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Peer Support: The Peer Support Movement and the Future of Mental Health Care

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Peer Support;
The Peer Support Movement and the Future of Mental Health Care
Amy Shutz
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Peer Support;

The Peer Support Movement and the Future of Mental Health Care

In 1908, Clifford Beers wrote a book title *A Mind That Found Itself; An Autobiography*, chronicling his experiences inside of State and private sanitariums. Thinking that he had epilepsy and that it would be a huge embarrassment to his *alma mater*, Yale, and a burden to his family, Beers attempted suicide by jumping out of a window hoping to die on the pavement below. His attempt failed to end his life but broke his body and his spirit further landing him in a sanitarium. The attendants at the institution were perhaps underqualified or just working a job for a paycheck, at any rate they were brusque and inattentive. Beers writes, “The two who were first put in charge of me did not strike me with their fists or even threaten to do so; but their unconscious lack of consideration for my comfort and peace of mind was torture”. He was shuffled from one facility to another as the family could afford with varying levels of care and abuse. Finding some peace and sanity in the written word after his physical convalescence, Beers resolved to try and effect some change in the conditions inside mental health facilities. While still a patient, he penned a letter to the Governor of Connecticut, (the state in which he was hospitalized), documenting the abuses that he and other patients had endured and proposed a number of reforms. Using some very ingratiating flattery and extremely thin-veiled threats of political embarrassment, Beers succeeded in convincing the Governor to visit the hospital he in which he was a resident. The visit put the management and employees on alert and the assaults on patients ceased for a few months. “My failure to force the Governor to investigate conditions at the State Hospital convinced me that I could not hope to prosecute my reforms until I should regain my liberty and re-establish myself in my old world” (Beers 1908). He did, eventually gain his freedom and worked diligently to establish himself as a credible member of society.

When he resumed his efforts to get politicians to take notice of the conditions within the walls of sanitariums, he did so with a manic persistence that put some people off and eventually led to his brother strongly suggesting, with the backing of ‘professionals’ and the courts, that he return to being hospitalized for a time. After his final stay at a hospital, he returned to his pursuit of reforms but handled it far more tactfully and heeded the advice of others to gain support and backing from other professionals before taking his cause to politicians. He made the acquaintance of William James, a philosopher that offered him critiques on his written proposals and supported his writing of his story which was published in 1908. At the end of his book, Beers writes:

Contact with sane people, if not too long postponed, means an almost immediate restoration to normality. This is an illuminating fact. Inasmuch as patients cannot usually be set free to absorb, as it were, sanity in the community, it is the duty of those entrusted with their care to treat them with the utmost tenderness and consideration.

“After all,” said a psychiatrist who had devoted a long life to work among the insane, both as an assistant physician and later as superintendent at various private and public hospitals, “what the insane most need is a *friend!*”

Fast forward to the 1960s a time rife with organized efforts of various civil rights movements, the Community Mental Health Centers Act was passed which authorized grants to build community mental health centers and later called for the deinstitutionalization of large state hospitals. By the 1970s, *thousands* of former patients had been released into the community with little care or support if any. These survivors of mental health institutions started finding each other forming small independent groups without knowledge of other groups to share their stories. They expressed outrage at the treatment they had suffered at the hands of the ‘the system’, they shared similar stories of abuse, maltreatment, and the death and horrors they had

witnessed. In the tradition of Alleged Lunatic Friend Society, (England 1845), Alcoholics Anonymous, (U.S. 1937), GROW, (Australia 1957), and the ensuing 12-step support groups and advocacy organizations, the peer support movement was born. One of the first organizations formed in 1970, was here in Oregon in Portland calling themselves the Insane Liberation Front. Such organizations held demonstrations at psychiatric hospitals, events of the American Psychiatric Association, and the offices of politicians. They were supporting each other, spreading the word, and demanding change. As is usual with great movements, news dies down and their existence is relegated to history and the initiated.

Though the beginnings of the peer support movement effected change in the treatment of mental health patients, a stigma still survives regarding the mentally ill. Within society, the stigma of being mentally ill is “expressed by the non-stigmatized general population as fear, distrust, disapproval, devaluation, derogation, avoidance and exclusion, and unreasonable dislike” (Anagnostopoulos & Hantzi, 2011). Day, Edgren & Eshleman (2007) suggest that there are seven factors of peoples’ attitudes towards the mentally ill; interpersonal anxiety, relationship disruption, poor hygiene, visibility, treatability, professional efficacy, and recovery. These seven factors can be mediated using Jones *et al*’s six dimensions of stigma: concealability, course, disruptiveness, aesthetic qualities, origin, and peril (Day *et al*, 2007). However, several studies have shown that familiarity with mental illness, (knowing somebody, family or friend, with mental illness), tends to result in more positive attitudes towards those with mental illnesses (Anagnostopoulos & Hantzi, 2011; Day *et al*, 2007; Phelan and Basow, 2007). Many people with mental health issues don’t get regular treatment *if* they even seek help in the first place. In a 2001 survey by Kessler, Berglund, Bruce, Koch, Laska, & Leaf, it was found that of people that reported having a mental illness, less than 40% received regular care or adhered to treatment

schedule (Phelan and Basow, 2007). Often there are biases against the mentally ill by mental health professionals. “Psychiatric training and practice are extremely vulnerable to a bias created by the fact that people using mental health services are typically at low points in their lives. Clinical experience thus tends to produce and perpetuate negative stereotypes about people recovering from mental illness and addiction” (Agrawal & Edwards, 2013). However, there is hope for the lessening of stigma suffered by the mentally ill as people with mental health issues are finding their way into mainstream media more and more in a more positive light such as television series like “Perception”, “The United States of Tara”, and movies such as “A Beautiful Mind”. Key to all of these examples are that the mentally ill persons represented in them have social supports.

So, what exactly is peer support? Phyllis Solomon offers a simple definition of peer support as “social emotional support frequently coupled with instrumental support that is mutually offered or provided by persons having a mental health condition to others sharing a similar mental health condition to bring about a desired social or personal change” (2004). It is person-centered that focuses on empowerment and self-determination and, under ideal circumstances, is bidirectional; the supported and the supporter both mutually benefit from the relationship in their recovery efforts. The Narcotics Anonymous Basic Text chapter *How it Works* states “We feel that our approach to the disease of addiction is completely realistic for the therapeutic value of one addict helping another is without parallel...for one addict can best understand and help another addict” (2008). Psychological and sociological concepts of social capital, experiential learning, and social learning, self-enhancement, and social comparison theories all come to bear in peer support efforts. Not only does peer support, (and other social supports), help with positive adjustment but can act as a buffer against day-to-day stressors and

unexpected adversities (Khatib, Bhui, & Stansfield, 2013; Soloman, 2004; Klein, Cnaan, & Whitecraft, 1998) but can provide companionship, empathy, and assistance to combat feelings of loneliness, rejection and frustration from discrimination, stigma, and isolation. Most of all, it provides hope. Relating to someone with a similar diagnosis that is living a life of their choice shows the supported partner that there is light at the end of the proverbial tunnel. One of the tenets of the Peer Support Movement is ‘We DO recover’; so often those suffering from mental illness have been led to believe or assume that they will never get better. A peer support partner is a living example that they can get better.

There are several categories or delivery systems for peer support. First are self-help/support groups. Most notable are GROW and Recovery, Inc., but includes a vast array of “anonymous” programs as well: Alcoholics Anonymous (AA), Narcotics Anonymous (NA), Schizophrenics Anonymous (SA), Emotions Anonymous (EA), Over-Eaters Anonymous (OA), Sex and Love Addicts Anonymous (SLA), and Dual-Diagnosis Anonymous (DDA) to name but a few. These groups meet independently and support each other by sharing their “experience, strength, and hope” and sponsorship under the belief that they “can only keep what [they] have by giving it away”. Whereas self-help groups work primarily within the group though sponsorship allows for one-on-one support and guidance, warm-lines are telephone hotlines that people can use to attain immediate one-on-one support telephonically. The more studied peer delivered services are those of peer run/operated services and peer employees. Peer run services are typically community centers or community run organizations (CROs) that provide programs, services, and activities geared toward socialization and self-sufficiency through the help of social supports. Peer employees are trained and paid employees hired into more traditional mental health positions such as advocates, consumer case managers, and peer counsellors.

Many studies have shown the benefits of peer support. For the consumer receiving support experience increased social networks and quality of life, improved coping skills, decreased hospitalizations (both in number and duration), improved adherence to treatment programs and medication therapies (Klein *et al*, 1998; Solomon, 2004). Peer supporters benefit as well. By helping others, peer supporters find personal growth, increased confidence in their capabilities, greater ability to cope with their own mental illness, increased self-esteem and self-efficacy (Solomon, 2004). They also gain new and personally relevant knowledge, professional growth, and social approval from the consumer that they are helping and others all while engaging in their own recovery. The health care system benefits as well by less strain on institutional resources due to lessening of hospitalizations and their duration which translates to savings in cost.

There are those that have criticism for peer support practices. There are some that believe that the supporter benefits more from the partnership citing helper-theory principle. Peer supporters gain self-worth and social approval for their ‘good deeds’ which some may argue can threaten the self-esteem of the supported if they become to feel dependent or inferior (Bracke, Cristiaens, & Verhaeghe, 2008). They also point to active concepts of caregiver burden, carer distress, and cost of caring as possibly causing a reverse situation where the supported benefits more than the supporter who may come to feel taken for granted or taken advantage of in a one-sided relationship; that they support the consumer and then have to get support for themselves from another party. Peer support workers are also subject to discrimination from their ‘non-peer’ colleagues as it is negatively assumed that the mentally ill cannot support the mentally ill (Walker & Bryant, 2013) though they are “experts by experience” (Agrawal & Edwards, 2013). There also comes the question of differing philosophies in risk management. Scott, Doughty, &

Kahi explain that those trained in peer support see crisis as a learning opportunity while those trained by various health boards or mental health services approach as a matter of risk assessment; are they a danger to themselves or others? Repper & Carter (2011) conducted a review of the literature limiting themselves to literature regarding peer support workers within mental health services rather than through the community. Within this narrow scope, they concluded that within statutory services, peer support workers do not make that much difference in benefits to the consumer but that in the broader scope, the benefits are more apparent. However, they do admit that peer supporters are more successful at promoting the hope and belief that it is possible to recover. Additionally, the question of boundaries comes up. Since most peer supporters are allowed and often expected to disclose personal information to the consumer, how much is too much? How close (in the relationship) is *too* close? All criticism aside, even detractors of peer support admit there is benefit to the practice though they may suggest more stringent qualification requirements, trainings, and supervision. Peer support workers experience low pay and few work hours that don't lend themselves to a living wage or job security. Some might say, "raise their salaries"; "increase their hours". Increased supervision and training may interfere with the advantages of being a peer while higher pay may result in co-option that may cause the peer supporter to feel unable to offer their unique peer perspective.

All in all, the majority of research suggests that peer support is mutually beneficial allowing for better outcomes in the treatment of the mentally ill. There is caution to maintain a *balanced* relationship between supporter and supported and some would see increased training and supervision requirements imposed. CROs currently outnumber the amount of traditional mental health organizations here in the United States that often are run by volunteers; caring and

devoted, passionate peers. Te Pou, the New Zealand National Mental Health Workforce Development Agency has this to say about peer support:

“Peer support is person-centered and underpinned by recovery and strength-based philosophies. The life experience of the worker creates common ground from which the trust relationship with the person is formed. Empowerment, empathy, hope, and choice along with mutuality are the main drivers in purposeful peer support work. There is a great deal of strength gained on knowing someone who has walked where you are walking and who now has a life of their own choosing,. In this way it is different from support work, it comes from a profoundly different philosophical base” (Scott & Doughty, 2012)

There is a fundamental difference, though semantic in nature, in the perception of on who feels “cared for” rather than “cared about”. Being “cared for” can be interpreted as a patronizing expression of prejudice while being “cared about” indicates that you are important and people value you as a person (Scott &Doughty, 2012).

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This Experience;

A Note from Amy

This research was very exciting for me. Not only is it a subject that I am passionate about but I also get to share it! Being a consumer of mental health services that has been both supported and supporter, I have seen first-hand the miracles that can happen when the hopeless are uplifted and empowered. I suffered many, many years with my diagnoses which lead me to dark places of suicide attempts, substance abuse, legal problems, and institutions. I never would have imagined that I would ever attend college, especially at this late stage of life, and be within reach of a Bachelors degree and looking ahead to graduate school. Without peer support, I would have never made it to this place in time.

In the past, I have been told what I 'need', I've been mandated to programs that did me no good, and wasn't listened to because of my diagnoses. When I 'found my people' I was so relieved and filled with hope for the future for the first time that I could remember that I burst into tears of joy! With the support of peers like myself, I slowly rebuilt my life and learned how to navigate the world without wanting to escape it; my confidence was bolstered as I learned how to cope and experienced success after success.

I have had the extraordinary honor and pleasure to be of support to women in various 12-step programs, other consumers, and organizations that promote peer support. I have served on the board of one such non-profit organization. I am finally at a point in life where I can be proud of who I am and the role model I have become for my children, my grandchildren, and others.

Working on this project, particularly the short film, I was very excited to work with my daughter, Zoe Harrison, who is a beautiful and caring soul that dedicates much of her time to the peer support movement. Also, I was happy to be able to feature my best friend, Dawn Nasset, who was my first real contact with social support, and to celebrate her in some small way for all that she gives of herself. Additionally, it was an extreme honor to meet Corbett Monica, the founder of DDA, and pick his brain; what a fascinating individual! And finally, I feel very blessed to have met Janet and give her a platform, (albeit a small one), to share a bit of her success story. I was very moved by her caring and devotion of others.

I am glad that I had this opportunity, if for nothing else than to spread the word about peer support and that you can support the movement and people in need of support even if you are not a consumer yourself. There are plenty of organizations that can use support in the form of donations of cash, in kind, or even volunteer hours. Thank you for this amazing experience and opportunity.

Amy Shutz