

Anger, Activism and Recovery: A recovery-oriented overview of the psychiatric survivor movement

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Abstract

The paper addresses the role and importance of anger, activism and the psychiatric survivor movement in people's recovery, and speaks to the inter-relationship between the survivor movement and the development of the recovery phenomenon. The paper makes the point that the survivor movement's emphases on self-help, self determination, rights education/advocacy, empowerment and a caring community provided the bedrock and the motivational spirit for what is now conceptualized as the recovery movement. The paper directly links the survivor movement with recovery as a paradigm shift, at the same time as it asks whether this link will result in increased influence and economic security for survivor driven recovery-oriented programs. The paper also addresses the necessity of professionals and policy-makers recognizing the primacy of survivors within a recovery process and supporting their autonomous role in service provision. And, it posits the necessity of sustained survivor activism for recovery-oriented reforms to occur.

The recovery model is generating a lot of excitement in the community mental health field. Psychiatric consumer/survivors such as Pat Deegan & Mary Ellen Copeland have become recovery experts, and are leading the field with their highly original approaches on recovery. However, they are just two prominent actors in a broad political movement that is rich in humanity and creativity, and that one way or another has always been about recovery. That movement goes back to the early seventies starting in the Bay Area and New York; known then as the ex-patient movement, it is now generally known as the psychiatric survivor movement.

The early survivor movement was a way for people to channel their anger and frustration with psychiatry and their experiences of abuse and social control. However, the movement did not get stuck in an adversarial role. The survivor movement also played a crucial role in creating the conditions that gave rise to the recovery model (which is based on statistical evidence that a significant percentage of people with serious mental health problems can, and do recover). The survivor movement's ideas and demands on self-help, self-determination, human rights, advocacy and a caring community were expounded as early as 1971, and these ideas are now treated as some of the key principles and provisions of a recovery approach. Essentially, without a survivor movement, the recovery model would likely not be unfolding before us as a paradigm shift in our field.

In order to better understand the interrelationship between survivor activism and the recent emergence of a recovery paradigm we have to consider the conditions that gave rise to a survivor movement. Ex-patients felt they had to get political in the form of a civil rights movement because they were angered by their own experiences of systemic abuse, depersonalization and

compounded hopelessness. People felt compelled to challenge a system that was notorious for its paternalism, intransigence and neglect. They sought social justice and reform so that other people would not be abused by the system. They felt moved and inspired by other civil rights movements, and were resolved to resist their institutional oppressors, and at the same time create a new tableau for increased hope and recovery.

Jacobson (2000) states “Recovery is, in part, an outgrowth of the consumer/survivor/ex-patient movement, a social movement with overtly political goals. Like many other social movements that emerged at around the same time, the c/s/ex movement sought recognition and rectification of the marginalization and oppression imposed upon people diagnosed with psychiatric disorders. The goals of the movement were voiced in the language of empowerment, a notion which encompassed both the individual sense of the word...and a broader more political agenda that looked for power sharing in all parts of society.” She also describes them as pushing for “societal changes that will facilitate human rights, and thus recovery...by reducing (and then eliminating) stigma and discrimination against persons with psychiatric disabilities.”

As with Deegan and Copeland, the survivor movement has spawned a great tradition of leadership, moral authority, political courage, eloquence, compassion and commitment. Within this movement it is rather remarkable there is such a great wealth of leadership. They seem to miraculously emerge from the ashes of oppression and adversity, resolved to challenge an uncaring system and bring hope and relief to their fellows.

A Historical Glimpse

As an example of inspired, and inspiring survivor leadership, we can go back as far 1840 when an extraordinary Englishman named John Thomas Perceval pledged to protect his fellow inmates from the cruel excesses of the madhouses. Perceval was a disenchanted aristocrat who had sought meaning in spirituality. Acting strangely, he was subsequently locked up by his mother, and remained in an asylum for three years. He endured terrible torments, and witnessed acts of great cruelty. He then devoted himself to becoming well, to being strong enough to speak for all the others who would never leave the asylum to tell the truth about the horrors of their treatment. As he became well, he took a vow:

“ I resolved – I was necessitated- to pit my strength and abilities against that system, to fail in no duty to myself and to my country; but at the risk of my life, or my health, and even my understanding, to become thoroughly acquainted with its windings, in order to expose and unravel the wickedness and the folly that maintained it, and to unmask the plausible villainy that carries it on.” (*see Podvoll*)

Perceval formed the “Alleged Lunatics’ Friends Society” which was highly successful in its advocacy work. For twenty years the society was tireless in its efforts to protect the civil liberties of mental patients, correct asylum negligence, expose asylum greed and corruption, and represent indigent patients before the courts. He was eventually named as the ‘Guardian of the parish of Kensington’, but Perceval preferred a more accurate occupational title, saying: “*I consider myself the attorney-general of Her Majesty’s madmen.*”

Imagine the awesome respect that the psychiatric inmates of that period would have had for Perceval, their champion. One can appreciate that he probably sparked a foreign emotion in most of them, for the first time, hope, the vital ingredient for the commencement of recovery.

Anger & Activism

However, aside from Perceval and some other encouraging historical actors (i.e. Clifford Beers), it was much later before psychiatric patients would take strength, inspiration and hope from brave and resourceful leaders. Well up to the seventies, people were still being treated like hopeless cases, and as fitting subjects for experimentation and heroic medicine. (N.B. In that regard, perhaps the most scathing and revealing examination of life on a modern psychiatric backward was captured by Richard Cohen and Kevin Rafferty in their chilling and deeply moving film documentary, "Hurry Tomorrow." - 1975). Finally, fired up by the example of other 'liberation' movements the ex-inmates began picketing and protesting coercive psychiatry, over-drugging, social control and injurious treatments such as electroshock.

These actions had predictable and noteworthy results. The ex-patients felt enlivened by finding their voice and stating their opposition to 'the system', and in so doing they effectively discovered that political outrage and recovery spin on the same axis. Oppression spurs resistance, and against the odds people frequently feel stronger for the effort. Survivor activist, Rae Unzicker says that her anger about her experience of hospitalization led to her getting stronger and feeling more defiant. She says "hope manifested itself largely as an upsurge of righteous anger." She calls "her spirit of defiance...a perpetual birthday gift that I am still uncovering." (see Ridgway, 2001)

Judi Chamberlin (1999) also stresses the link between anger, activism and recovery. She says:

"What I'm saying is that there's something about being a "good patient" that is, unintentionally, perhaps, incompatible with recovery and empowerment. When many of us who have become leaders in the consumer/survivor movement compare notes, we find that one of the factors we usually have in common is that we were labeled "bad patients." We were "uncooperative," we were "non-compliant," we were "manipulative," we "lacked insight." Often, we were the ones who were told we would never get better. I know I was! But twenty-five years of activism in the consumer/survivor movement has been the key element in my own process of recovery."

Arguably, 'righteous anger' can have as much to do with recovery as good therapy, regular exercise, good nutrition and walks in the country. Finding your voice and trusting the spirit that enables us to speak truth to power is very freeing and definitely restorative after a period of self-doubt and vulnerability. And, as a British study (Drury, 2002) demonstrates, any form of activism in the cause of the common good and social justice is good for one's general and mental health. The researcher comments on the "centrality of emotion in the accounts" of protest events. He says, "Empowering events were almost without exception described as joyous occasions. Participants experienced a deep sense of happiness and even euphoria in being involved in protest events."

Righteous anger in the form of a protest, however, is not an adequate in and of itself. And, the survivor movement should not be limited in our conception to a picket protest outside a psychiatric conference. The movement has been much more constructive than it has been reactive. It has channeled its collective anger into outbursts of productivity in the areas of advocacy, rights education, social support, community economic development, political theatre and other forms of creativity. Basically, the survivors have succeeded in creating the conditions for supportive communities to develop and thrive, and this again, is the basis for recovery to take hold.

Community Development as the Basis of Recovery

The early years of protests were significant as a chapter in people's recovery saga. For many survivors, it was the beginning of the end of their isolation. Hope was fostered because people felt like they finally belonged in a community, and this was added protection as they explored their new life project as activists. Similarly, Drury addresses the relationship between activism and health, and says, "The main factors contributing to a sense of empowerment were the realization of the collective identity, the sense of movement potential, unity and mutual support within a crowd."

This new experience of community was instructive to those who felt that anti-psychiatry protest was not enough, and that their new community needed much more than political stimulation in order to be well. This led to a development where the survivor movement essentially branched off into its two main strains of activism, one service oriented, and the other political in nature. O'Hagan (2001) says, "The survivor/user movement works on two main fronts – self help and political action. In self-help we aim to change ourselves and recover from our experiences. In political action we aim to change the people and the systems that affect our well-being."

The political and the service orientations were not mutually exclusive, however, as key anti-psychiatry activists, such as Don Weitz of Toronto and Sally Zinman of Berkeley, started the first self-help groups back in the seventies. Other support groups developed similarly, but over time certain tension presented. As limited health funding became available for 'self help' there were arguments about taking 'tainted' money and co-optation. There were accusations about people being sell-outs, or on the other hand as being too radical. These tensions have been terribly vexatious for many, but still the movement prevailed. This is owing to the fact that whatever the tensions, the psychiatric survivor movement constitutes a community, and in their varying ways all of its members are deeply committed to its development and each other. That level of social commitment is also the basis for the creation of a parallel support system for people who need substantial help beyond the provisional parameters established by psychiatry and professionals. O'Hagan (2001) describes this unique service system:

"It is not uncommon in some countries for people with psychiatric disabilities to run their own services and support networks. These may be drop-ins, crisis houses, arts projects, housing projects or small businesses. Services run by people with psychiatric disabilities usually have a strong commitment to the full participation of people using the service and to honouring their rights. Self-help initiatives provide valuable clues on how we want all our services to be."

Leadership & Recovery

Most of the survivor leaders were people who had been through great adversity, yet through the eighties and nineties they were able to achieve greatness with few resources and little funding. Their accomplishments and the spirit that drives them to those goals are a testament to human resilience, and proof that madness frequently intermingles with genius. It is as Ridgway pointed out at a recent recovery conference in Toronto, “Having endured great suffering, survivors can frequently end up feeling transformed and able to function at a higher capacity.” Or, put differently, people who pass through fire often burn most brightly. Through their own politically-inspired transformation, similar to Perceval, they provide compelling evidence of the extraordinary rewards of recovery. (Note: So convincing in their moral authority and eloquence, however, they are then accused by their critics of never having been ‘sick.’)

Curiously though, until relatively recent time survivor leaders did not speak in terms of promoting recovery. Yet, while the leaders, activists and organizers rarely named recovery as the focus of their work, it was always oriented to that very outcome through their emphasis on independence, physical health and security, the experience of community, increased awareness of rights and advocacy, and opportunities for creative expression. And, as individual leaders their actual recovery legacy is profound. To name just a few:

- Howie the Harp (1952-2003) et al. created the Oakland Independent Support Center, and addressed homelessness and created housing for survivors well before homelessness became a widespread problem throughout N. American cities.
- Judi Chamberlin took her own personal thesis (On Our Own, 1978) on survivor strengths and autonomy and turned it into reality. She and the Mental Patients Liberation Front, one of the earliest ex-patient groups, operate Boston’s highly regarded Ruby Rogers Advocacy and Drop-In Center.
- Pat Deegan (2001) says a psychiatrist offered her a “a prognosis of doom” when she was at her lowest. She could have crumpled up in despair. Instead she found herself thinking “I’ll become Dr. Deegan, and I’ll make the mental health system work the right way so no one gets hurt ever again.” This plan became what she calls her “survivor’s mission,” and she has been putting it into practice ever since.
- Jay Mahler worked with the Costa Contra Consumer Affairs (CA) to achieve a rare level of personal and political greatness. Starting in the mid-seventies as state hospital advocates, they grew and developed a complex, multi-service survivor support center. Recently, within the last five years they steered an extraordinarily successful recovery implementation campaign throughout their county, a simply breath-taking achievement for its innovation and completeness.
- And, if Toronto, Canada has a vibrant survivor community with a strong tradition of anti-psychiatry protest, peer support, advocacy, anti-poverty work and innovation, it is largely owing to the groundwork and inspiration of these two, Don Weitz and Pat Capponi. Their respective contributions to their own community are huge.

Strong leadership has brought us to a place where survivor advocacy and practical recovery projects are more effectively conjoined. Here in Ontario, the Ontario Council of Alternative Businesses is an example of successful community economic development; its member groups, like Fresh Start, the Raging Spoon and Green Thumb provide job training, social support and a paycheque. Or, survivor-driven support centers like Sound Times in Toronto are the social bedrock in the lives of many survivors. These recovery-oriented programs are the result of sustained hard work by dedicated community activists, and they do community mental health at its best because the emphasis of their work is on their own community.

Doubts & Suspicion re: Recovery

The good work will go on, but there are real impediments to the widespread implementation of the recovery vision. Curiously, a major impediment relates to the apparent reservations that survivors have about the phenomenon. Many survivors are skeptical about the chances of a successful integration of the recovery concept within mental health reform. There is a reasonable degree of cynicism in the survivor community that planners and bureaucrats are posturing, and that providers are going to appropriate the recovery concept for their own interests? It is assumed that if recovery becomes policy, then the main beneficiary of recovery will be the larger mainstream agencies and not the survivor community, but this is one area where survivors should not be shut out. In the overall scheme of things, recovery is their personal, political and intellectual property. Survivors are the established experts in this domain, but without getting due recognition. The recovery movement will grow in an authentic fashion if there is more respect and material support for its philosophical architects. That's not revolutionary, just common sense.

Meantime, influential anti-psychiatry groups like the U.S. based Support Coalition International (SCI) seem unimpressed by the opportunities presented by the recovery vision because likely they see the model itself as antithetical to their philosophy and political agenda. They may eschew recovery because they view the term as an implicit validation of the bio-medical position that one is 'recovering' from an illness, which they loudly refute. But even though the SCI stance is viewed as being too categorical and idealistic, or criticized as being too radical, they are not so easily dismissed. The SCI is a very effective trouble-shooter where treatment problems and excesses are concerned, and it is also a very vocal opponent of coercive treatment laws.

'In your face' radicalism has always been a striking characteristic of the survivor movement. As a result, there is a lot of wishful thinking on the part of psychiatry and many professionals that survivors would get with the normative program, or just go away, which misses the point of the vital role they play in keeping all of us honest about the limits and the failings of the mainstream mental health system. However, we should also bear in mind some of the problems that occur when one can see nothing good coming out of the mental health system. Obviously, it is not helpful to view the entire mental health project as a mechanism for social control. Even with righteous anger you can have too much of a good thing it appears.

Survivors Save the Soul of the System

If recovery is to take root as a practical and social approach throughout community mental health, then professionals and policy-makers need to do a lot more to support the survivors' approach to recovery work. Anything less is ungracious. After all, the survivor movement has effectively saved the mental health system from its own paternalism and mediocrity, and the system has a moral responsibility to offer some form of gratitude and compensation.

The system has gone some distance in recovering some of its own dignity, as initially, survivors picketed and protested for years, reminding the system's minders of key ethical concerns. And, through the eighties there was a distance and wariness between survivors and providers, but relations have warmed considerably since then.

Clearly, long-term benefits have accrued to the system as a result of survivor activism and empowerment. The system is now less repressive and is much the better for having made allowances for the ideals and wisdom of the survivor community. Many professionals now appear to appreciate the down-to-earth approach and the common-sense value of the ideas and work of the survivor community, and from a subjective perspective the system now appears more humanist in its orientation. Apparently, the system has recovered from an over-blown sense of its own importance, and has become a more reflexive and interesting field within which to work, especially as survivors have assumed a relatively prominent role throughout the system.

As a result of a warming trend between providers and users of the system a state of 'glasnost' occurred, which has since paid dividends for both survivors and the professional sector. The survivors were ceded respect and sufficient funds to demonstrate their mettle, and the professionals were given some valuable lessons in humility and humanity, thus making the overall work environment that much more supportive and stimulating.

Now, survivors are 'at the table,' as partners, consultants and equals. They create innovative programs, and do countless hours of volunteer work on committees, boards and councils. They influence policy-makers with their practical ideas, political savvy and moral authority. And, survivor leaders such as Pat Deegan, Judi Chamberlin, Laurie Hall and Pat Capponi have had a significant impact on the hearts and minds of many mental health professionals. Their particular contribution is to emphasize the utter humanity of this enterprise, that survivors' recovery is contingent on their being recognized as people with dignity and rights, and not as diagnostic types with particular symptoms. Important work, but one has to wonder how we ever managed to stray so far from this obvious and essential fact.

Ultimately, as a result of the survivors' general agitation for change the mental health system has become more humane and respectful of people's rights and dignity.

Even the most stolid conservative can appreciate the obvious appeal of concepts such as recovery, self-help, economic independence and quality of life. This was made clear last year at a public forum on recovery. Michael Wilson, the ex-Tory Minister of Finance, made some complimentary remarks about the survivors who worked with him on the Toronto/Peel Mental Health Implementation Task Force. He was explicitly grateful to them, saying that he had

learned a great deal from them, and was wiser for the experience. His simple comments amounted to an authentic and heartfelt gesture, one that seemed as sincere as it was fitting.

Implementation Issues

Human relations are warmer between the survivor and professional sectors, but what are the indications that the system is actually moving towards a recovery orientation? In Ontario, the Mental Health Implementation Task Force made strong recommendations that the provincial mental health system be recovery-oriented, but it is unclear whether anything will come of that. Up to this date, the current governing party has not even acknowledged this recommendation, and the other political parties have not incorporated the recovery vision in their platforms. And, survivors may be asserting their influence in mental health planning groups, but it is another matter predicting what the actual funding outcomes will be. Survivors make a compelling case for essential recovery reforms that include housing, adequate income, employment opportunities, peer supports, anti-racism, etc. but other than in isolated pockets such as New Zealand, Kansas, Massachusetts, Connecticut, Ohio and California change is slow to come. It is interesting however, that the President's Freedom Commission on Mental Health has called for a national policy on a recovery-oriented system.

The recovery vision is too important, however, to wait on governmental interest. There is a lot that can be done well before recovery becomes the official policy. It is up to the survivors, community support agencies and family members to come together with coordination strategies and training & education proposals to push the recovery agenda. For instance, recovery competency workshops in community agencies could address some of the problematic clinical practices and assumptions among social workers and counsellors. Ridgway (1999), reporting for the Recovery Paradigm Project, speaks powerfully to this topic area. She makes an assertion for a new service approach emphasizing our shared humanity:

“Authentic relationships between staff and consumers also engender hope. We really know very little about mental illness and staff need to admit their ignorance and powerlessness, accept people's feeling and not meet human feelings with a false façade (what Knight called phony ‘WalMart helloism’), inaccessible language, intellectual abstractions, or a standardized treatment protocol. Inauthentic, paternalistic, and unequal power relationships, artificial professional boundaries, low staffing ratios, pseudo-human exchange of ‘active listening,’ keep people feeling estranged and hopeless. We must be able to say when people walk into programs "We have a tremendous hope for you to recover and have a good life." Healing relationships are two-way, with each person disclosing his or her own humanity, each person learning from the other.

This message, and recovery education generally, should not be confined to agency settings. Survivors and others should be funded to take the recovery model, its values and its change agenda to the hospitals, as well as to the university and college classrooms.

Other implementation issues relate to the need for a renewed and revitalized approach to self-help, as well as inclusion and affirmative hiring practices. Ridgway (1999) says:

“We must support the great adaptive strengths people have, and honour the healing power of active coping, symptom self-management, and peer self-help. People who are farther along on the path of recovery must be available in all programs as mutual self-helpers and peer-providers so they may serve as guides, living exemplars and role models of recovery. Other natural helpers, such as family members, must be supported to facilitate the processes of recovery and resilience.”

This point encourages mainstream agencies to do affirmative hiring of survivors, but it should be made more explicit. Survivors need to be on staff in all positions in all community mental health settings.

Also, implementation of a recovery vision cannot proceed without substantial funding for survivor-driven programs and initiatives. The pilot project period for these survivor-driven, recovery-oriented programs is over, and they need to be adequately funded and established more broadly. In order to support that outcome one can only conclude that the survivor movement has to sustain itself in its activist project. More hard work, but it is essential if the recovery approach is to be as influential and successful as it can be.

Finally, there are other topics and questions that need to be addressed by mental health professionals as we contemplate the authentic implementation of a recovery agenda:

- Are we clear about the implications of a recovery policy, that we should be less like ‘professionals’, and more like concerned, committed people deeply invested in important work, aiding recovery outcomes?
- Will we check our tendencies to think in terms of ‘low-functioning’ levels, and be less inclined to think of people as ‘sick’ or hopeless, no matter how distressing their circumstance?
- Are we in a position where we could act on our excitement with this topic and deliver on our positive rhetoric? Are we prepared to initiate change?
- Are we prepared to focus our energies and promote the services that most effectively promote recovery? Is the professional sector prepared to lobby for increased funding for survivor initiatives?
- Do we support the Madness culture? Are we motivated to learn more about the history and the politics of psychiatry/mental health? Are we interested in knowing more about the spiritual and existential aspects of madness? Are we in this work for the right reasons?
- The key question, are we ready to enact the personal and political changes that are embedded in the recovery model? Can we make it into something that will do us all proud? We would be crazy not to.

Conclusion

Clearly, if survivors had not organized protests and called attention to systemic issues of discrimination, neglect, abuse as well as chronic under-funding then the mental health system would not have made significant reforms of its own accord (and for its own good as it turned

out). And, without psychiatric survivor political action in all its forms, a parallel, peer-driven support system would not have been developed. Neither would the recovery movement be gaining international legitimacy as it is right now. At this time, activism and recovery are inextricably linked, and Deegan (2001) maintains that it should remain linked, “encouraging people to view recovery not simply as a personal process but as a larger human struggle for liberation, social justice and humanity.” This process, or struggle will hopefully continue as significant recovery reforms are contingent on the sustained activism of the psychiatric survivors. Without their idealism, leadership, and hard work, then prospects for significant reforms in the provincial arena are slim.

In respect of that struggle, we shall leave the last words to Chamberlin (1999):

“Let us celebrate the spirit of non-compliance that is the self struggling to survive. Let us celebrate the unbowed head, the heart that still dreams, the voice that refuses to be silent.”

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Biography

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