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TOWNSVILLE

PARTNERSHIPS · LEADERSHIP · ENGAGEMENT

Putting people front and centre: co-designing youth mental health services, Barrett Adolescent Centre Commission of Inquiry Implementation (Panel discussion including Q&A)

Video 2

APPLAUSE

LEONIE SANDERSON: Come up to the stage, please? Thank you. I just like to thank Kathy one more time for sharing her story. I've seen that so many times

APPLAUSE

It's just so moving and it doesn't matter how many times I see it, so I guess just to get started I probably direction from question to Jeannine and Kathy, what have been the best things about being a part of this project as consumer and carer representatives?

JEANNINE KIMBER: Good morning. Thank you for coming to our presentation today, we really appreciate your attendance. I guess the first thing is that I was involved in the Barrett process from the very beginning from when they announced the closure and I guess I'd be fairly generous in describing the attitude and process of consumer involvement as consumer containment. And the process that we've had to date since the commission of inquiry and working on the implementation of the Government recommendations has really given a legitimate opportunity for carers and consumers to contribute their opinions and thoughts and really given validation to the needs of the young people that need these services. It's really given an opportunity for us to raise really significant issues for this particular patient cohort of young people with severe and complex mental health issues and that has to a degree previously been ignored or certainly not addressed to the extent that it needs to be and you can see that Kathy is a shining example of what is possible and I guess that this process has given us hope that through meeting the needs of these young people that will will be a whole lot of young people who might have otherwise fallen through the cracks or not received the treatment or their time to recover has been unnecessarily extended by not getting the appropriate treatment so that they can fulfil their potential and hopefully have happy lives where they are contributing to society and able to meet their own goals. Just a third thing I'd like to say is that it's really given us a platform to also expand the conversation beyond the Barrett issue. It's no secret to the people from Queensland Health that we have other issues that we like to address and that's looking beyond just the extended treatment facility, that treatment facility has to be integrated into the youth mental health system and in order for that to work effectively I think we also need to look at other areas within that system to make sure it all those areas are working really effectively and doing what they need to do for the young people that access those services. And the other point I think that's been really important is that we've have been able to have conversations and I believe have some influence at the executive level. Myself and Kathy and another carer consumer are on the steering committee and on that steering committee sit the deputy director general as our chair, we have John as the executive director of mental health services in Queensland, other deputy generals from education, people from the Premier's department, so it's a very good platform for being able to have those people and they're the people that decide on budgets, locations for services, really important decisions at high level and I think we've really been able to have an opportunity through being on the steering committee to access that level of Queensland Health and those other departments to try and inform and improve the awareness around what the needs of this particular patient cohort is.

LEONIE SANDERSON: What has it been like being on a steering committee which such high level public servants?

KATHERINE MOODIE: It's been mildly intimidating. I feel like everyone has done their best to make us feel welcome. I've never at a steering committee meeting felt like that my voice was not appreciated or not heard. Which has been fantastic. As part of this process, consumers and carers have also been encouraged to attend prebriefings which I think has been fantastic, it really helps us get up to date and understand what is going to happen at the meeting so that we can - we know what is going on and we can voice our opinions.

LEONIE SANDERSON: I'll direct this to John and Stacie, can you maybe give us some - for people who don't have context, maybe describe some of the processes where consumers and carers have been involved in this project from the different perspectives of health and education?

STACIE HANSEL: I think for us it's been an exciting opportunity to collaborate collectively around the needs for our students and that's what we're here for. It is around that continuum of care and ensuring that our students are catered for in the best possible way. I don't think I've been part of a more Exciting project and facilitation of great work shops around what that looks like at every level, through to steering committees through to us meeting with parents at schools around what the means for their students in their context.

JOHN ALLAN: Great to be back in Townsville, thank you very much for all coming out today. To me it's a continuation of process that we started a long time ago that got lost in this particular thing where people should have that particular input and do it. The two good things about this one is that yes we have to say, we have everything on the table, the second is that it's not just the representatives in the room that we have an opportunity to reach back into community and the grassroots and get that feedback. Think about the way that consumer movements work in the last 30 years, always been about everybody having one input in, not just the voice of a few. That's been a really important process.

LEONIE SANDERSON: Just to give everyone some context, one recommendation is specifically around the Prince Charles Hospital for young people with adolescent mental health issues. As part of that there have been some work shops around the design of that facility which Gunther has been very involved with. Has there been - have you experienced some shift with process of having consumers and carers involved? What's been beneficial about that?

GUNTHER DE GRAEVE: Absolutely. There has been an enormous change in our design development through this process. First reason, there was a bench benchmark, an example globally, we found one under construction in Canada that has a lot of similarities but there was nothing really to start from. This codesign process really allowed to us reach very deep into the operational requirements into the therapeutic requirements and also the day to day requirements and then safety of this facility and it gave us a very wide platform, traditionally this engagement goes to clinicians and nursing staff and very little with the consumers and in this platform we could draw it all on the table, we had the drawings up on the table, we moved people around, moved parts of the building around and did that process to get informed. It wasn't us going out, this is what we cooked earlier, what do you think about it? It was a process of trying to understand what the needs were and to date I still say that if we didn't do that process we would have designed a very different facility and it probably wouldn't have been as caring as that facility could be for the patient. It's made an enormous difference and I'm hoping it will make a huge difference for the patients and the users in the future.

LEONIE SANDERSON: Kathy and Jeannine, you've had this involvement over some period now from September last year or even beyond that, would you recommend it to other young people to get involved as consumers?

KATHERINE MOODIE: Absolutely. I think we need you essentially. The process has been incredibly rewarding for me to sort of feel like that hopefully what I'm doing will hopefully make a significant difference do people that were like me 13 years ago. That's sort of what drives me and keeps me going. I feel like my main weakness as a consumer is that ultimately I am one voice and I can only really provide a personal perspective of one story, of one story, so I feel like you'll I do my best to verdict for other people's stories and wishes and opinions, I certainly didn't love their experience and I don't feel like I can tell their story or tell their opinion or perspectives as powerfully as they potentially could. In this process it has been really difficult to get a lot of consumers involved, particularly surrounding - the consumers of severe and complex mental health issues, around the past five year, they haven't had really positive interactions with health services, health staff so they've been very difficult to engage and unfortunately my generation that have suffered from severe and complex mental health issues in the last ten years w, we don't know where these people are now. It's been difficult to get consumers involved and to anyone out there that is thinking of doing something similar, and is wanting to get involved, I think we need your voice.

JEANNINE KIMBER: I'd definitely reiterate Kathy's comments there. For a lot of young people, if they've had a negative experience, or if - even if the journey has been so difficult and they are now in recovery, a lot of young people want to close the door on what's come before that and are reluctant to get involved. The other issue is that some people are still in recovery and may not be well enough to engage in this process so through health consumers Queensland with their support we're looking at trying to find the ways that we do get access to that consumer voice but in terms of the value of young people who might be reluctant to be involved I could give a really quick example of being in one of the model of service decline work shops and we had a service provider we were talking about referral pathways so how young people may get referred to this service and this particular service provider said, "Look it's really clear, they need to come through this agency, everything needs to come through this agency. That's the way we will be able to monitor and ensure referrals will appropriate." In our group you had a young person who had actually had a very difficult time with her mental health over a very long time and lots of very significant damaging issues, and she said, "Well, I see your point but in my experience I had a really bad experience with that service, and disengaged. That doesn't mean that I don't need the help but I'm not going do get it if you're saying that you're the only place I can obtain a referral to this new facility." After explaining her story the service provider actually said, "You are absolutely right. And I agree. It totally changed the conversation and the approach and the attitude." That wouldn't be possible if that young person hadn't been able to provide that direct experience and contribute that to the conversation so I guess it's so powerful for people who are delivering the services to hear what it's like for the young people on the end of that. As a carer I can represent my own experience as a carer and pass on as Kathy said you do your best to pass on and respect other people's stories, you can communicate other people's stories but it's much more powerful when it comes directly from those people.

LEONIE SANDERSON: Similarly for the development of services whether they're health services or education services, what - this is for the people on the end, what would be the things then that - coming out of consumer and carer engagement, what would be the things most beneficial about having consumers and carers at the table in that process?

STACIE HANSEL: From our perspective our students really needs to be a statistic of our decisions around that. Being able to talk directly with their families, being able to talk directly with students around really made a difference so what was it that actually allowed our students to succeed or not succeed and we need to learn from that and it really is our decision to be very committed to ensuring that our students' voices are heard also around what educationally will help them be successful in their future lives with that absolute continuation and continuum of education and care.

JOHN ALLAN: The notion of recovery, people taking control of their own lives, getting some some say in what happens to them. This is part of that voice of recovery in there all the time. We have to do that. Secondly, it really consolidates change. One thing is when you have that face-to-face confrontation with the stories and you deal with people at a human to human level you can relate melt away some of the that resistance. People got to work to try and do good. They just need to find better ways to do more good. They're not trying... Kathy's story is important to show that you think you're doing something with the best intentions and it's really not very good at all. You need that constantly reframing of that model and accelerated changing and the other one is quite powerfully politically. It get the money, it gets the notice to the politicians and it gets people like me to do stuff and I think that if I look over the successes that we've had over the years it's been when we've had that proper partnership and voice, I think about the stuff in Townsville all those years ago, it was about community having some kind of say when they didn't have a say before. That's really important.

LEONIE SANDERSON: Keeping on that note and maybe Gunther, has it been different having consumers and carers and you touched on it a bit but right from the beginning so not presenting something that's kind of already marked down but right from the beginning, what has been the benefit from your perspective?

GUNTHER DE GRAEVE: It has reset a lot of thinking about space for us. There is guidelines and there's stuff that's been done before, traditionally you grab what is in a guideline and you rebase it together. Through this process it really made us aware, a lot of this is wrong and is no longer relevant and we had to go back to what I call the basic ergonomic, understanding what is happening in these spaces and how that space needs to support that. We had to look at the guidelines and start again with a blank sheet. It's interesting because hopefully I'm only halfway in my career but been doing this almost for half of your career now, this copy pasting, and interpreting, we need to go all the way back again because things have changed so much in general in health care as well. Models have changed, people change, cultures change and we need to reset the clock on a lot of these things and dig deep again to ensure that we're not creating another white elephant, that would be the worst thing we could be doing, that we are investing all this money and it would be a major missed opportunity not just for the facility but for those patients as well. Mal has been the resetting of the clock for me and my practice now, we need to take that opportunity to dig deeper. It's sometimes hard because things are on a process and on a timeline and there's a lot of - this one has been very well planned. There is the willingness to contribute the time as well. That is very important and it's made a big difference.

LEONIE SANDERSON: We do have a few minutes in order to throw some questions to the audience. Keep them brief.