

# **LEADERSHIP FOR EMPOWERMENT AND EQUALITY: A proposed model for mental health user/survivor leadership**

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## **ABSTRACT**

The leadership of people with lived experience of mental health problems is underdeveloped, when it comes to leadership in one's own recovery, at the service level, and at the systemic level. Unlike the mental health system, the user/survivor movement has a values base of empowerment and equality. But the movement has not yet created an explicit model of leadership based on these values. Conventional models of leadership have little to offer but critiques of it provide a good framework for users and survivors to build its own model of leadership upon. If user/survivor leadership is to thrive, new roles, practices and competencies need to be developed. At a deeper level there needs to be philosophical, psychological and political shifts in service systems if user/survivor leadership is to ever take root. Furthermore, the leadership of empowerment and equality should pervade all the leadership in service systems and beyond.

### **Keywords**

Mental health, leadership, service users, survivors, equality, empowerment, values, lived experience.

### **Implications of the article for leadership in practice**

We need to develop an explicit model of user/survivor leadership based on the values of the user/survivor movement. This will enable:

- recognition of user/survivor leadership and a debate on it
- more attention to be given to its development
- other mental health leaders to reflect on the relevance of the user/survivor leadership model to them
- greater equality and empowerment at all levels of the system.

## 1. INTRODUCTION AND BACKGROUND

This paper has been written for mental health leaders. Its purpose is to start a discussion within mental health circles on user/survivor leadership in mental health. A user/ survivor is a person who has used services, often specialist mental health services, to assist them resolve their mental health problems. Mental health leaders need to develop a more nuanced understanding of this emerging group of leaders. What are the origins of user/survivor leadership? What defines it? How does it need to be developed? What roles and practices support it? And what are the unique competencies required to be a user/survivor leader?

This paper explores user/survivor leadership at three levels - the individual level, the peer run organisation or mental health service level, and the systemic level. It draws on generic models of leadership from the military, government and corporate worlds, and from critiques of these models of leadership. It then suggests a model of leadership that fits the purpose and values of the user/survivor movement, followed by a discussion on how this model can be expressed in practice.

The international mental health user/survivor movement has been around for nearly 40 years (Chamberlin, 1990). It started as a protest movement but over time it has become more diffused into the mental health system. The movement has created leadership opportunities in its independent activities and the idea of leadership in one's own recovery, but policies of service user participation in mental health services have failed to deliver consistent participation, let alone service user leadership.

Part of the problem lies with the unequal distribution of power and resources, which is reflected in the lack of infrastructure to develop peer-run initiatives, and the failure to provide users and survivors with mentoring, tailored training and development, career pathways, standards of practice and so on. Part of the problem also lies with the concept of participation itself. To participate people have to rely on the goodwill and invitation of others. In the last decade some users and survivors have used a stronger concept, one that visualizes users and survivors as equal to others, as the most informed about our needs, and able to take the initiative. This concept is leadership. Unlike participation, leadership assumes people with mental health problems have the power to set the agenda, make major decisions and control resources. Having said that, leadership of any sort must have boundaries; it should never be absolute and it needs to be shared.

Although there is a growing body of literature on user/survivor leadership, the movement has yet to engage in an explicit discussion on the best models of leadership for users and survivors (Brown et al, 2006; Gordon, 2004; Happell et al, 2006; Orwin et al, 2009; Potter et al, no date; Ten Hoor, 2002; Victorian Quality Council, 2007; Wituk et al, no date). A search turned up only one paper that broached this subject (Fisher, n.d.).

Before starting a discussion on user/survivor leadership in the mental health arena, it is important to acknowledge the changing landscape of the movement and of mental health sectors.

A high proportion of people who use services are young, indigenous, or from ethnic minorities. All these groups have their own experiences of marginalization and all to some extent have formed social movements based on the same principle of self-determination as the user/survivor movement. People from these groups may be doubly disempowered in the service context. The user/survivor movement in many countries is predominately white and middle aged. There are signs that young people do not identify with the user/survivor movement in the same way as people who are older than them. This has more to do with identity than values. Young people are less likely to have spent long stretches in large institutions and to take on a strong 'mental patient' identity, which for the older generation who joined the movement, became the psychiatric user or survivor identity. Ethnic movements, indigenous movements and today's young people will probably accelerate the diffusion of the user/survivor movement into services and other social movements. The fundamental values all these movements share will probably remain.

To a degree this paper assumes users and survivors are located in or around specialist mental health services. This may turn out to be as anachronistic as the current conception of the user/survivor movement. If as predicted, mental health sectors merge more with prevention, primary health, social services, non-profit or voluntary agencies, they will lose their bounded identities. User/survivor leadership needs to occur in all sectors that provide them with services or assistance. The diffusion of both the user/survivor movement and mental health sectors can be seen as a downstream consequence of deinstitutionalisation.

## **2. CONVENTIONAL MODELS OF LEADERSHIP**

Historically, the study of leadership started in the military, which at the time was a major driver in European conquest of many parts of the globe. Since the middle of the 20<sup>th</sup> century, western expansionism has been driven more through large multi-national corporations.

Traditionally, corporate leadership was exercised through a transactional military style command and control regime, with the individual Chief Executive Officer giving commands from the top of a steep pyramid. In recent decades corporate leadership has evolved from transactional leadership to transformational styles of leadership, with flatter hierarchies, delegated responsibilities and the use of 'inspiration' rather than 'commands' to motivate the workforce. The ultimate purpose of both these corporate styles of leadership is to make a profit for the shareholders.

The mental health system has mimicked and adapted both corporate styles of leadership. The asylum era was characterised by command and control, and echoes of this continue today. The new right economic ascendancy of the late 20<sup>th</sup> century had a profound impact on the public sector in a number of western countries, and led mental health sectors to adopt more modern corporate leadership styles, including the introduction of management professionals in place of psychiatrist and nurse administrators.

Publicly funded mental health systems do not have to generate a profit for shareholders. Their dual and somewhat conflicting purpose is the facilitation of recovery, as well as the

control of people diagnosed with mental illness who are deemed a danger to themselves or others. In response to professional beliefs, community expectations and political pressure to ensure control, leadership in large mental health services tends to be preoccupied with risk management at the expense of more responsive or innovative goals that private sector companies are often more able to pursue. At the individual level, the leaders in the professional-patient relationship have traditionally been the professionals, deemed to have a near-monopoly on expertise and in knowing what is best for the patient.

In today's world military, corporate, and government funded systems either co-exist, collaborate or compete in the quest to control resources, people or risk – sometimes for the greater social good, sometimes not.

The user/survivor movement arose from the oppressive treatment experienced by people diagnosed with severe mental illnesses. This includes forced interventions, damaging treatments, segregation in institutions and social exclusion. In response, the user/survivor movement was founded on the principle of self-determination; it has non-negotiable values on equalising the distribution of power and on 'empowerment' for users and survivors at an individual and group level. These values apply to power and relationships within the movement, but the movement also advocates for their expression in mental health services and in the position people with lived experience have in society.

## **1. CRITIQUES OF CONVENTIONAL LEADERSHIP**

Neither the traditional transactional nor contemporary transformational styles of leadership, nor their public sector variants, sit comfortably with the user/survivor movement, or with many other socially marginalised groups.

Some leadership thinkers, including feminists, have comprehensively critiqued conventional transactional and transformational leadership thinking, and they offer the user/survivor movement an alternative framework to build its own model of leadership upon (Calas et al, 1991; Collinson, 2005; Czarniawska et al, 1991; Fletcher, 2004; Fournier et al, 2000; Grint, 1997 & 2000; Gronn, 2003 & 2006; Knights et al, 1992; cited in Sinclair, 2007). These thinkers have raised concerns about conventional leadership which resonate with the experience base and values of the user/survivor movement. It's not difficult to construct an alternative framework for understanding user/survivor leadership, based on these critiques.

### **3.1 Conventional leadership approaches focus on the 'how' of leadership without examining its purpose.**

The purpose of user/survivor leadership is clear because its values are clear. Leadership must work towards the equal distribution of collective power and the empowerment of individuals and groups.

### **3.2 Conventional leadership approaches tend to assume that leadership is inherently good.**

The user/survivor movement would claim that if leadership strays from the purpose of empowerment and equality, and takes power and responsibility away from others, it can no

longer be seen as morally good. This view is largely based on life experiences of being subject leadership in the mental health system and society that marginalizes people and takes away their personal power.

### **3.3 Conventional leadership approaches deny the darker forces at play, such as power and greed.**

Users and survivors, like all marginalised people, are often more sensitive to control and exclusion than people whose predominant experience is one of privilege (such as some professionals or corporate leaders). Users and survivors are likely to have an intuitive feel for the misuse of power, both subtle and obvious. Suspicion of power has been so strong in the user/survivor movement, that it has been difficult for people within the movement to exercise leadership without being 'shot down' by their peers. On the other hand some user/survivor leaders have been known to exercise unacceptable control over others; people who lack an alternative approach to leadership may mimic the leadership that they have experienced earlier in life, including within the mental health system. A more adaptive response than this is needed in the user/survivor movement – one that practices 'power with' rather than 'power over' and shares leadership for the greater good.

### **3.4 Conventional leadership approaches focus on the individual leader as the hero, who takes away responsibility from followers.**

In order to reach a state of empowerment and equality, users and survivors tend to believe that their leadership should be distributed through the sharing of responsibility and recognition, and through a broader definition of leadership than the lone hero preaching from the top of the pyramid. Leadership in the group user/survivor context needs to recognize there are a variety of leadership roles in the collective user/survivor or mental health settings, and key decisions need a broad consensus. Leadership in one's own recovery includes shared leadership with the mental workers involved in providing an individual a service.

### **3.5 Conventional leadership approaches lack inquiry into the personal and sociological factors that shape their leadership.**

The user/survivor movement bases much of its knowledge on lived experience. For many this includes marginalisation, trauma, deprivation and other negative life experiences, both as determinants and consequences of mental health problems, as well as the trauma created by the mental health services. Context has consciously informed the movement's approach to power and leadership.

### **3.6 Conventional leadership approaches believe their creed on leadership is universally applicable.**

A close parallel to this critique is the respect for individual and diverse subjectivities that lies at the heart of the user/survivor movement. There is no universal or 'correct' reality. Users and survivors do encourage each other to reframe their stories, but the purpose is to increase wellbeing rather than to 'correct' their stories. User/survivor leadership must be respectful of diverse experiences.

### **3.7 Transformational leadership does not bring better results than transactional leadership, despite a huge leadership development industry that supports it.**

In today's world biological psychiatry and the multi-national drug companies exert the most powerful leadership in the mental health arena. They dominate the discourse, evidence base, resources and service delivery in mental health. This leadership critique has a parallel when one considers the huge resources taken to maintain psychiatric and drug company leadership, in contrast to their modest contribution to recovery and wellbeing for users and survivors.

### 3.8 Summary of user/survivor critique of conventional leadership

Conventional Leadership	User/survivor leadership
Focuses on the 'how' of leadership, not its purpose.	The purpose of leadership is equality and empowerment for peers.
Assumes that leadership is inherently good.	Leadership is only good if it enhances empowerment and equality.
Denies the darker forces at play, such as power and greed.	User/survivor experience 'power over' has left them suspicious of it and in need of a model of 'power with' leadership.
Focuses on the individual leader as hero who takes away responsibility from followers.	A broad definition of leadership and a belief in sharing it.
Lacks inquiry about personal and social factors that shape leadership.	Knowledge base is one of lived experience.
Believes their creed on leadership is universal.	Respect for diversity of lived experience.
Transformational leadership does not bring better results despite a huge industry that supports it.	Biological psychiatry and drugs make a modest contribution to recovery despite huge resources that support it.

### 3.9 Other critiques

Some of the criticisms of conventional leadership resonate with the experience and world view of many marginalised groups, including indigenous peoples. For instance, colonised indigenous people are familiar with the dark side of leadership, they understand issues in a broad ecological context, and they straddle multiple world views (Goldsbury, 2007; IIMHL Indigenous Leadership Group, 2009). It is inevitable that indigenous peoples' views of leadership will not fit well with conventional western views.

It's interesting that the critiques on conventional leadership also resonate with the user/survivor movement's critique of biological psychiatry. This includes the movement's observations that psychiatry believes in its own moral good when the profession has also done harm, psychiatry tends to take responsibility away from the patient, it is reductionist and lacks inquiry into the context of people's lives, and it believes that medicine has a monopoly on evidence and solutions. There are of course thinkers and networks within psychiatry, who have similar criticisms of the dominance of biological psychiatry, to the user/survivor movement criticisms (Bracken & Thomas 2005; Double 2006; Cohen & Timimi 2008).

## 4. PRACTICES AND ROLES

How can this framework for user/survivor leadership be put into practice? Many of the answers lie half hidden in the user/survivor movement, the recovery philosophy, anti-discrimination and in exemplary user/survivor initiatives and partnerships.

#### **4.1 Leadership at the individual level**

Leadership in one's own recovery forms the backbone of the recovery philosophy. All the following approaches promote the leadership of users and survivors in their own recovery:

- Use of peer support e.g. intentional peer support (Mead, 2009) and WRAP planning (Copeland, 2009).
- Engaging in recovery education (Centre for Psychiatric Rehabilitation, 2009; Vocal, 2009).
- Collaboration with mental health professionals e.g. strengths assessment and personal planning (Rapp, 1998), and shared decision making in medication management (Deegan & Drake, 2006)
- Personalisation (Department of Health 2009), and self-directed care (University of Pennsylvania, 2009)

#### **4.2 Leadership at the service or user/survivor run initiative level**

##### ***In peer-run initiatives***

Although these initiatives are led by users and survivors, the movement's values insist that leadership should be shared within the group. Successful user/survivor initiatives often use the following processes to ensure this:

- Articulating and promoting an explicit values base.
- Governance by the members or other users/survivors.
- Management decisions by consensus with staff and members.
- Active promotion of different types of leadership within initiative eg leading one's own recovery, leadership in particular activities, informal leadership among close peers.

(O'Hagan et al, 2009)

##### ***In mainstream services***

User/survivor leadership in mainstream services needs to occur both in generic roles and in user/survivor specific roles. Mainstream services need to take on the values of empowerment and equalising the distribution of power if user/survivor leadership within them is going to thrive. User/survivor leadership at this level can take place in governance, management, delivery, training and evaluation.

#### **4.3 Leadership at the systemic level**

Similarly, at the systemic level, user/survivor leadership needs to occur in generic and user/survivor specific roles that both provide an opportunity to express equality and empowerment values. Users and survivors can take on systemic leadership roles such as politicians, senior public servants, planners and funders, researchers and systemic advocates.

## **5. COMPETENCIES**

There is a history of failures in user/survivor participation and leadership. The reasons are often complex. They include lack of definition of the role or initiative, a lack of a supportive infrastructure, burnout from expectations that outstrip capacities and resources, benign neglect from mental health funders or managers, discrimination, lack of workplace adjustments, and lack of user/survivor skills and competencies. These failures can also demonstrate a lack of an explicit understanding among user/survivor leaders of the nature and obligations of their leadership. All these issues need to be addressed directly, but the approach that can gain the quickest and easiest traction is probably increasing user/survivor skills and competence.

Users and survivors need the same skills to fulfil leadership roles as anyone else does, but they may lack some of these generic skills due to previous loss of opportunities. A good number of users and survivors also enter into participation and leadership roles without a formal process to check they have the skills for the task. It's not uncommon for user/survivor run organisations to collapse because the leaders lack financial, human resource management or governance skills. Users and survivors who lead within the mainstream system may lack a guiding professional infrastructure, an intellectual platform, a coherent values base, or the skills to challenge in ways that are safe for them and effective for others. Coming from a marginalised position in society, user/survivor leaders may not always know the unspoken 'rules of power' that the people who run the mental health system are so familiar with.

Many of these problems can be ameliorated with training and development in the generic competencies as well as those specific to users/survivors. All user/survivor training and development needs to be overlaid with equality and empowerment values, (in fact all mental health training should be overlaid with these values). These values and the competencies that derive from them are often not explicit in current training programs or are crowded out by other values and leadership models.

### **5.1 Competencies in individuals leading their own recovery**

The competencies needed by individuals for their own recovery include:

- Viewing themselves as experts by experience.
- Knowledge of service options, treatments and rights.
- Knowledge of how to get the most out of services.
- Positive communication and assertiveness skills.
- Negotiation and collaboration skills.

At the same time, mental health workers need to take on these competencies as well as encourage them in service users.

### **5.2 Competencies in users and survivors working for the collective good**

Both the generic and specific competencies needed to enable user and survivor leaders to express their values at the collective level. Many of the specific competencies also strengthen user and survivor leaders' ability to apply their values to the generic competencies they have learnt.

### ***Generic competencies***

- Understanding of mental health issues.
- Understanding of other stakeholder groups and their drivers.
- Knowledge of the mental health system and how to navigate it.
- Strategic thinking and political judgement.
- Organisational skills at governance and management level.
- Ability to meet multiple accountabilities.
- Meeting protocols.
- Positive communication skills, flexibility and constructive responses to resistance and conflict.
- Self-awareness and the ability to reflect on one's behaviour.

### ***User/survivor specific competencies***

- Personal development through the experience of mental distress.
- Familiarity with user/survivor movement knowledge and values.
- Familiarity with critiques of mental health treatments, services and rights.
- Familiarity with trauma and negative consequences of compulsory processes.
- Ability to not collude with compulsory processes.
- An analysis of power.
- Empathy for other users/survivors.
- Self-disclosure of personal experience to peers when it benefits them.
- Respect for the autonomy of peers.
- Ability to encourage others to use their strengths and resources.
- Ability to enable consensus decision making or others to make decisions.
- Ability to relate to diverse groups of users and survivors.
- Ability to be non-judgemental about other people's realities or stories.
- Ability to role model above.

Of course, mental health workers without lived experience could do with many of these user/survivor specific competencies as well.

## **6. CHANGES NEEDED**

The mental health system was founded on values that are the antithesis to empowerment and equality. Therefore, user/survivor leadership will only thrive with some seismic shifts in the mental health arena on every level.

Firstly, there needs to be a philosophical shift in the way people view madness, from the deficits-based pathology view, to the view that madness is a crisis of being that value and meaning can be derived from (Mental Health Advocacy Coalition, 2008). This is essential because the root of all forms of discrimination is the denial that madness is a legitimate human experience; the deficits-based view perpetuates inequality and disempowerment, despite its benign intent.

Secondly, there needs to be a psychological shift within users and survivors themselves, from a marginalised disempowered identity to empowered identity. Similarly, some people in the mental health workforce need to change their identities from expert authorities to expert advisors.

Thirdly, there needs to be a political shift from power and resources dominated by professionals and managers without lives experience to at least an equal power sharing with users and survivors. This is more likely to happen if users and survivors are in leadership roles at all levels of the system – as bureaucrats, managers, academics and in their professions. We need position power.

Fourthly, there needs to be a practical shift that enables services, systems, users and survivors to:

- Create opportunities for users and survivors collaborate in clinical decisions.
- Define peer run initiatives, their competencies, ethical standards and new practices.
- Plan and fund peer-run initiatives.
- Develop the peer workforce.
- Democratise decision making in services and systems.
- Hand over more resources, decision making and responsibility to service users.
- Encourage users and survivors to enter into mental health training and employment.
- Continue to develop recovery-based services that promote hope, self-determination, a broader range of options, and equality for users and survivors in services and in society.

## **7. CONCLUSION**

The views on leadership in the user/survivor movement are not as explicit as they could be. This is partly due to the movement's lack of a well developed or recognised intellectual tradition, lack of infrastructure, as well as a deficit of money and power. There is a strong consensus within the movement that empowerment and equality are not negotiable. This presents a major challenge to the mental health system and wider society. User/survivor leadership cannot grow unless services become democratised and genuinely implement the recovery philosophy. In other words, the values of personal empowerment and equality need to drive helping systems and the way wider society responds to mental health issues, as well as driving the user/survivor movement.

This paper has proposed an explicit model and explanation of user/survivor leadership. It has also touched very briefly on some of the changes, practices, roles and competences that support user/survivor leadership. Much more work needs to be done on debating and refining this model of leadership, and on defining and implementing the conditions that will allow genuine user/survivor leadership to thrive.

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