

Citizen In The Making

psychiatric disability support work and the long march towards citizenship

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As is the custom at these events, I wish to acknowledge the traditional custodians of the land on which we meet. It is also useful for my current purposes to do so, since this illuminates something about citizenship. Although Australian citizenship was granted to Aboriginal people 37 years ago, it is clear from their health, mortality and socioeconomic indicators that they are yet to enjoy the full rights and privileges of this citizenship. Compared to white Australia, Aboriginal people die 20 years earlier, are less than half as likely to complete year 12, are three times more likely to be unemployed, have 38% less household income, and are more than twice as likely to live in rented accommodation^{1,2}. Thus formal citizenship – the right to vote, own property, hold public office, and receive protection under Australian law – is not necessarily linked to one's quality of life, or to the possibility for achieving one's aspirations.

So it is for citizens with a psychiatric disability. We know what the general trends are for their physical health, income levels, employment status, life expectancy, and rates of homelessness. And so we could make similar observations about the achievement of real citizenship rights for people who live with a mental illness or psychiatric disability in Australia. This was the message of the Burdekin report in 1993, and sadly it is still largely true today.

But for the people I meet with a psychiatric disability, these indicators seem at odds with their so-called "lived experience". I get the strong sense from them that true citizenship means something else. It is mysteriously bound up in other realms of life, in dimensions of their experience not easily measured but which are more intensely real than mere socioeconomic data. For many people with a psychiatric disability, I believe true citizenship is connected to five key things:

- Enjoying relationships of mutuality and depth
- Having a diverse and accepting community to live in
- Creating a sense of place for themselves (which includes, but is broader than, having a home)
- Having the opportunity to contribute to something greater than themselves
- And, as needed, having access to a range of responsive services.

I am not denying the significance of poor physical health or poor vocational outcomes. I am not trying to romanticise life under the poverty line, or life under a bridge. Neither am I saying that we should abandon the struggle for the kind of systems reform that might reverse these rates of unemployment, suicide and homelessness. What I am saying is this: in the people I meet, I see a hunger for the kind of citizenship which mere voting rights or protection under the law cannot grant – a longing for something else. Something more holistic, more intensely personal, even mystical or spiritual. So it is that I cannot help wonder whether people with psychiatric disabilities have something to teach the rest of us about citizenship, about what constitutes real citizenship, and about those things most of us settle for instead.

A friend of mine recently told me about his niece, a woman in her early 20s, who lives with the ongoing effects of a traumatic brain injury following a car accident. Although the accident was horrific, her outcomes were much better than those of many people with acquired brain injury.

Despite memory and cognitive deficits, and problems in finishing her TAFE studies, she has managed to keep working at a local shop (with some support from the owner), where she is valued. Her personality has also changed. She is now very physically affectionate with people she knows, she is highly expressive and carries her emotions close to the surface. She often says just what she thinks, and lacks a certain amount of socially-prescribed inhibition. My friend commented ironically that it had taken a brain injury for someone in his (otherwise disconnected and aloof) family to become “normal” and express a “normal” range of emotions. This got me thinking about the people I have met with a psychiatric disability.

This paper is titled, *Citizen In The Making: psychiatric disability support work and the long march towards citizenship*. I want to offer some reflections on citizenship, psychiatric disability, and your role as support workers. In doing so, I hope to be sensitive to the fact that neither do I have a psychiatric disability nor have I worked as a support worker. I speak as an ally of the sector, as a systems advocate, and as a personal ally for someone in my own life who has a mental illness. I am conscious of the fact that so-called experts on sidelines (be they advocates, academics or ideologues) *can* get it wrong, and can sometimes be more devoted to their ideology than to the people their ideology was set up to serve. So I hope to approach this topic with a certain amount of humility and even hesitation, and I’ll rely on your feedback as to whether I’ve achieved this. I also hope to revisit this notion of humility a little later, and the hidden strength that it can offer to you as support workers.

So my original thesis, based on my experience with people who have a psychiatric disability, is this: true citizenship is that elusive promised land where open (rather than closed) community systems, soulful understanding of self and other, mystical participation in something beyond the self, a backdrop of responsive service systems, and the discovery of one’s place within the cosmos all conspire to make possible the *retrieval of the self* – despite, through or, in some cases, even *because of* the experience of mental illness. This idea, if you agree with me, has much to say about your role as support workers. It determines whether you see yourself as medical paraprofessional, as community-based alternative to a clinician, as babysitter and taxi driver, as unskilled personal care attendant, or as something else.

So here is my second thesis. I propose that this “something else” might well be a midwife or catalyst, an agent of citizenship who helps to facilitate the birth of another person’s vision – a vision which, after all, is basically the same one we all aspire to. Just like a midwife you help facilitate this birth process; you are a direct participant in the birth rather than some detached professional who just pops in every so often to check on progress. In working with the person, you help give life to something completely *other*, something greater and more mysterious than either of you, something that takes on a life of its own and has the potential to outstrip your expectations.

Now I’ve spent much of the last three years of my working life knee-deep in the formal services and support arrangements for people with a mental illness or psychiatric disability: advocating for programs, complaining about funding, critiquing policy and legislation. So the first thought that comes to my mind (and perhaps yours) is this: have we any hope of reaching this place of true citizenship when the formal service and support systems still lag so far behind the real need (despite the revolutionary changes in mental health over the last few decades)? Why bother talking about something so intangible as citizenship when you have a client at risk of suicide who cannot access any service, when it seems impossible to get someone out of an abusive living situation and into a real home of their own (which you know will help keep that person well), when as a support worker you can’t get the formal health or disability services to even return your phone calls let alone collaborate about a person’s care? What’s the point of citizenship?

And my response is to turn this question on its head. It is precisely *because* the system is in crisis that the ideal of citizenship is so important. You have a clear choice. You can wait for the slow tide of systems reform to bring about the necessary changes in how formal services operate and are funded – doing your little bit in the meantime and complaining loudly about the injustice of it all – or you can follow another path. So here is my third thesis: it may well be your daily actions as a support worker, and the seemingly insignificant actions taken by people who live with a psychiatric disability (and by their informal allies), that will bring about the cultural change which in turn allows for the eventual systems reform the sector longs for. For in journeying alongside someone with a psychiatric disability you are in a position to assist them to claim their own citizenship rights – however insignificant these rights might seem to others, and even in the face of evidence that suggests these rights do not yet exist. You are in a position to help them assert their right to have real relationships in their life, to assert their right to be a fully-fledged member of a local community group, to assert their right to be treated with respect and without discrimination, to assert their right for an equal place in a community that doesn't want them, to assert their right to have a secure sense of home and place, to assert their right not to be stripped of every last shred of dignity and self confidence by formal services (whether these be inpatient or community-based).

What I am talking about is adopting a faith-based practice as a support worker. That is, in working alongside someone on a particular issue you step out together in faith – believing everything to be possible, knowing what the worst outcome might be, and realising the most likely outcome is somewhere in between. And above all taking every opportunity to push the envelope, to expand the imagination of everyone you encounter, to stretch the limits of what is known and possible a little further each time. This takes faith – an inherent belief in both the value of your actions and the ultimate success of your endeavours, regardless of their immediate outcomes. It takes faith because in stepping out alongside that person, you are in fact conjuring up the idea of a society which might not yet exist. You might be calling for a level of acceptance, inclusion and innovation which others have not yet even imagined possible. But I propose that it is your expectation that this society can (and should) exist, and the concrete actions you take in support of this expectation, that may ultimately create the cultural change which is needed to drive the systems reform we need in psychiatric disability. This is my fourth thesis.

What this faith-based practice might look like is for each of you to discover for yourself. I will suggest only one thing. That it represents not only a catalyst for change, but is in fact your inner source of strength. It is that hidden place of quiet within you, from which you act and speak. It keeps you from lapsing into hysteria or cynicism or belligerence when things go badly. It is akin to the Aboriginal concept of *dadirri*³, through which you are like a tree amidst a raging bushfire. Your bark is scorched and your leaves burnt, but your roots still survive underground and your sap still flows deep inside. When the fire is over and the timing is right, you will be reborn. This is *dadirri*. I would argue that no lasting, positive social change is possible without it.

What I am saying in no way removes the need to pursue ongoing systemic advocacy and achieve systems reform in psychiatric disability – it does not. In fact, I would argue that these are two sides of the same coin, neither of them complete nor effective without the other. Systems change is constrained by broader cultural norms and limits; similarly the short-term success of your support work is constrained by the system's capacity for flexibility, responsiveness and innovation. What I am encouraging you to do (and here is my fifth thesis) is to find your own way, as a psychiatric disability support worker, of “holding the tension” and allowing this tension to creatively drive your daily practice.

This tension is between, on the one hand, acknowledging and confronting the systemic barriers to your work and, on the other hand, thumbing your nose at the system and its limitations and embodying this very change within your daily practice. As the (somewhat trite) saying goes, *become the change in the world you long for*. In challenging you to take up this creative tension, my hope is that you will be lifted beyond the vale of powerlessness as support workers. (How many times have I heard the words *I'm just the support worker*, or something to this effect?) As a systems advocate I know how powerfully a system can constrain someone's personal vision. But I am also aware of how quickly we revert to the default position of helplessness. It's so easy, and we all do it from time to time. We encounter some barrier in our work, we throw our hands in the air, point feebly to some broader issue, and retreat to the comfortable safety zone of powerlessness.

So what are the barriers? What is stopping you as a support worker from taking up this challenge to be an agent of citizenship in the lives of people with a psychiatric disability? The first barrier I wish to address relates to the previous discussion of power. Here I would like to introduce the concept of *resonance*. A clinical colleague of mine recently introduced me to this concept, and those of you with a counselling background are no doubt more familiar with it than I am. Here is my layman's attempt at it. Resonance relates to the interconnection between things – it speaks to the effect of one action or situation being felt (or *resonating*) within the orbit of another. For example, there is an inherent danger that an agency working in, say the domestic violence field, might gradually assume the characteristics of those who populate this field, both its victims and aggressors. So over time, without deliberate care and planning, the organisation could possibly become a highly dysfunctional morass of abuse, victimisation and emotional turmoil – not because “bad” people run it, but because of its *resonance* with the distressing and destructive landscape of domestic violence.

So what's this got to do with psychiatric disability?

In my time in the psychiatric disability sector, I have heard dozens of personal stories of humiliation, abuse, discrimination, failure of duty to care, misunderstanding, inappropriate or illegal incarceration, appalling neglect and sometimes brute physical violence. Many people who live with a psychiatric disability are very vulnerable, many have been disempowered through their interaction with a variety of human service systems. They've simply been *done over* – there is no more polite way of saying it. And these experiences have been woven into the fabric of the collective unconscious of our sector. I would argue that in many places, an almost tangible pall of grief hangs over the psychiatric disability sector. This puts our workers and our organisations at risk. The risk of resonance. The risk is that, through working day-in-day-out amidst the milieu of historic abuse and entrenched powerlessness, the tenor of our work and our mindset begins to shift. What starts at first as faint whispers – the quiet, confident winds of change rippling through the sector – become ever so slowly more frantic, more disillusioned, more anguished – become a howling crescendo of grief and powerlessness. When this happens, I would argue that our capacity for change – either individual or systemic change – is lost. In short, internalising your clients' experiences of helplessness and vulnerability does nothing to help them.

So here is my sixth thesis: the challenge for our disability support workers and support organisations is to remain *fully with* the people you serve – people who *are* vulnerable and *are* often powerless – but with the capacity to also stand apart from them and thus not become powerless yourselves. The challenge is to acknowledge and address the powerlessness of the people you serve while creating organisational cultures, workplace routines, styles of communication, your own individual practice frameworks, and especially individual advocacy approaches which are

not powerless. To identify with, but not internalise. For I would argue that this potential for entrenched powerlessness is both insidious and destructive. You are intrinsically powerful as support workers, whether you acknowledge this or not. Not least because of the role you play in the life of someone who may have no one else significant in their life.

Another barrier to becoming an agent of citizenship relates to those formal service deficits that I discussed earlier. Most of the workers in the field of psychiatric disability that I have met are acutely conscious of the shortcomings in the formal service systems in Queensland. Most of them can speak articulately about the dangers of the medical model, the limits of clinical-based treatment, the lack of government funding to community-based services, the involuntary treatment regime as agent of social control, government's historic poor understanding of psychiatric disability vis-à-vis intellectual disability, the disregard that professionals within formal service systems have for those working outside this system, the low expectations that traditional health and disability models have for a person's capacity for recovery, and so on.

None of these things I take issue with. I have seen first-hand examples of most of these systemic barriers over the past few years. Neither do I believe that continued systemic advocacy is not required on all these fronts – it is. What concerns me, however, is the discourse that we have created around these issues. It is the particular conversation we have with ourselves and with each other about these problems, and what this means for the individual who lives with a psychiatric disability, that concerns me. I want to propose that our preoccupation with the shortcomings of the formal service and support arrangements will guarantee that the people with psychiatric disability who you serve will forever remain patients, clients, consumers and service users. Perhaps over time they will become better-served, more independent and better-functioning patients, clients, consumers and service users. But that is all.

So here is my seventh thesis: unless our support workers and support agencies have the capacity to imagine something more than just a well-resourced and humane formal service system, the intensely personal, mystical vision of citizenship that I talked of earlier will never be realised in the lives of people who live with a psychiatric disability. My hope is that you won't allow yourselves, your collective discourse, and your imagination for what is possible to be constrained by the formal service agenda. It is enough that the formal systems have let people down – don't allow them to dominate the agenda for your work and your vision as well. Most people who have a psychiatric disability seem to know this already. They know that even in a perfect world the health and disability systems won't deliver what it is they essentially want out of life. So again, this is about holding the tension – to drive for the necessary reform in formal service systems, and to pursue something else that will always lie beyond these systems' reach.

While on the topic of imagination, I'd like to talk about the temptation and tyranny of frameworks. Others in the field have worked to promote the importance of frameworks to guide our decision-making and help us examine the hidden assumptions that underlie our work. So I won't revisit this territory. Instead, I want to discuss our *use* of frameworks. There are various models and frameworks for direct support work practice. They each have their devotees and their detractors. Two frameworks relevant to this discussion are, in the disability field, Social Role Valourisation and, in the health field, the Recovery Framework. From what I know of each, they both have elements and principles that are highly useful for your work as psychiatric disability support workers. I'm not going to critique these frameworks – I don't believe it's my place to do so. But I am going to urge you to resist the temptation and the tyranny that any framework presents. The temptation is to find in them a readymade, one-size-fits-all way of understanding and responding to the world. The tyranny is that they can become the last word, the *only* word, and a weapon in the ideological battles we have with each other.

In talking with people whom I consider good support workers, people who believe in and value their work, I have been struck by how creative, flexible, boundless and lateral-thinking they are. They have a knack for finding an original solution to a complex issue. They unearth new perspectives on old problems, and will pursue multiple, seemingly conflicting possibilities at once. They borrow elements from this framework, and principles from that model. They can live with the tension of uncertainty and unknowingness. They can work with *what is* and with *what is yet to be* at the same time. They turn the idea of *muddling through* into an art form. There is something unique about the quality of these human beings. So here is my eight thesis. I would like to propose that perhaps good psychiatric disability support work is an art form rather than a science, and is perhaps a little like motherhood. They say that motherhood engenders in women the capacity to do several things at once, balance competing demands and operate on a number of different levels simultaneously. So I encourage you to take those practice frameworks you consider useful and apply your own innate sense of creativity, spontaneity, insight and even risk-taking.

Two more quick comments about frameworks. First, be cautious that, in using a framework which emphasises the *vulnerability* of someone who lives with psychiatric disability, you do not blind yourself to the person's capacity for wholeness, achievement and recovery, nor to your potential role as agent of citizenship. Second, I encourage you to critically evaluate the content and the spirit of any proposed framework in terms of its potential to serve the goals of citizenship. I wonder if any of the current paradigms in disability support work explicitly address the realisation of genuine citizenship as a primary goal? If not then perhaps I could take this opportunity to call for one that does. These points constitute my ninth thesis.

And finally, as I promised, let's return to the idea of humility. I want to propose a tenth (and final) thesis: that humility is an essential component of psychiatric disability support work.

Mental illness is still a mystery to us. For all that we do know about it, there is still much we don't know. Its causes, its cures, the courses it takes in people's lives, and the essential components for retrieving the self. This is very humbling, both for the psychiatrist and the support worker. At the end of the day you are simply one human being journeying alongside another. But this simple, humble thing is also intensely powerful. In many cases it has been the simple presence of another human being, acting with integrity and constancy in journeying alongside someone with a psychiatric disability that has made all the difference in that person's life.

This humility is important for all of us. How many times have we seen people wear the badge of "consumer" or "advocate" or "service provider" with angry defiance and a self-righteous arrogance that asserts the right to speak for everyone and to make wild claims? You may well have done this yourself. I think I probably have. It is often the same people who complain about being "locked out" by the system, unable to effect the changes they want. I sometimes wonder whether it would be more powerful to wear the badge of "fellow human being" instead. Consumers and advocates are all too easy for bureaucracies to dismiss. (To them, consumers are self-involved patients with no real life of their own, who live vicariously through the problems of others. Advocates are seen as self-righteous ideologues who care more for their dogmas than for people.)

But the badge of "fellow human being" has an intrinsic strength – a natural authority that is invested in you as a citizen standing alongside, and expressing your alliance with, another citizen. (This is what I understand to be one of the strengths of the citizen advocacy approach.) In something that seems small and unofficial, hovering in the margins, there is strength. It is the quiet,

confident strength of someone who simply believes in what they are doing and who knows they have a right to be there doing it.

So your role as a support worker may be a humble one in the big scheme of things. I suggest that this is not necessarily a bad thing, and I encourage you to wear the badge of “support worker” or “advocate” with some humility. For this humble role is one in which you may yet find an unexpected and intrinsic source of strength and power, as you chisel away at your daily task: citizen in the making.

Thank you for listening.

Overview

Thesis one

True citizenship is that elusive promised land where open (rather than closed) community systems, soulful understanding of self and other, mystical participation in something beyond the self, a backdrop of responsive service systems, and the discovery of one's place within the cosmos all conspire to make possible the *retrieval of the self* – despite, through or, in some cases, even *because of* the experience of mental illness.

Thesis two

Your role as psychiatric disability support worker might be like that of a midwife or catalyst – an agent of citizenship who helps to facilitate the birth of another person's vision.

Thesis three

It is your daily actions as a support worker, and the seemingly insignificant actions taken by people who live with a psychiatric disability (and by their informal allies), that will bring about the cultural change which in turn will drive the eventual systems reform the sector longs for.

Thesis four

Adopt a faith-based practice, in which your daily actions conjure up the idea of a society of acceptance, inclusion and innovation – a society you believe in, but which does not yet fully exist. This practice is fuelled by *dadirri*: your inner source of strength and quiet.

Thesis five

Find your own way of “holding the tension” between, on the one hand, confronting the systemic barriers to your work and, on the other hand, thumbing your nose at the system and its limitations, and embodying this very change within your daily practice.

Thesis six

You need find a way to remain *fully with* the people you serve – people who are vulnerable and often powerless – but with the capacity to also stand apart from them and thus not embrace powerlessness yourself.

Thesis seven

Don't allow yourselves or your imagination to be constrained by the formal service agenda. Imagine something *more* than just a well-resourced and humane formal service system, so that this intensely personal, mystical vision of citizenship can be realised in people's lives.

Thesis eight

Perhaps good psychiatric disability support work is an art form rather than a science, and a little like motherhood. Use your own innate sense of creativity, spontaneity, insight and risk-taking.

Thesis nine

Critique any proposed practice framework in terms of its potential to serve the goal of citizenship. Be wary of embracing a framework that emphasises someone's vulnerability at the expense of achieving their vision of citizenship.

Thesis ten

Your role as a support worker may be a humble one in the big scheme of things. But it is one in which you may yet find an unexpected and intrinsic source of strength and power, as you chisel away at your daily task: citizen in the making.

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Endnotes

- ¹ Australian Bureau of Statistics, Australian Social Trends 2002: Health – Mortality and Morbidity: *Mortality of Aboriginal and Torres Strait Islander peoples*.
- ² Australian Bureau of Statistics, Population Characteristics, *Aboriginal and Torres Strait Islander Australians*, 2003.
- ³ Miriam Rose Ungunmerr in Stockton E. *The Aboriginal Gift: spirituality for a nation*, Alexandria, NSW: Millennium Books: 1995.