

WHAT DOES CONSUMER PERSPECTIVE MEAN TO US?

In Australia, when someone has a lived experience of the mental health system, they are typically referred to as a 'consumer'. When they work in that system in a specified consumer role, they are often said to be providing a 'consumer perspective'. However, what it actually means to use this perspective in our work is harder to define.

Members of the Consumer Academic Program at the Centre for Psychiatric Nursing, University of Melbourne, wanted to have a conversation exploring definitions of consumer perspective and how we use it in our work. To do this we held an audio recorded conversation among seven of the consumer academics in January 2018.

We choose to use the word 'conversation' in keeping with the character of the task which was to share our diverse thinking with each other about how our experiences shape how we do our work and what this means for us as a consumer academic team. While our primary aim was to understand more about our own team's thinking, we also wondered if this activity could provide a contribution to broader understandings of consumer perspective, how it is applied, and contribute to the valuing of consumer perspective as a unique discipline, appreciating its complexity.

In what follows, we think of consumer perspective as a collective lens or way of looking at the world that draws on its roots in socio-political rights movements (Epstein and Shaw, 1997) and our conversation was concerned with further articulating this 'collective' lens. It is important to differentiate this from an individual perspective, which refers to someone's specific personal views and outlook.

We began tentatively asking ourselves, *what is consumer perspective?* Many of us were a little unsure. Simply put we found it "hard to define". Thus, our starting point, was acknowledging that we do not necessarily have the words to easily articulate it. We thought that this was in part because the body of knowledge informing consumer perspective is still being developed. As a collective, we have lacked the intellectual infrastructure to enable us to easily move ahead with producing "knowledge *for* the movement and *within* it..." (Cresswell & Spandler, 2013, p142). As well, we have been a movement that has been 'mined' for our individual stories by others, and we have only more recently begun the task of thinking about ways in which our first person experience forms valuable knowledge:

"service users ... offer.. their own analyses of their experience and of the services and systems they encountered and which were imposed upon them. A key issue for such groups has been gaining equality for their experiential knowledge, research approaches and knowledge claims" (Russo & Beresford, 2015, p155).

So, despite consumer perspective being hard to define, identifiable principles and values nevertheless emerged as key ingredients of consumer perspective, within the conversation.

What was clear for us is that...

CONSUMER PERSPECTIVE IS DIVERSE

Through the conversation, we discovered that there were a range of understandings of what consumer perspective is and how we use it. In the conversation we talked about 'perspective' and how people may hold similar or conflicting perspectives. Another way to think about this is that there is a difference between the 'views' one has and the *collective* consumer 'perspective'.

There is diversity or polyphony of views. This presents us with a unique challenge as sometimes consumers are expected to express uniform opinions and beliefs and when our individual views contradict one another this can be used against us. We are still learning and wish to know more about these experiences:

Consumer perspective is different from an individual consumer's views. Consumer perspective is a collective theoretical approach, or discipline borne out of a socio-political movement whereas consumers' views are individual and contextual.

Example: I take medication that works, and I wouldn't want to ever be deprived of that, however, that does not mean I would recommend that everyone in my situation should be prescribed this medication and take it.

How is consumer perspective different from the personal view expressed in this example?

CONSUMER PERSPECTIVE VALUES SUBJECTIVITY AND EXPANDED IDEAS ABOUT KNOWING AND BEING

Whereas other disciplines may claim the value of 'objectivity', for us, consumer perspective acknowledges and highly values knowledge gained through subjectivity – including how feelings and associated bodily and emotional reactions can produce knowledge. We considered how consumer perspective can involve authentic sensitivity to events, actions and ideas that others may not or cannot notice or experience. For us, such 'noticings' can be conceptualised as ways of knowing and being (epistemology – and ontology).

How does your own body tell you things (knowledge), is it easy or difficult to interpret? Can you think of instances where you were/were not able to act on what your body was telling you?

CONSUMER PERSPECTIVE SEEKS TO REMAIN DISTINCT

Consumer perspective often operates in contexts where it is competing with or is complemented by other disciplines such as nursing or social work. Nonetheless, it is important that Consumer Perspective remains unique. We don't want consumer perspective to be subsumed by other schools of thought or approaches. Nor do we wish for it to be subsumed by other well-meaning or otherwise movements or perspectives. Thus, we are invested in maintaining the integrity of consumer perspective, lest it become indistinguishable from other schools of thought.

Why do you think it is important that consumer perspective remains distinct?

CONSUMER PERSPECTIVE IS INEXTRICABLY BOUND TO PERSONAL EXPERIENCE.

Together, we acknowledged that there are many experiences which make someone a consumer. Interestingly, we did not think to ask each about what specifically these experiences were. This is because our experiences are tacit and understood by our claim to them. It is these experiences which inform and shape our consumer perspective. In addition, our specific experiences may shape our attitudes on certain topics. However, it is the experience of being a consumer that allows us a consumer perspective. Having said this, we also noted that not all consumers who work in mental health services actually work from a consumer perspective – they may be using their own lived experience but be separated from the collective, socio-political roots that comprise consumer perspective. Another example is when a consumer is employed in a nursing role and is therefore not working in a designated consumer perspective role.

What personal experiences do you draw on in your work?

CONSUMER PERSPECTIVE PROVIDES UNIQUE ANALYSES AND OFFERS CREATIVE ALTERNATIVES

From our personal experiences to our experiences in the workforce, we have been exposed to mental health systems in unique ways. Such experiences mean that we are uniquely positioned to provide systems analyses, identify gaps and problems and challenge anything which does not address needs or interferes with people's freedoms. We use consumer perspective to observe the status quo and we can articulate how it is lacking. We use consumer perspective to contribute to, challenge and create space for new ideas and alternatives to, and within, the current paradigm. We promote the need for and, create safe physical spaces.

What is a creative alternative idea you have for the mental health system?

CONSUMER PERSPECTIVE WORKS TO SUPPORT SELF-DETERMINATION OF PEOPLE

One of the aspirations we hold for our work is to contribute to the conditions people need to exercise self-determination. We consider this important particularly in the context of the denial of people's self-determination that we see in the context of legislated services. We did not specifically define or outline what self-determination means to each of us, however, it is evident that we desired for people to have the ability and support to control their own life and make their own decisions and we consider lack of self-determination to be an injustice.

Can you think of any other groups of people that have been denied their self-determination? What practices have they engaged in to resist this?

CONSUMER PERSPECTIVE ALWAYS HAS CONSIDERATIONS OF JUSTICE

We have experienced, witnessed and know of the injustice that occurs in mental health services and more broadly. This leads us to consider what is just and fair for people. We consider justice to include freedom for people to be who they are. When this expression is impinged upon we feel the need to defend freedom in whatever ways we can from within our particular contexts.

When have you experienced limits to your freedom and how did that make you feel?

CONSUMER PERSPECTIVE IS CONTEXTUAL. SOMETIMES WE FEEL LIKE WE ARE DOING 'BAND-AID' WORK, BUT WE STILL RECOGNISE THAT WE NEED TO STAUNCH THE 'BLEEDING'

The performance of consumer perspective is influenced by person and setting. Settings include hospital community, academia and government. Sometimes it is 'band-aid' work. By this we mean that it does not remedy structural problems. However, this is still important as without it there may be no one to staunch the 'bleeding'. When we use consumer perspective in our work, we are also connecting to those broader aspirations and desires informed by our principles, such as justice and freedom. We recognise the need for change in society, not just in mental health services, in all possible areas of life, from the individual to the political.

Accordingly, our work is pragmatic, principled, aspirational and more. We will work with people individually in a consciousness raising exercise or speaking using our stories to group of people. We will try and create something new through out writing and our research. With this we hope to influence government and influence society. This will require us to work on different levels, from outside and from within. Some of us use diplomacy. Others want to rebel.

What is an example of broader social change which be useful in addressing some of the problems within the mental health system?

CONCLUSION

We think that exploring consumer perspective is not a consensus building exercise. We have found it interesting to consider what it means for us, and we are interested to hear other people's thoughts on this. Has this helped others to think about what Consumer Perspective might mean to them? We wonder what consumer perspective may look like in your context and how you might use it. We would love to know.

REFERENCES

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