Peer Support: What Makes It Unique?

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Abstract

Peer support in mental health has recently gained significant attention. There is increasing talk about funding and credentialing, standards and outcomes. But what is peer support and how is it different than services, even services delivered by people who identify themselves as peers? In this paper we would like to present a perspective on peer support that defines its difference and also maintains its integrity to the movement from which it came. We will offer some thinking about practice and evaluation standards that may help different types of peer initiatives sustain real peer support values in action.

Peer support for people with similar life experiences (e.g., people who've lost children, people with alcohol and substance abuse problems, etc.) has proven to be tremendously important towards helping many move through difficult situations (Reissman, 1989; Roberts & Rappaport, 1989). In general, peer support has been defined by the fact that people who have like experiences can better relate and can consequently offer more authentic empathy and validation. It is also not uncommon for people with similar lived experiences to offer each other practical advice and suggestions for strategies that professionals may not offer or even know about. Maintaining its non-professional vantage point is crucial in helping people rebuild their sense of community when they've had a disconnecting kind of experience.

Peer support in mental health however has a more political frame of reference. Whereas some support groups form around the shared experience of illness, peer support grew out of a civil/human rights movement in which people affiliated around the experience of negative mental health treatment. (e.g. coercion, over-medication, rights violations, as well as an over-medicalized version of their "story"). In other words, the shared experience has had more to do with responses to treatment than the shared experience of mental illness. The Independent Living Movement has been the quintessential guide to this way of thinking.

The Independent Living Movement grew out of a reaction to social, physical, and treatment barriers for people primarily with physical disabilities. It arose at a time when

other movements were gaining headway in establishing rights for oppressed groups of all

kinds. Through a strategic advocacy initiative, the Independent Living Movement

focused on three general areas: The first, to enforce the civil and benefit rights for people

with disabilities; second, to develop a way of thinking created by people with disabilities;

and third, to create alternative services and advocacy centers (Deegan, 1992, DeJong,

1979).

Dejong (1979) writes:

> According to the IL paradigm, the problem does not reside in the individual but
> often in the solution offered by the rehabilitation paradigm- the dependency-
> inducing features of the …professional-client relationship…The locus of the
> problem is not the individual but the environment that includes not only
> rehabilitation process but also the physical environment and the social control
> mechanism in society-at large (pg 443).

In identifying the critical elements of peer support Solomon (2004) reminds us that

"Consumer provided services need to remain true to themselves and not take on the

characteristics of traditional mental health services (p.8). Campbell (2004) also notes that

consumer operated programs should present an alternative worldview (pg.32). So what

does it mean to stay true to itself, to provide a different worldview? Identifying skills and

ingredients that support this difference will help in determining what constitutes "good

outcomes" for peer programs. It will help us to become more self evaluative and

therefore continuously build on emerging knowledge, and it will help us simply to

challenge 'how we've come to know what we know."

<u>Critical Ingredients literature</u>

There have been many recent studies exploring the 'critical ingredients' of peer support. Findings are congruent with the IL framework and offer both structure and process standards (Holter et al, 2004). Structural standards are elements of peer initiatives that define the basic rules and how the group is constructed. They include being free from coercion (e.g. voluntary), consumer run and directed (both governmentally and programmatically), an informal setting with flexibility, non-hierarchical, and non-medical approach (e.g. not diagnosing, etc). (Solomon, 2004; Salzer, 2002; Holter et al,2004; Clay ,2004; Campbell ,2004. Hardiman, 2004). Process standards are more like beliefs, styles and values. They include the peer principle (finding affiliation with someone with similar life experience and having an equal relationship),the helper principle (the notion that being helpful to someone else is also self healing), empowerment (finding hope and believing that recovery is possible; taking personal responsibility for making it happen), advocacy (self and system advocacy skills), choice and decision making opportunities, skill development, positive risk taking, reciprocity, support, sense of community, self help, and developing awareness (Campbell, 2004, Clay, 2004).

While these ingredients are clearly essential for maintaining a non-professional relationship, they also may fall short of describing how to provide a true alternative. This is where it becomes crucial that we begin to define those practice elements that really lead to different assumptions about ourselves and our relationships, different ways of thinking about our experience, and ultimately define our unique and valuable role in the larger 'help' arena. We must ask ourselves, " What is it that we need to offer in order to help people begin to see things in a new way? What kinds of relationships really build community? How can we construct reciprocal help so that it is not attached to any particular role or interpretation of the problem (e.g. a non-medical interpretation of the experience)? Without

thinking carefully about these questions it is likely that peer support will be defined and judged within the context of the dominant paradigm. Further, if we can establish some common parameters for all of peer support, it will support peers working in the service delivery system with a unique and fully distinguishable framework for thinking. If this framework becomes more widely known and considered, there should be less likelihood of cooptation. In order to create this identity and way of thinking it may be useful for us to consider some of the skills in peer support that build different kinds of help and ultimately a different recovery outcome.

Achieving difference

Recovery in mental health has most often been defined as a process by which people labeled with mental illness regain a sense of hope and move towards a life of their own choosing (President's Freedom Commission Report, 2003). While this definition on the surface seems obvious, what remains hidden is the extent to which people have gotten stuck in a medical interpretation of their experiences. With this stuckness comes a worldview in which one is constantly trying to deal with their perception of what's wrong with them instead of what's wrong with the situation. In other words, even if I have hope of moving into a better life, I have been taught to pay a lot of attention to my 'symptoms.' This interpretation of my experiences leaves me constantly on guard for what might happen to me should I start to get 'sick.' Even with recovery skills (learning to monitor my own symptoms), I find myself creating a life that is ultimately guided by something inherently wrong with me. With this understanding, I may continue to see myself as more fragile than most, and different than 'normal' people. I then continue to live in community as an outsider, no matter what goals I have achieved.

Critical learning

As we've noted before, peer support in mental health grew out of an affiliation based on the shared experience of negative treatment. Yet it is the medical model that has given us language, self definition, an interpretive framework, and a notion of what it means to 'help.' . In peer support we may pursue different kinds of conversations in which we start by thinking about "how we've come to know what we know." This means actively examining how we have learned to name our experience, what utility the naming has now and create the ability to step back and think about how that naming may be keeping us stuck.

Following is a typical example of interactions where peer roles often fall short in opening up this new conversation

Helpee: My depression is really acting up lately and my doctor says I need to increase my medication but I don't really want to.

Peer Helper 1: Boy, when my depression starts, I have to take a bit more medication or I get in trouble

Peer Helper 2: Don't you remember the last time you didn't do what the Doctor said and you ended up in the hospital?

Peer Helper 3 What do you need to say to the Doctor so that he doesn't increase them?

Peers 1 is clearly operating on learned assumptions about help and borders on coercion. Although the second helper's role is more of an advocacy role, it is still presumed that the depression and the medication are the issue rather than what may have happened

situationally. We don't learn what constitutes depression vs. sadness or grief, what the medication does and doesn't do, what depression means for that person, or about what is it that's being medicated.

In a different kind of conversation, new ways of thinking about the experience may emerge. For example:

Helpee; My depression is really acting up lately and my doctor says I need to increase my medication but I don't really want to.

Helper: What does it mean for you when you say that your depression is acting up?

Helpee: Well, I'm sleeping more and don't really feel like eating.

Helper: Boy I can remember a time when it seemed like every time I didn't feel too great I would interpret it as depression. I saw it as an illness that I had which meant, at best, that I could only learn to cope with it.. I had learned to think about many of my experiences and feelings through the lens of illness andI started getting kind of afraid of my own reactions. I've had to work at thinking differently so now when I have some of those reactions I simply wonder if it's just my body's way of saying I'm exhausted or frustrated.

Helpee: But the last time I felt like this I ended up in the hospital.

Helper: Was that helpful?

Helpee: Well they changed my medications around and gave me shock treatments…at least I wasn't so depressed anymore.

Helper: I wonder if there are other ways you could think about what you might need when you're feeling tired a lot and not wanting to eat…

Helpee: Like what?

Helper: Well sometimes when I'm doing something new or uncomfortable I don't feel very confident. In the past being uncomfortable led to going to bed and not wanting to eat. Then I'd just call the Doctor and they'd adjust my medication. Now I try to simply let it be ok to be uncomfortable. Instead of going to bed I go to the gym, or I ask myself how others might react if they were feeling uncomfortable about doing something new.

Critical learning doesn't assume a medical definition of the problem and opens us to exploring other ways of thinking about the experience rather than trying to deal with the 'it.' Asking about the phenomena of eating and sleeping vs. calling it depression, we change the direction and consequently the outcome of the conversation. By sharing our own process with this shift we aren't telling the other person what to do but offering our own critical learning experience. In this sharing we are exposing the other person to a potentially larger story which may help them consider other ways of thinking about what's happening and therefore options that were not previously available.

Mutuality: Redefining help

Everything we have learned about help in the mental health system pushes us to think of it as a one-way process. Even when we refer to the helper's principle we are only talking about role reversal and we simply mean that now that we are in the helper role, we feel better just by providing help. This kind of help continues to maintain static roles of helper and helpee. Further, as Friere (1995) points out it is not uncommon for someone who moves from helpee into helper role to build a sense of confidence and even to abuse

power in much the same ways as was done to them. One starts to identify as the more 'recovered' person and begins to see the relationship with his or her peer as one of service. Unfortunately, this dynamic will never really lead to meaningful community integration. Mutual help in peer support (and obviously in community) implies both people taking on both roles with each other. It means sharing our vulnerabilities and our strengths and finding value in each other's help. If we continue with the example above, the conversation might have led to

Helper: I was just on my way to the gym, would you like to come with me? I've actually had some difficulty going alone, I always feel so overly conscious about my body. I feel like everyone's staring.

Helpee turned helper: Wow I used to feel that way and it kept me from even wanting to use the locker room. Finally I just asked myself if I worried about what anyone else looked like. I realized that we all kind of think about ourselves and decided that probably no one really was paying attention. That thinking took practice, but now I feel pretty comfortable at the gym. I'd be happy to go with you if you think it might help.

The reciprocal nature of this interaction helps both people see themselves in multiple roles throughout the conversation. It is this level of mutuality that most resembles community type relationships and allows us to move towards full citizenship rather than feeling simply like the integrated mental patient in the community. It is crucial that even with paid peers we must figure out how the relationship can be more mutual and

reciprocal Perhaps we can consider it our job to model peer support rather than to be a provider of service.

Language

Using language that helps explore each individual's subjective experience is important in beginning to redefine recovery. The new use of language, however, becomes especially difficult when we are doing peer support in a traditional setting. When we are working with a team of traditional providers it becomes a much more simple and quick communication to talk about symptoms, illness, coping etc. As peers we find that we are misunderstood if we use other language and in order to feel part of the team, we begin to talk about people in medical terms (sometimes even without the presence of the peer). For example: Dr. A runs into a peer specialist in the hall one day and asks him how Peer 1 is managing his symptoms. The Peer Specialist says: "gee Dr. A, Peer 1 seems really symptomatic today." Aside from the fact that this conversation should not be happening without the presence of Peer 1 the symptom language has generated a set of assumptions that have major implications, and secondly, what are both of their assumptions about symptoms and what constitutes them. Unfortunately, this simple conversation may result in the team deciding to increase peer1's medication.

Different language supports a different conversation as we saw previously. If we avoid the code language of mental health we find that we are having very different conversations which then require a different type of response. One example of this shift in language might include talking about experiences instead of symptoms, The language

of experiences allows not only for unique description of that particular event, it also presumes only one person's interpretation. With this starting point we can explore other ways of knowing as well as reflecting on how the use of medical language keeps us stuck.

As long as we continue to adopt the language of mental health, we are stuck in power structures that impose a narrow meaning on our words and conversations. We then assume a lot about our experiences as they've been interpreted by the traditional system. It becomes easy to talk about "my depression," rather than I'm feeling pretty down and out today. This leaves us with a "thingness" that is intrinsic to us, generalizable to others, and occurs because we have "it.".. The language and constructs of mental illness begin to limit our much more subjective experience. If we can struggle with the language of the phenomenal, play with metaphor, take the time to really explain to each other, we begin a conversation that is rich with possibility rather than limited by what we know about the "illness."

<u>Mutual responsibility</u>

We have talked about the need for mutuality in the peer support relationship but what do we mean by mutuality?

- It is assumed that both people learn from each other

- Both people figure out the rules of the relationship

- Power structures are always on the table and negotiated

In traditional helping relationships, it is assumed that it is primarily up to the helper to take responsibility for making the relationship work. When things are not working so well this kind of dynamic has led helpers to feel like they're 'doing something wrong,' or to blame the other person for not trying. We stop saying what we see, what we need and we begin to disconnect, falling into an assessment and evaluation role rather than working on it together. On the other hand, as patients we have been implicitly taught that we cannot or don't have to take responsibility in a helping relationship. We fall into believing that we are victim to our own reactions and then wonder why people disconnect or take over when we say things like "I'm suicidal."

In peer support relationships it is important to remember that it is not our task to assess or evaluate each other but rather to say what we see (our perspective), what we feel, and what we need to build connection. For example,

Peer 1 : I can't go with you today, I'm really suicidal

Peer 2: When you talk in the language of suicide I feel kind of scared and a little bit frustrated. If you're feeling lousy and don't want to go out with me, I need for us to figure out a way to talk about it differently.

In this scenario rather than starting a suicide risk assessment, we are once again exploring the use of language without presuming it means an imminent action. We bring the relationship back to negotiating what will work for both of us and we remember that both our needs are important.

Redefining safety: Sharing Risk

We can not talk about doing something fundamentally different until we address the topic of safety and the fact that it's simply come to mean risk assessment in the field of mental health.. We've been asked, "Are you safe, will you be safe, will you sign a safety contract? As recipients this has left many of us feeling quite fragile, out of control, and has left us thinking of safety as simply soothing someone else's discomfort. If we don't begin to address issues of risk and power, we cannot help but replicate many of these dynamics in peer support.

For most people a sense of safety happens in the context of mutually responsible, trusting relationships. It happens when we don't judge or make assumptions about each other. It happens when someone trusts/believes in us (even when they're uncomfortable), and it happens when we are honest with each other and own our own discomfort. It is with this interpretation of safety that we can begin to take risks and practice alternative ways of responding. We can choose who to be with and when and we can begin to talk about shared risk. Sharing risk in peer support tackles the issue of power, what it's like to lose it, abuse it, or balance it. We talk about how we each are likely to react when we feel untrusting or disconnected. We begin to pave the way for negotiating the relationship during potentially difficult situations. This level of honesty works well in trusting relationships but is critical to the health of a peer support group or program.

Staying on track

When we think about how to stay on track, how not to drift back to old ways of doing and being, one helpful process can be to formulate standards specific to peer support. The standards would represent statements about the alternative worldview that peer support tries to create - the ideal, or 'what ought to be' in the helping relationships. While we have addressed some of the current efforts in exploring 'critical ingredients' earlier in this paper, here we would like to offer further thinking about developing standards specific to peer support.

First, the kind of knowledge peers bring into the support relationship can be best characterized as practical knowledge, or a lived knowledge from which learning and understanding are embedded in contextualized lived experiences (Schwandt, 2002). When persons operate from this kind of lived knowledge, sometimes what is known is not necessarily evident, but rather is expressed through common values and stories that have been formulated through participation in a shared historical community – in this case that of being persons who have received mental health services.

So when peer support communities explore how they are different and what they know, the sophistication of the knowledge they posses is often not easily brought to the surface. The challenge presented in developing standards for peer support is in finding ways to translate practical knowledge into clear accounts of "what is the ideal" and why this is so. This 'realizing process' goes beyond soliciting information from peers related to how they act - to digging deep to discover what each and all peer supporters know.

Second, peer support knowledge is passed on through an oral culture and storied ways of meaning. This means that being attuned to the practical knowledge of peer support will require adopting a narrative framework for articulating peer support standards (MacNeil & Mead, 2004). It is a good method of fit. This can get very tricky when peer support practices are under the umbrella of traditional service organizations or when peer organizations are providing traditional services. Sometimes it can be difficult to tease out whose narratives are really being represented.

As one example, an organization can be viewed as a collection of people who interact with one and other primarily through dialogue (David Cambell, 2000). In this dialogue they have the opportunity to constrain or influence each others way of thinking and acting – and it is inevitable that this collection of people creates the organizational belief system. And within the organizational belief system there are more influential or dominant narratives that steer the activities of the organizational culture. In this regard, narratives are both structures of power and meaning (Bruner, 1984).

In initiating the development of standards in peer services or support communities, it can be very helpful to discuss within an organization the kinds of discourse that guide their activities. With that, we can then reflect upon whether these organizational narratives more so represent the attributes of peer support or if (consciously or unconsciously) they reflect a drift towards more traditional service practices. This process of examination also can create and reinforce a platform for mutually responsible dialogue.

Our third thought about standards development takes a transformative stance (Mertens, 2005). We assume it is possible to transcend thinking and practices that have been shaped by the lens of dominant narratives or power structures through the process of developing standards for peer support. Elevating different or historically marginalized narratives can help us to redefine the problem, seek new solutions and step outside of the box in our thinking about program standards. Likewise, creating processes of deliberation among organizational participants who hold different viewpoints about 'what ought to be,' and whose viewpoints are situated from different positions of power, can have positive influences on shaping shared understandings about standards, and can serve to better represent traditionally disenfranchised narratives (House & Howe, 1999; MacNeil 2002).

The possibility also exists to broaden the scope of evidence-based practices. Evidence-based practices have mostly been described by their program structures (staffing, case load size, etc.)…and have overlooked the ingredients of the helping processes that occur within each practice and which research has shown to be related to how people change and grow (Anthony, 2003). Thinking further about standards of peer support guided by the constructs offered in this paper: *Achieving Difference, Critical learning, Mutuality: Redefining help, Language Use, Redefining safety: Sharing risk* will help us to push our thinking around the parameters of evidence-based practices and to frame how peer support is different from other services – whether they are provided by professionals or peers.

Last of all, we have given some forethought to next steps beyond developing standards, those involved in creating 'measurement' strategies that are coherent with the values and standards of peer support. We must remember that the history of peer support shows us a culture that emerged as a response to doing things differently. Peer support programs are not intended to be routine mental health practices. It seems to us then, that the measurement of peer support standards should also look and feel very different. The fidelity of peer support is embedded in its storied culture and consideration should be given to developing narrative measurement strategies that can be acculturated into peer practices – the method of fit will also help to sustain the evaluative practices overtime. This is a future challenge for the field of evaluation and peer support programs.

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Peers working in services: Can we do peer support?

There is currently a national trend towards integrating peer services within the traditional delivery system. Certified peer specialists are funded through various Medicaid and VR waivers and recipients are finding meaningful support with their paid peers. Clearly this role has been beneficial in acknowledging the expertise of lived experience. It has also offered recipients a forum to speak about their experience differently, be exposed to strong role models, and develop new skills and strategies to help them heal and recover. Peer services, if done well, can provide hope, role modeling and simple safe strategies for recovery.

While the task of the peer provider may coincide with the task of peer support, (e.g. working on recovery strategies, or sharing like experiences), there may also be times

where the peer provider simply is not allowed to challenge the medical description of the client's experience. While empowerment and self-advocacy are important tools one can learn from a peer provider, it is not likely that a conversation may entail the "deconstruction" of the client's experience. One can't both work for the medical system and refute its very foundation.

With the development of this practice of doing peer support we can begin to help peer providers create a platform from which to offer their unique perspective. Perhaps it is here, with this new influence, that other providers may also begin to question the over-medicalization of people's experience. Either way, it is important that we don't lose sight of true peer support in our efforts to 'legitimize it.'

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