Unparalleled co-design of youth mental health services with consumers and carers

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Breakout Room 2: 15/06 11.00-11.30

CAPTIONER ON STANDBY:

Gabrielle: We'll start in a minute. There's a few stragglers still coming in. If you've got a spare seat, do you mind moving towards the inner circle, or the inner side, just so that people who are coming in now can find a seat on the outer edge. Thank you very much for coming. We're just waiting to close the doors and I have actually asked just for the temperature to get checked, because I think once we close the doors, the room's going to get stuffy. So we're already working on that but I would like to say welcome and thank you for coming to today's workshop. My name is Gabrielle Quillian. I am one of the new Board members for Health Consumers QLD and in my other role, I am Co-Founder of Hummingbird House, the children's hospice here in Brisbane.

It is an absolute pleasure and privilege to be able to facilitate today's conversation and introduce you to some quite extraordinary health consumers, health consumer advocates and leaders in health consumer engagement. So how today is going to run, we've got two 30 minute sessions and they'll actually run concurrently. So we're hoping that if you could remain in the session for the complete one and a half hours, simply because it's so packed and the transfer between a half hour session here and trying to get somewhere else, you'll probably miss components of both.

So we also will have then a 30-minute Q&A session after the two concurrent conversations. So please feel free to have those questions ready to go. I'll have a microphone. We'll try and bridge the gap across the internal seating process and we'd love to have engagement and I doubt there would be a question that's off the table today.

So first off, we'll have unparalleled co-design of Mental Health Services with consumers and carers. I had a chat to Judith and she said I could have - Judith Piccone, thank you, Judith. Now I can move on. Who is the Manager of the Mental Health and Alcohol and Other Drugs Branch with Queensland Health. Leonie Sanderson who is an Engagement Adviser with Health Consumers QLD and Katherine Moodie who is a Consumer Representative.

The second session will be the integration of - actually, I'll swap this around. The integration of peer support workers into mental health, clinical mental health and service delivery under the Metro South Addiction and Mental Health Services. The presenters will be Karen McCann, who is a Team Leader of the Social Inclusion and Recovery, and Georgina Moshudis who is a Peer Support Worker. So I would like to invite the team to present unparalleled co-design of youth mental health services with consumers and carers.

Katherine: Hello. Thank you very much for coming along. We're very much looking forward to having a discussion with all of you, in terms of the consumer and carer engagement that's been happening within the child health youth reform. Over the past couple of years. Myself, Leonie and Judith were having a discussion around two years ago we were thrown in together. It's been such an amazing journey for the past couple of years and we're very much looking forward to having a chat to you over what's happened over the journey, what hasn't worked so well, what we've learnt in the process and where we are in terms of moving forward.

I'm the Consumer Representative as part of the group. There will be a carer representative presenting here today. Unfortunately she's unwell at the moment. We'll send her best wishes today. Carers have very much been in the process and there will certainly be some slides up on the PowerPoint in a couple of slides time, so it goes through exactly how many consumers and carers we've had through the process.

I suppose today we'll talk a lot about perspectives and complexity. I suppose today I'm talking to you from a consumer perspective. I was a consumer of child youth and Mental Health Services from about 5 years to the ages of 12, 13. I will mention, I do have a clinical perspective as well. It's not all mental health but I also do work as a physiotherapist within Queensland Health as well. I've got that clinical cap. I've been a clinician for about four years as well.

Judith: Just to give you an overview, as Kathy said, it was about two hours ago. Sometimes time seems compressed or slow depending on what you're doing. This all came out of the Queensland Government first establishing a Barrett Adolescent Centre Commission of Inquiry back on the 16th of July 2016. This was around the closure of the adolescent centre. It was a statewide. As part of that commission of inquiry, elements of the process and what has come because of that, that's often the story about these things. It's about what comes next. The commission then delivered a final report to the premier on the 24th of June 2016.

There's a quote there from the Commissioner report which was around her findings which you can read there. So when the government response to the Barrett Adolescent Centre Commission of Inquiry Report was publicly released, the premier in that response accepted the principles and acknowledged to work closely with consumers and carers, including those that had been associated with the former Barrett Adolescent Centre and that's literally where it began.

Then there was a need, I came on board as the Manager of that team and one of my former team members, I won't out them is in the front row of this audience today as well. People know who you are, Karen. Sorry. People are looking at you. It's been a journey for quite a number of us. The first part was to go, how are we going to do this. That's actually where the first meeting commenced with people who had been carers and consumers of the former BAC and Health Consumers QLD and that might be a good segway to you, Leonie.

Leonie: So Health Consumers QLD came on board at the same time. The role of Health Consumers QLD and my role specifically has had a lot of different elements to it. From that very first meeting of the committee, we have provided advice on the engagement of consumers and carers in this process. To do that, to be able to provide that advice, we've had to actually engage with consumers and carers to be able to do that. That's another part of the role that we've had had.

We've done some training and support for all of those consumers and carers, as well as the recruitment processes to fulfil the very many roles that consumers and carers have been asked to undertake in this project. We have also, I guess, part of my role on this project has been around doing the mentoring and advice to support consumers and carers to be on a project of this nature. So as you can imagine. When something comes out of a fairly tragic circumstance, there are a lot of emotions around the work that follows after that. So it was really important for us to make sure that consumers and carers were supported in a safe, but also a meaningful way, to engage on the work that this project was going to do.

The other part of our work, of course, has been about reporting back to Queensland Government about that work. So if you - and you may have followed on our Health Consumers QLD website but we have a whole page devoted to this project where we've shared updates and reports that we've written and created with consumers and carers along the way. We did some cartoons as well.

Judith: And we linked our website to Health Consumers QLD and if anyone knows about bureaucracy and Health QLD websites and how exciting they are, the moment we linked them, you can find our website way easier.

Katherine: This next slide takes you through the numbers of consumers and carers that were recruited as part of this process. There were 50 representatives in total. Really great things, there's probably equal numbers of consumers and carers which has been fantastic. I suppose one of the really great things about this process is that it hasn't just been 50 people in one group, it's been two or three consumers, sometimes more, sometimes less, across multiple levels of government. Across multiple meetings, committees, really getting consumer and carer engagement at almost every level of the process of this child and youth reform which has been an absolutely fantastic part of the process.

Leonie: That was just the first 12 months. We're into the second 12 months. We probably have that many consumers and carers involved, not all the same people.

Katherine: One of the things the slide doesn't show, for us as consumers and carers, I suppose one of the things we're still working on is getting greater representation with the outreach community and the LGBTI and particularly young males with a consumer background. That's probably consumer groups we haven't been engages as much as we would like to, that's a continual process we're trying to get people involved within those communities as well.

Judith: I think it's amazing to make a point with how they've been able to keep up with the pace of the work. I think we're underestimating that. Two years ago, we're thinking about. Quite a lot has happened within that time. I think that's a challenge why we haven't still got the representation Kathy is still talk about. This has been a lot of work within a very short amount of time with meetings that require pre-briefings and readings of agenda papers and all these sorts of time lines that come up particularly this first 12 months which was reportable up to premier and cabinet. It was a government response.

When we're talking about committee meetings, this was across agency that committees and carers are sitting on and different departments. You couldn't just slow things down - well, we slowed a lot of things down but there's certain things that have to go and a certain order to keep things progressing. I think it's been quite an achievement to keep that happening between all of us

Judith: So we just put this slide up. We've got through a few iterations of how we describe this process but we really wanted to make sure that we could describe the way that different perspectives have come together. So we have had Department of Education at the very highest level being involved. Department of Health, Health Consumers QLD, consumers and carers and architects and developers because the first couple of years of this project has really been about designing new facility and with that comes a lot of work, in terms of government having to make business cases and budgets and going to cabinet, really bureaucratic processes that have really definite time lines that we've all had to work through but we've actually influenced the two departments and the developers and architects to do it a different way. So bringing everyone's perspectives together for hopefully a better outcome.

Do you want to say anything on a perspective here before I give an idea? I suppose the other thing I wanted to say about this, this is fairly a quick presentation. We're trying to give you an overview so we can hear the other presentation and get to your presentations. This is quite indepth. From my perspective, a couple of things I find interesting each time we do this, each time I add a little bit more, I came from a clinician background to get into the Manager roles that I am now in. On one level I thought I understood what consumer carer engagement was about.

I don't feel uncomfortable with that idea. Yet even two years on, and Kathy and I had a conversation about this two and a half weeks ago, two weeks ago, while we were in the Netherlands, another story, again I realise that the more you're engaged in this, regardless of everything you know, you still get another little insight. There's another layer and it's like that little peeling onion and everyone's onion is a little bit different. So it's not always easy because it can be bumpy, despite what I think everyone has a different viewpoint and different people come at it and there are constraints in working in a government bureaucracy, more constraints than working in a hospital and health service or private practice, which was my other experience. You have to work with those constraints and try and be open and transparent about those. We all get stuck with them and it is what it is.

It's even about how it's always changing and evolving and what I think is engagement you get another aha moment and not everyone is at the same spot you are. It's this constant journey that's evolving and changing and not static and definitely not easy

Katherine: To just add on what Judith has been saying, I suppose what I've found in the past couple of years is my role as a Consumer Representative, that's changed as well, in terms of how I think about these things and initially I really came to the table, right, I'm a Consumer Representative. My role here is to give a consumer perspective, based on my story and experiences. I suppose talk to other people within the community and advocate for their stories and experience as well.

What I've found over the past couple of years is that's just expanded to so much more. It's been advocating to get other consumers and carers to the table. It's not just my voice being heard, but 20 or 30 other consumers and carers being heard as well. Advocating for the more vulnerable populations and how we hear their voices in a safe manner and in an experience that's positive and safe for them. How we get their views and opinions as well because they are a population that's quite difficult to capture but my role at the moment has gone from just talking about my story and other people's stories to helping get other people engaged and giving their views and their stories, in a way that's safe and effective for them.

Judith: It's not about consensus. It's about maintaining those different perspectives and that we won't always agree.

Katherine: Respecting everyone's perspectives. Letting everyone have their voices be heard and coming to a consensus, as a group rather than he said, she said.

Judith: And total agreement that we know talk the same.

Katherine: I'll let Leonie talk to the next slide.

Leonie: We did have very distinct timelines to the government inquiry. As a result of the first 12 months, there has been a body of work that has continued on. We've still got to build a building, that's happening. We've still got step up, step down units that have to be built. We've got two day programs that have to be built and designed. We've got a lot of work to do. As I said, the focus has been really in these first stages around what will those buildings look like. How will they make sure that this is what consumers and carers want, remembering that the age group for these facilities is 13 to 18, up to 21, young people?

Judith: You haven't even talked about the buildings.

Leonie: We've had a lot of workshops around design, now we've got a tick from government of how that will work. That has involved sitting down with floor plans, being in immersive situations. We're very lucky that Queensland Health has excellent clinical facilities that we've been able to repurpose so we feel like we're inside a bedroom. Inside an activity room or an educational classroom and do the thing where we go, you know what, it's too bright. Can we change the way that those lights are looking there and can we move the screens over to there and can we turn - actually can we turn the whole room around. Sometimes that's possible and other times that's not possible but it's been going through that process.

So this is just to give you a little bit of an idea up to now where we've been focused. 65% plus participants has included consumers and educators as well. Consumers and carers have been in the room with doctors and nurses and teachers making these decisions and hearing each other's perspectives. We're still going. We've still got - we probably still have at least another 12 months until we have buildings built and opened.

Judith: I don't think this will ever end. It's an ongoing journey.

Katherine: I hope not.

Judith: As long as there's a need for facilities, how can it ever end? We're trying to bring new processes and bring new people into it and keep it going and make it the norm.

Katherine: I think that's it, we're trying to make it the norm and engage consumers and carers across all levels of services and government. We'll now have a bit of a discussion about the impact of and we'll go into the impact on consumers and carers throughout the last couple of years. Things that stand out for me, in terms of the impact, I will go through a bit of a chronological timeline, just because that's the easiest way for me to make my brain work. This isn't thing that's somewhat organised.

When we think about, in terms of the impact of consumers and carers, I suppose one thing that's been - we think has been particularly impactful, I suppose that sharing of stories and storytelling. There was a steering committee at about February last year in which some of the consumers and carer representatives, including myself, shared some personal stories and mind you this committee is confidential. I suppose we did have that element of protection as well. But we did share personal stories and we did also share a survey of the wider consumer and carer group and in terms of people talking about what their story was like, what they liked, what they didn't like, how they felt like things could be improved.

We have found that personal story telling has been a really impactful way of getting across what it feels like and what it looks like, to be a consumer or a carer on the ground, engaging with health services, whether they're mental health or physical health. One of the things that - thinking back on what I do a little bit better next time, we didn't necessarily evaluate that, in terms of the reactions from the steering committee members. We didn't have a survey before or after, in terms of what the steering committee members felt like they got out of the presentation and that's probably something we'd do a little bit differently next time.

That being said though, even when, as a Consumer Representative, I don't feel up to telling my story or don't feel like sharing everything, one of the things that's been great is we've all said, like, from my experience. So even if we're not sharing the whole journey, we're able to share little bits here and there that are relevant to the topic of conversation and in my experience is a great way to lead off that conversation.

Another really great thing was that as part of the steering committee presentation, the consumer and carer group decided to come up with an idea of a wish list that we presented to the Health Minister that was there at the time. One of the key things on the wish list was this idea of a child and youth team or branch within the wider Department of Health or mental health alcohol and other drugs branch.

So I believe that Judith, as well as many other clinicians within child youth and mental health, had been advocating for something like this or a bit of a better lens or priority with child and youth mental health but I suppose what we found after that steering committee presentation is we did get a child and youth team for which Judith now manages and -

Judith: It's very exciting.

Katherine: It's a really great example of how sometimes consumers, carers, clinicians, architects, departments of education and training representatives, sometimes we need to agree to disagree and that's okay, but sometimes we can all advocate together for shared goals and shared aims and I think that's a perfect example of that happening, in terms of the development of the child and youth team.

One of the other things that - as being really great within the process is, as I mentioned before, advocating for that vulnerable voice. So consumers and carers, we have advocated for youth specific co-design processes. What we tended to find sometimes is when consumers and carers and clinicians are all lumped in together, some voices are louder than others and sometimes that consumer voice maybe isn't the loudest in the room and so we're able to advocate for youth co-design meetings where young people, at the same age that would be engaging in these facilities within the community would come together with a co-design process and be involved in that 3D room and have the room flipped around and be able to see a 3D of the room and the facilities that they potentially or other people in their age group would be involved in.

Leonie briefly mentioned consumers and carers giving feedback, in terms of like architectural design of the buildings. For example, can we have a breakfast bar, speed charging ports. Even that minute detail. We have the child and youth team as an example where consumers and carers have impacted on the broader policy, really broad policy frameworks. USB charging ports, breakfast bars, location of basketball courts or outdoor areas is an example of that really specific information about how consumers and carers can be involved in the process and the information that we have been able to provide back and hopefully make an impact on how those buildings are built.

The last thing I was going to mention as well is changing clinical perspectives. Judith probably alluded to this before but one of my main - one of the main things that I want to give other people, out of being a Consumer Representative, is that ability as a clinician to walk into a facility and sit down with the consumers and carers at that facility and get their ideas about the facility or the service, what they don't like, what they do like.

Sometimes what we see is maybe there's a bit of a divide. That's not reflective of any one party but there is a bit of a divide between sometimes clinicians, carers, consumers, policy-makers and I suppose I see my role as a Consumer Representative in trying to break down some of those barriers and getting people, clinicians, policy-makers, to have those discussions with consumers and carers.

One of the Department of Education and Training representatives that we've been working quite closely with, one of the things I asked her when she went to a new facility, just to have a bit of a look and see how the facility was running to get some ideas on how they could better design education facilities as part of this child and youth reform. She said we went up to Townsville, got an idea. I said, did you actually sit down with students and families and get an idea of what they thought of the process. She said, yes, I did. I sat down with them. I was the needle in the hay stack when I sat down with the group of students. They were wondering, what are you doing here. She sat down and had a bit of a discussion. It was maybe awkward at first but as the discussion continued, she was able to get some ideas about what they were doing at school, what they thought they were doing at school, whether they liked it or didn't. That's been part of our role as well.

Judith: The only thing I would like to add to that is I know our focus is very much about the impact consumers and carers have on our government processes and impact on design. I think we demonstrate that well. I don't want to forget the other element that's useful, even sitting in a bureaucracy. The understanding and impact it has when consumers and carers understand the constraints we work in and almost develop a health literacy of understanding because it means they can work with us. I found that incredibly useful, also being a little bit bureaucratically challenged coming from a clinician background because with you also have consumers and carers who understand within the limits of confidentiality and so forth about the process, then the disagreements or the hard decisions or touch points don't become about you're doing this on purpose to be obstructive, it becomes about oh, you've got to get that document through that thing and you've only given us this time to get us to look at it, it becomes a consultation of sorts. It gets us working together which is more useful and we put more energy into the different perspectives and teasing out what has to happen and puts more perspective into our goal.

Leonie: I added in a slide some of the comments consumers and carers had passed on to me about their participation in the first 12 months. I think the take away for me is there were low levels of trust at the beginning of the project and we're still working on those levels of trust but they're shifting and changing and I think most importantly, the consumers and carers who have been a part of the work have felt - I think feel that they have a lot more power than they thought they had initially. They probably don't really need me to be there for most of the time, in fact. I'm probably doing myself out of a job, which is a really, really good thing.

Judith: I love putting this in there. Kathy be warned. I'm passing to you to close. This is my way of capturing the complexity of the work that we do. There's complexity systems theories that you can go look up and if this really interests you, I can babble on about it quite nicely with you later in the hallway. It's my example of why it is not so simple and easy to do. I think we've given a highlight of that. I think in health and many other areas, we try to simplify things down. Everyone likes to think everything is simple, cause and effect. Our brains do it. We try to simplify things down. I think that comes back to that trust thing. If you don't know something, you come to a conclusion which is about - fear driven. From the days we had to fight flight or whatever.

The work we're doing is not simple like baking a chocolate cake. If you have a recipe that's been tested and tried, we could give it to any one of us and if you follow every step, they articulate it and we don't muck up the steps we'll get a great product every time. We're not playing in that space. There are some things that can be written like that. When we write manuals for stuff that's like chocolate cake which is more complicated than that then we're in trouble.

In this theory it talks about com placated is perhaps more about building a rocket ship going out to space. If you get the right smart people in the room, they'll show you how to build a rocket ship. There may be a few different ways but it can be done. The work we're doing is like raising a child. It is complex. It is shifting and evolving. You can have a parenting course, that's not going to help you. You can raise one child successfully, doesn't mean the next one will be successful. It will depend on the characteristics of the child and the environment you have no control over. It is constantly changing and evolving and unknown and scary, you try some things out and you fail and you back away quickly and try something else. That's the space we're playing in. It is uncomfortable and we don't like it and we try to turn it into chocolate cake and it ain't.

Katherine: One of the things I was grappling with was the fact that sometimes consumers and carers were suggesting things. Certainly some things definitely came to light. We certainly saw changes to the way the building looked, that kind of stuff, not everything was going away. I don't think as part of this process, as a consumer and care, just because everything doesn't happen doesn't mean you're not doing a good job. When we're building a building, consumers and carers, we put forward our ideas. At the end of the idea the consumers have to be happy and feel safe is supported working in that environment. Department of Education and Training, teachers need to feel safe ask supported working in that environment as well.

The architects need to comply with the building codes and standards of which there are many and they're very complex, from what we have seen. And sometimes they change as well. I think that was a light bulb moment for me. It's not about whether we get our way, to put it bluntly. It's about everyone coming together, putting forward their ideas and opinions, really us coming to a compromise or working together to achieve a shared outcome, which for these projects was to achieve better child and youth Mental Health Services to be out there.

At the end of the day we all have the one goal, the same goal, we all come from very different perspectives and lenses but it's been about working together to achieve that shared goal.