

*Sidestepping tokenism: Building a dynamic mental health
consumer group, Wide Bay Partners in Recovery*

BRENDAN: I'm Brendan Horn, I'm a member of the board and it's my job today to introduce this session. And this session is on side stepping tokenism, building and dynamic mental health consumer group and it's been presented by Sarah James and Evan Fulton. Sarah has worked around the disability area and mental health area, both State and non-Government profit organisations for a considerable time. She's with the primary health network in Wide Bay as the partners in recovery coordinator and Evan is the manager of Flourish Australia's 100% pure operating service in Hervey Bay they are going to present a session now. I think we'll have an informal session where they can walk around and consult because it's more in deep keeping with that they're on about.

(VIDEO) I'll just be giving some questions, I want some quick reactions. Tax cuts, petrol prices, better roads, let's keep going? What benefits would you like to see from the budget? Stamp tutee. It's a killer. That's a State Government issue, we're talking agent Federal Government. What's another issue. We need bigger pits. That's a local Government because Federal... We still need them. Someone mentioned something before, handouts, something about health? You mentioned health when we said vision? Something about health insurance. Premiums are too high.

Especially for working families. You're listed here as unemployed. It's even tougher and a lot of working families. Water? What about it nothing it's just one of those words that came up a lot like hospitals. There are certain words that people associate with long-term vision like technology, innovation, renewable energy, nuclear power, nuclear power? Are they for it or against it? I don't know. I was just up for words which

have forward thinking initiative. They really respond to that and the Federal Government initiative, they love that. They didn't offer anything more specific? Housing initiative, they love that? Let's make it a housing initiative. I'll dial the housing Minister right now, he would love to splash around \$5-10 million. A particular bit of water infrastructure or just the word? They like the water initiative. I suspect they would. Do we get one of those. I also analysed the vision time frame, how far into the future it should run? 2020 still came across as quite visionary. 2030? 2050. Very visionary. Sounds very sci-fi. I can let the PM know that we're making progress. We have dates and initiative and words and phrases. Good news. It's not good news.

EVAN FULTON: Maybe we can poke fun at some of the things that have happened in the past. Sarah, would you like to...

SARAH JAMES: I'm Sarah. So I'm work for partners in recovery and I started in the program about nine months ago and I think it was my third day and certainly within the first or second week, someone told me to go and meet with Evan because we have to do something about consumer engagement. OK, I went with Evan.

EVAN FULTON: I'm the manager of a very peer operated service provider for service Australia in Hervey Bay. I love bringing that experience word. I won't do that today because it's not what this space is about. I'm not using a microphone at the moment, is that OK with the group? Sort of? We'll do our best. Please let us know if ear not hearing us and we'll change strategy. I personally don't wish to stand at the dais or sit at the table. I like to be in and around the group or part of the group rather than not in the group and that's what we're trying to build around the Wide Bay. If that's OK the with group I'd like to continue like that. For a bit of a not note, we - the anxiety we feel today is that we're going to try and demonstrate the values that we demonstrate they will be contradicted by the available time frames. We would love to invite discussion or statements or sharing values or some reflections, that's hopefully not what we're working towards in our building conversations with people in community, but if we do keep moving forward or respectfully ask to keep going forward, let's not be disrespectful, it's just the time constraints.

SARAH JAMES: We had a meeting about what the consumer engagement stuff that I'd been told that we have to do and where we started was a really awkward space that we all start in when we first meet a new person and we're new in a job and we're 100% peer operated service. I am obviously very mindful and nervous about not stepping on anyone's toes. We started from the same point that we start with when we go out and engage with people which is that we ask these questions of each other and ask these questions of the people we engage with. I was very nervous on that first day that I didn't want to state an idea that people went "oh well, if new girl." But "can we do this in a way that's about the people we engage with?" Because I've had experiences with consumer engagement where it's developed around the convenience of the service who needs to consult, rather than the people who need to be involved and often in the mental health space we often talk about how if you happen to end up needing support from the mental health system you are then someone who has a mental health issue and that is the only role that sometimes you're unfortunately labelled with and we wanted to start from a place of respect and assumption that people have full lives, part of their life is engaging with a service and we would really like to hear their thoughts about how that service works and sometimes doesn't and we need to know what's going to work for them in how to engage, because we didn't want to block people out and - I think really what we said at the beginning was we don't want to end up sitting around the table with the same people asking them the same questions every month so we can take a box and say that we've consulted. That's where we started. We got HCQ in to help and look at how can we facilitate a process of finding out how people want to engage.

EVAN FULTON: When we started that was about not having an agenda. Even though that has a limited life span possibly, we don't have an agenda. We get a bit stale. We need a shared interest to come about. Even there with those questions there, this is not a direct question but offering if anyone has something to share, just looking at those three questions today in their own space today, whether it's in the room right now, is there a way - anyone diabetes one person per reflection on those things, anyone - what brings you here today?

I'm keen to hear because I'm from Prince Charles Hospital and we have an engagement group across Metro North and we have like 12 paid consumers so are your positions funded?

EVAN FULTON: We're fully funded, staff funded, we're looking to incorporate some corporate management

That will be unpacked.

I take your point about having the same people there every month and trying to get the same type of feedback. Try and commit broadly I think...

EVAN FULTON: Anyone today, if there was an opportunity to contribute either in this room or in the broader space, is there anybody who has something they wish to contribute and like to share that at the moment.

SHIRLEY EDWARDS: I come here today because I hope to spread awareness of what the problem is with people who have a hearing loss, dealing with public health system. A person with a hearing loss might not necessarily have sign language, they might have Cochlear implants, they might line read and hearing aids, they're all very different and I don't think that is something that health professionals that they're dealing with understand and I think there's room, a lot of room mind you, for education in the health sector towards someone with a hearing loss. This is why I'm here today and how I wish to contribute into the concept of change with the health sector.

SARAH JAMES: Thank you. That's very important and one of my passions is having worked in disability a lot of people with intellectual disability experience mental health problems at very high rates and yet the way that we often look at engaging consumers in the mental health space immediately counts them out of that table. It was about going "how do we create models that people can come in and out of when they have something that they're passionate about talking about and we can engage them in a way that works for them rather than it being about this is my schedule and this is how you need to engage with me. We wanted to flick the power balance on that as much as possible." Thank you for that.

EVAN FULTON: Moving on to the last reflection there, there was a gentleman.

SARAH JAMES: Thing we should make them thumb wrestle to see who gets to speak.

I'm from Townsville. My concerning area is labelling process and who initiates and who owns the label and my observation from the client group's perspective is that people don't actually create labels, they don't own them, they don't have any role or power in disowning them and when we know that the labels are produced by the so-called profession or the health community at that level, varies the consumers power to negotiate terms in terms of how we are being abled because these labels are powerful in terms of giving the power to the professional and taking power away from the consumer, particularly, we are very much critical when it comes to mental health area because it's one thing that you label someone as a diabetic. It's not just a label. It's a print on the skin, people have no ability to negotiate why I'm being labelled and also there is no science behind those labelling and they keep changing anyway and the medications keep changing depending who create, what, where and who is in the bed with who. My concern is in this area. For the reason I came here, the label is like a rag to the bull, I'm here. Who, why?

EVAN FULTON: I particularly thank you very much for that comment. From a lived experience, perspective, lived experience is the only quality and skill hopefully I bring to my role in opposition and one of the main messages that we were given at our very first formalised groups was we don't want the word consumer. We don't want to be a consumer. That's no disrespect to any other group working with that consumer but we understand that all these things often come from good intention and good spaces but maybe are not - when we get to that space to work through those spaces we discover new things, that's my personal stuff.

If you don't like the label consumer, that's a particular mental disorder, if you get yourself checked!

SARAH JAMES: Resistant to treatment indigenous we call that.

EVAN FULTON: Did you want to add something?

LESLIE: I'm Leslie from the Sunshine Coast. My interest was more to found out how you structured this. I think there's a forgotten community with the older patients that come through, people think mental illness is something that they have from an early age. It comes on from late stages, now with men if their prostate and they go into surgery and they can bring on Alzheimer's and dementia and that is a form of a problem for them because depression, so I'm very keen to see how we can carry that through not only from the ones diagnosed but later on in life and let them go forward.

EVAN FULTON: That might be a great way to keep moving.

SARAH JAMES: Share certainly we do not say that we're experts in this thing called consumer engagement. And we're still learning and still in the early stages of trying to set up a foundation to ensure that we're creating a way of engaging that means that we're accessing all of those groups and we'll talk about some of the mapping activities we want to do around that. We talked to HCQ and went "we don't want to go in with a plan, we want to go in with some values and have a conversation with people," and part of that was being very honest. I work with a PHN. It was a form of a bureaucracy. We have KPIs to meet and things like that. I wanted to be very honest with the group and part of it might be me coming to a group and saying that I've consulted on this ten page document, how shall we go about doing that but your right is to say to me "bugger off that's not the way we want to consult." And one of the reasons that this is a very conscious partnership between a PHN and a peer operated service is to keep that healthy tension about how genuine we are in our approach to engagement. There are a lot of issues with the term 'consumer' for a lot of people we talk to so that's a number of them, they decided to call themselves champions or refer to themselves as champions of change, we try to refer to them as people we work with and for, but when we talk about consumer engagement in formal settings it's almost an understood way of saying "and this is what we do." They're all the other words that people come up with of these are really annoying ways that you talk about us and recovery is there in terms of how that word has for some people that we talk to has been cooperated at in a bureaucratic way and as in some ways lost its intent for them because of

that. We're very respectful of how we use that that term in that we don't coopt it. Everyone sees that term as little.

EVAN FULTON: There's some things very key to me and my personal beliefs and some that aren't. Hopefully we can respect that space.

SARAH JAMES: Last October we rocked up into a room, we just advertised as much as we can, come far and wide, we'll interested in hearing from you and how we engage and virtually we walked in that room and thanked people for coming, we asked them all why they had come and these are the values that we bring to today and this is the way we want to commit to working with you and we want to share in the process with you. Purposeful is very important to me, because sharing stories is an incredibly important part of what we do but it's very important for me as someone who is getting paid to fulfil a role that I then use the privilege of people sharing those short stories in a purposeful way to influence change in organisations.

EVAN FULTON: On purpose, my experience as quite often, very meaningful opportunities as far as being an experienced representative on Wide Bay representations but sometimes it's about the full feedback group, the purposefulness of what we're doing. We never hear what is the outcome and only six months down the track. Purposefulness is about also making sure that the information and feedback is going around.

SARAH JAMES: A senior member of the PHN when we were starting to discuss working this way her phrase was "we're wanting to build relationships not buy opinions." Certainly that guides me in thinking about how we do this. Flexible is around ensuring it's the way people want to access it and that we're not providing such a restrictive way of people accessing or engaging in the process that there are a large majority of people in our community that immediately can't engage so that was something we said we don't know what flexible looks like but we want to talk to you about that.

EVAN FULTON: Consumer-led. One of my things and something I shared with this and the group upon was that consumer-centred or person-centred or peer-centred, peer-led, person-led we take a direction, we've been informed by what's there, not focusing on the problem or the people that are the problem, we take the lead by others

who wish to take lead. Talking about how that happens and how that fits into how traditionally feedback is gathered or offered, often I know a lot of very passionate and wonderful clinicians who say it's not about being anti-clinical, it's about the system more so when people have feedback that offer a genuine need to share something that they don't fit into the feedback criteria. They're not well enough or they haven't filled out right paper work and we have to work to get the feedback, not the person off doing the feedback.

SARAH JAMES: Access accessibility also talks about things that make our community less accessible for some people. How do we make things accessible and I'm skipping ahead a bit but one of the first things comment on when we first met with people was "look I have three people really interested in coming today but the moment I told them it was in a meeting room that turned them off." The phrase that the group kept coming back to was the idea of sitting under a tree and having a yarn and being able to engage or sometimes listen and not having a lot of pressure on what level of engagement was placed on a person at any given point in time. As part of that, some of the activities we do do take place in parks and we are even talking about maybe running things in shopping centres on Thursday nights and walking up to people and going "want to talk about mental health services in your region." By saying that to people walking their dog past the table, we've had some really interesting insight and experience. Unfortunately, my experience of services are you either have so many mental health services involved in your life you cannot get a break from them or you're standing outside looking in and going "where's the doorway?" And I think consumer engagement is the good place to start in breaking that down because how many flights have I been on? A lot of in the last two weekses and people next to me ask me what I do and when I say that I work in mental health everyone can tell me a story. It is far more necessary for us to engage with people who would never think about engaging.

EVAN FULTON: Accidental insight, it's about having conversations outside our comfort zones. Giving that person the opportunity to share or not share. It happens everywhere you go. Everyone has a value of honesty. That person says to me it's about

transparency of thought. I acknowledge that I'm not real comfortable with this or that, or disagree or this is what came back. It's just about being transparent.

SARAH JAMES: That is modelled in our relationship. We have spoken consciously about disagreeing openly in front of people. It's not about having a brawl.

The next room has started its next session. We need for everyone to keep for times to allow for the swaps.

EVAN FULTON: Whatever happens, this is what it's all about. I'm not upset if we don't get through every slide. Maybe push through some of them.

SARAH JAMES: Some people point out specific things.

EVAN FULTON: This is the traditional feedback. That's what our community looks like. This is what we want our engagement to look like. We understand that our community is stagnant, that it changes. This is the model that was developed and it very much reflects, like we pretty it up and we might have changed the lingo so that it was understood but this is what group told us they thought would work. The first was online. They wanted a way to communicate with each other online. We have a way. Regional pop-up. That was the idea of sitting under a tree and having conversations. Every now and then,, we cover a really wide region so we'll pick a week and we'll travel. We're going to be up in Bundaberg and we're going down near Fraser Island and come along and find us. We use balloons. People can find us and have a conversation with us. As those develop, there'll be themes connected to that so people can access and talk about that because you're talking about part of the mental health service that I have lot of opinions on or experience about. That's where the feedback loop comes into that. That information is collated and fed back to the group. Giving people an opportunity online if they haven't been able to attend on the day. This involves the health and hospital services and a number of service providers in the area. We feed that back to them but part of their agenda is to feed back to the group. And to let the group know that they have listened to that and any things that they might be doing as a result of that. Evan is the representative of that.

EVAN FULTON: Full-time please come and see us, we're happy to email. There's not a lot in that. It's about having a conversation and discussion and change and whatever it is. We'll be playing at the casino all week.

SARAH JAMES: And there is the development stuff. People identified the need to be given tools and ways of engaging with people so they can build their confidence. We'll also have formal projects from time to time where people can apply and be reimbursed. That was just some feedback we got. The hope thing is a big thing and we were just going to talk about the challenges because what we are trying to create is a model more convenient for people accessing it than people in our roles. We're going through a process of looking at what infrastructure is needed to make that work. Evan talked about bringing on a projects officer who can help us do some community groups so they can help us further expand and understand where we should be going and having conversations. We have this intent of sitting with discomfort. There are a number of times during this process where it would be much easier to form a board or a reference group, but we're committed to sitting within that discomfort because we believe that in the long-term this is something that can become very robust and dynamic and we think that's worth that discomfort to get there.

APPLAUSE