back and working one-on-one with the people that you love and care for, because that's the reason why we're doing it in the first place. Then thinking about how we can do it better. I don't want people to think they've got to chuck NDIS aside or believe the stuff they hear in the media because I know that it actually works and it works incredibly well but there's some stuff that's not working for people and we need to acknowledge that as well and I know parents that live in absolute fear of what's going to happen with their kids especially, but with adult kids and the whole age parent carer area and I just would say, I can't take on everything but I'm a Chair of a disability council. I want to hear that stuff and I want to see where we can make a difference in those areas.

If there's information that you want to put forward, talk to Melissa and she'll share that stuff with me. I know there won't be any problems with that. If there's questions that you've got and pathways that you think we can progress stuff forward and do it in a better way, don't just send all the negative problems because I don't believe anything will get helped with that, but if you've got a solution, we can try and put those things in place. So I put my disability council hat on. I don't usually. I usually only speak from a personal perspective but I do think as a group you've got so many gifts that you can actually share and I don't want to lose any of those today. So go home, think about all the stuff you did today and maybe how you can utilise some of those ideas that come into your head to support those hidden areas especially.

I didn't get to show the rest of my PowerPoint. If any of you want to, I could put it on - and I've got like my life, background and just some of the work jobs I've done before you go, but I will have to close and if you want to stay, I'll put it on. Okay.

APPLAUSE

Steve: Thanks, Sharon, for a most challenging and up lifting session. I'm sure you would all agree you've never been to a forum or a conference before where you've been challenged in this way. Hopefully that you've taken some learnings away from that and you'll share -

Audience Member: We've all got bracelets.

Sharon: Really good to see. Put your bracelets up, guys.

Steve: Even some of the males have a bracelet on. That's good. It's about inclusivity

Sharon: We've also got certificates for everybody as well.

Steve: Are there any quick questions? We've got time for one or two questions and then I'd like to invite you to join the Health Consumers QLD for a soft drink or alcoholic drink perhaps. Don't tell anyone I said that. You're welcome at 4.30 out here in the concourse and then tomorrow, of course, we've got another very, very full agenda and I'm hopeful that you can all be here again tomorrow. We've had 325 participants. Isn't that great? This is our third conference and they seem to just get better and better. Would you all agree with that? This session alone we had 40 participants and Sharon was saying to me earlier that she wasn't sure whether we'd get 10. There you go.

Sharon: Really, really good.

Steve: Lastly, I've got a little gift here for Sharon. It's just a token of our appreciation from Health Consumers QLD. You're not on a diet, are you?

Sharon: No, no. Can you imagine I'd be on a diet?

Steve: Otherwise I can take it home

Sharon: Isn't that kind-hearted of him to offer. I don't think so.

APPLAUSE

Steve: Are there any questions? A brief one here

Audience Member: Hi Sharon. I'm James from Arthritis QLD. One of the things our consumers ask us is arthritis is one of those conditions where it can be... particularly for younger people now that we've got new treatments that have emerged. An issue we find is although it's a physical impairment of sorts it's the workplace in a 9 to 5 job isn't necessarily appropriate for people with profound -

Sharon: Yes?

Audience Member: We get a lot of people calling us and inquiring, how do they approach that. How do they deal, when they're not being treated well, they ask for 15 minute breaks every hour and they get denied or their workplace sees them as lazy. Have you had any experience working in - or how to help people in the workplace? We try four methods and explain that. Sometimes it's giving them the tools or conversations they need to have.

Sharon: I actually think that. You're right in the fact that everybody is different within that process. When I first probably started working and my first job was working at the University of Queensland and doing tutoring one-on-one with students. So I could make my own timetables and things like that. When it started to come to lectures and I was working with lecturers and having to do marking and having deadlines of marking, I felt that people were putting limits on me. They were thinking, and I worked with some of the best people and some of the lecturers gave me the best chances I could possibly have, it came to marking sometimes and I'd say, yeah, I want to do 10 classes and I remember my lecturer saying, well, that's actually going to be 300 assignments you've got to have marked in one week and three lots of that through a semester. Is it possible?

I go, yeah, of course it's possible. I want 10 classes. He'd go, it's not possible for me. I have no disability and I've done it for 20 years. So the reality is that a person like me absolutely pushed myself to prove I could do it and a person with a disability should not have to do that. The reality was it wasn't good and I was so lucky I had people who looked out for me and I was sensible in the end but it really did challenge me to think about that sensibly. My advice would be that you have to think about the situation. You have to equip people with the fact that it's best to share their story but in my PowerPoint often people are scared to share their story because people will then come up with pre-conceived ideas and judge in a different way. So it's a catch 22 sometimes.

I do find often that by getting into a workplace first and then sharing, after people know your track record and your credibility and your absolutely desire to have a job and love that job, it doesn't matter though when things go wrong sometimes. What I mean is it doesn't matter and make any difference when things go wrong, you really do have to discuss what's happening and I think it is important.

Steve: One quick question. Yes, sir

Sharon: While we get that last question, Mary, can you just hand out the evaluation forms to everyone, please. When you come out the door, we've got a certificate as well for you that really you can put in your resume and things like that for disability awareness. Keep that and if you need more information, you can do that. Last question.

Audience Member: A question and a comment. The gentleman regarding the people that ring the arthritis foundation. People ring you concerned about their workplace and the fact that they might need time off, 15 minutes every hour, I just want to know what people think here. I worked in the disability sector until I became totally impaired and disabled. I'm a classic example to someone who doesn't have a major disability but I do. Anyway, one of the solutions - one of the many solutions I offered employers was that they could be on a productivity-based wage and a supported wage system. On occasion I had a sheet metal worker who knew his output wasn't the same as his co-workers and he felt terrible about that and he approached me. He said, "Can you arrange for me to have a productivity assessment, so that I get paid for what my output is". What do you all think about that?

Sharon: I like that idea. I know that the person that was completing that job would probably get a way, way better wage in most cases because I know that people with disability give 110% with any workplace where they're asked to actually perform a job and I think that arthritis is one of those disabilities and often it is a disability but with a lot of new drugs like Shamira and a lot of methotrexate they worked incredibly well for my arthritis but for the rest of my body I ended up osteoma, with being in a coma, with ending up with septicaemia. They were way worse than anything else I could have possibly done. I think that sometimes those hidden side of things need to be really - something that we're educated about and I think that the arthritis foundation, while they Dodo a very good job, they could do a better job about the hidden disability side of things. It's huge, the impact it has on people and the interface with the NDIS, how do we capture that if we don't have good rheumatologists and doctors and people to talk about those issues.

I know that as a group you all have amazing abilities to work for stuff that you actually have to share back with consumer groups to educate - every day you're educating, aren't you? We have to take that further and actually, I think, raise that awareness level and put it across the whole state.

Audience Member: Sharon, just one more last comment. From my 20 years helping people with disability into employment, into accommodation, into the community, what I found is that people with disability in the workforce were the first to be asked to leave because often times they were regarded as a - assured because their productivity wasn't up there with the rest of them and all the co-workers would say, I'm putting more output than them. More times than most we have to negotiate a productivity-based work because it is better to have a job than no job at all.

Sharon: So they made more money, is that right? Yeah. One final question.

Audience Member: ...

Sharon: Absolutely. I have to agree there. That's where if we look at activities like this, we can say we really have no idea how you feel every day but we tried this and it was five minutes and I don't know how you live that life every day. You then are engaged with that person and you have a way forward. It will work. I guarantee you. Give it a try and don't give up. Okay.

Audience Member: ... the language is so important.

Sharon: It absolutely is.

Audience Member: The number of people who don't know how you feel and...

Sharon: You're like no, you don't.

Audience Member: The judgmental things like, oh, she's only hearing impaired. She's not vision impaired. Actually, she's both but people only choose to see.

Sharon: Nobody is living that life but what we're doing is hopefully supporting, empowering. We're trying to get a handle of it and moving forward. People assume I know everything about disability. The reality I've learnt so much from the people I work alongside because they've shared their story and that's what we need to value from people. So thank you for coming today.

APPLAUSE

Steve: Thanks to Mary, Depa and Marie for their assistance. We'll see you tomorrow

Sharon: On your way out, if you can hand those to Mary, she'll give you a certificate as well.