

## **IPS: A Personal Retrospective Shery Mead 2010**

The door of the mental hospital locks noisily behind me and I realize that already I've succumbed. "You know that you need to be here. You are ill and we're here to help." It's been 5 minutes and already I am a mental patient. Up to this point, I've understood my experience as a "normal reaction to abnormal events." But that understanding is now shattered with the realization that I am ill and science is on their side. Reactions become "symptoms," feeling at the end of my rope is "suicidal ideation," and forgetting becomes "dissociation."

All my life I have been running from messages from the outside world that define how I see myself, interpret others, and generally how I operate in the world. Early on it was all the messages of shame and otherness. "It's your fault, you made this happen. You are just bad." What's wrong with you anyway, what's your problem?"

I have learned that others can assign fault, that somehow it always seems to be mine, and that pain is controlled by the person who has the power (e.g. "it doesn't hurt that much.") Their cumulative messages become truth and truth becomes my skin while otherness becomes my identity.

Shame becomes an indictment of who I AM as opposed to a reaction to anything I've done. Rather than feeling ashamed, I become shameful. My body is bad, I am bad. It's like a megaphone in my ear and I can't remove it. It is the story without context, and it is all-encompassing. The "Otherness" of always feeling like everyone else knows how

to do things, how to act, what to say... But I feel “different,” always watching others to see just how “normal” people act.

I am a teenager and the shame is starting to leak out. Up until now I’ve squeaked by rather unnoticed but adolescents are compelled to act on feelings. I am convinced that I can fly and believe me, I try. Night after night I don’t sleep. I start to see things that other’s don’t and I begin to shake and stutter. My communication becomes more and more obtuse until my mother finds me one snowy day walking barefoot around in circles muttering to myself. I don’t know I am here but I do know that I’m supposed to be. My mother is afraid and doesn’t know whether to be mad or ignore me but finally reacts and does the inconceivable. She calls a psychiatrist who tells her that I am not safe and the next thing I know I am being dropped off at the local psychiatric hospital. My mother drives away, worried that maybe she’s been seen here with her child. No one in our family has ever even seen a psychiatrist. People should learn to pull themselves up by their bootstraps and get on with their lives.

It is the late sixties/early seventies - not times when it is “cool” to be crazy. I live in a small WASPy New England town where everyone wears the same clothes, goes downhill skiing on weekends, and has vacations at their summer homes. If they have any problems they don’t tell, although I can remember a time when my friend’s sixteen year old sister got pregnant and was sent to Florida. When she finally came home, she was the person everyone in school gossiped about but no one talked to.

I walk in the door of the psychiatric hospital and fearfully go inside. The walls are made of ugly cement painted light green, and I don’t know what I’m supposed to do. I meet with the psychiatrist who says they’re going to watch me for a while. I get a room with a little window that nurses periodically peek into. He tells me I have something

called schizophrenia and I have a feeling that I'm going to be here for the long haul. I quickly learn the doctor's "story." All that I have been experiencing is part of the illness. These kinds of things will probably keep happening, but with medication and occasional hospitalization, it can be managed. I am told that after I leave here there will be a group home I will go to where there are others like me. Those others like me include my roommate who is just in for a medication adjustment. After our door closes she shows me the stash of drugs she keeps "in case she needs them," and she shows me how to "cheek" my medication.

The drugs make my tongue thick and I am leaning down to the ashtray to smoke my cigarette because it's too much effort to reach with my hand. On New Years Eve, we are taken for a walk around town. We are a herd of sheep and the nurse is our shepherd. My legs are heavy as lead and I pick them up with my hands to put one foot in front of the other. "Come on legs," I say..."move!" My roommate gives me the signal that I shouldn't say anything. On the ward it's the staff versus the patients and each has their own power. I learn to hoard "sharps" and pills for the time when I might need them and they tell me many times a day..."you are sick, you need to be here, just do what the doctor tells you to do."

One day I commit an act of revolution. I take the LSD that my roommate has given me thinking it will help me tolerate occupational therapy where we make belts. Just before it kicks in, I am told that I have to go have an EEG, whatever that is. I am paraded through a tunnel to the "regular" hospital and when I get there, they tape electrodes to my head. Is this for real? I am in outer space and the technicians are aliens. When it's all over and the drugs wear off I go see the psychiatrist for the results. He says it was the strangest thing, there was no brain wave motion at all. I freak, thinking he's found out about the LSD, but he is

joking!. After several shock treatments and large doses of Thorazine I am discharged , for better or worse, to my parents custody, the halfway house plan somehow never materializes. I vow never to speak of this experience again (bless the family secrets).

At home, I belong to a band. I am a musician and it is the one thing in my life that makes me feel whole and real. I will never tell the other band members that I've been in a mental hospital, but inside, I still know I'm crazy. I put all my intensity into music and try hard to put the strange experiences and feelings into my playing. I just never want to end up hospitalized again. The other guitar players seem to somehow understand the intensity of my feelings. We talk, and I begin to discover the power of true "dialogue." We all speak from our hearts simultaneously and create something altogether new, albeit illusive. We connect in some special way, as if our true language is music and through it, we all know what we mean.

This takes care of the feeling side of things, but I still struggle with my thoughts -- trying to understand my own experience. It is my head that won't change. I go on to college and I find that there are others like me who also struggle to comprehend what their feelings and experiences actually mean. We are all curious about "reality." I study phenomenology trying to get to the essence of things. Is there a truth or is it all relative and constructed? I'm curious about how meaning gets made, how things get defined to be one way or the other. I have some great conversations but on the inside I still know I'm bad/crazy/different. I decide that the only language with any credibility for me is music.

For years this back and forth between head and heart serve me well until I am going through a divorce, single parenting three small children, working part time at the local boarding school and quickly going broke. Although I am teaching music I know that I am a fake because my music

school experience was too short. But I love the energy of the teenagers and so want to keep them from learning to think that their intensity and their ideas are crazy. One summer one of the band members is killed in a car crash. The school wants to hire a grief counselor so that the other kids can get “help.” I pull them all together and we talk. We decide to spend the summer writing a piece of music for our young friend to perform at the beginning of the next school year. Over that summer, the music that we play not only speaks our grief, but binds us together in a way that transforms much of the pain.

The summer is over, the kids graduate and I know that I’ve got to do something else. I decide that maybe social work school is a place where I could learn to work with teenagers using music as a medium. It occurred to me that many of the kids that I worked with in the music department were the same kids that got talked about in faculty meetings as “having problems.” The other teachers thought that they were not college material and suggest they get into counseling. I have hope that I can create a new kind of opportunity to build voices rather than silencing kids as I had been silenced.

School is hard. I like the headiness of it but the walls that for so long contained the messages of shame in me begin to leak once again. Desperately trying to stay in school, I vow that I will never end up hospitalized again. But I am doing things that scare people. I can’t slow down, I can’t sleep and I feel like I’m doing school while I am also running with a ball and chain. There is one person who keeps saying, “it doesn’t have to be like this,” but I am totally out of control. There are no options but hospitalization and I am terrified. I will not see myself as ill; I am a scholar, a musician. But...the door locks and I am there again.

This time there are yellow concrete walls and they search my bag for anything dangerous, including paper clips,

and I find that I'm tired, maybe they're right, maybe I am just crazy. In some ways the diagnosis is a relief . I no longer have to take responsibility for myself. That is good because the responsibility of parenting 3 kids with no support and too little money has been grueling and I am tired.

But then they suggest I go on disability -- perhaps give up custody of my children. I am far too ill to care for them, they think they know.

Right then, there is a little spark of anger. Who are these people?, I think. But almost as soon as it flares the spark expires. I am too worn down to fight them. It has been too long of a haul. They are too clear that they know what they know, and that nothing that I know about me matters.

Soon I am just doing what they say. It appears to work. For a while, I go back to my life and "cope." And then "it" happens again.

I am back in the hospital. This time something happens that revives my anger. My lawyer calls me shortly after I'm admitted and says that my ex husband is demanding custody of the children. He doesn't want to pay child support. The nurses, however, say that I can't worry about that now -- I'm here because I need to be. Another patient sits with me through my hysteria and, when I can listen, says that she too was told that she would lose her children. She is angry and challenges me to think about what's important My love for my kids, the connection we have, the emotionally abusive life they will have with him.

This is the beginning of dissonance. Not a lot. A little. But still something. Something she is saying makes sense to me even though she, like me, is a patient. Something they are

saying does not, even though they are doctors and experts. And the distance between what they are saying and what she is saying is the beginning of my seeing things differently.

Time passes. In between hospitalizations, I'm in and out of school and I go through this for several more years until I realize that most of my conversations are about mental illness and my friends are all mental patients. We believe that we are sick and all we can really do is commiserate. I learn to live the life of a "mental patient."

There comes a time when I am interning for school at a domestic violence program. A woman comes to see me. She has been told that she is a courageous survivor by other workers but she probably should get into counseling. She gets sent to a community mental health program. The next day she comes to see me and says that she has a serious mental illness. She no longer sees herself as a survivor but as sick.

What happened here? Why the sudden shift in explanation? Yesterday we were talking about what happened to her. We both knew the problem was abuse in the world. Today she is talking about what's wrong with her.

This troubles me. Over the next months, as we talk I gradually get the courage to bring it up. How did she go from talking about what had happened to her to talking about what is wrong with her?

Together we ponder this question. Our shared stories spark a modicum of self-reflection. We talk about what our lives have looked like since we were diagnosed and slowly we start to make some decisions about whether we want to stay there or not. We both acknowledge some comfort –feelings

of safety, perhaps relief – from the fact of our diagnoses. Yet, somehow, our experiences begin to mean something different to us. Increasingly, we begin to challenge the idea that something is “wrong” with us, and consider instead that it is perhaps the events that happened to us that were wrong.

Sadly, however, almost nowhere else in my world is this message reinforced. We are two small women on a large and indifferent planet. We are not yet strong enough to stand on the strength of our fledging convictions. I continue my bouts of going in and out of mental hospitals.

Fortuitously, however, insight and understanding can be found in unexpected places. One is, believe it or not, a psychiatric nurse in one of the hospitals I am frequenting. It is Thanksgiving time and I once again am told that I am losing custody of my kids. I go to the locked door and demand to be let out. When everyone ignores me I start pounding on the door. The nurse, whom I know quite well at this point, comes over and says to me. “Shery, you know you have a choice. You can decide whether you want to be a mental patient for the rest of your life or a social worker. Maybe you can decide in the next ten minutes.” I am taken aback by this dressing down -- I hadn’t known that I had that choice!

This time I make it. I get out. Continue on. Don’t lose my kids. Continue to discover that there are other ways to understand what happens to me than through the lens of illness. I am lucky. I make a few more friends who help to reinforce this message.

As time goes on, I work with women trauma survivors using music as a communicator. We think that instead of therapy we are doing social action. We decide to record some of our pieces. One day, something strange and wonderful occurs to us. We wonder why we hadn’t noticed before. But we do now, and we all get it: We notice the

power of our music. And, through this we notice our own power. We realize what we can achieve and what we can say through it. We realize that the music we make—the poignancy, the meaning, the rhythms and melodies that cut to the core of things-- expresses something entirely different from our view of ourselves as mental patients. The dissonance is mind-blowing. It is at that point that I know something. I know that it is about me. I know that it is important. And I know that I know it.

I know that I have a choice.

I know that I have the choice to see myself as mental patient and continue to live into that role. And, I know that I have the choice to own and live into the power of the self that my music I make is pointing me to. The vastness of the chasm between these two stories about myself is unavoidable. And, I know I cannot escape my responsibility to choose. And I know what I will decide.

My internship in the Domestic Violence Center ends, but my work continues. I decide to find some way to work with the idea that stories can be redefined. I am betting that there are others, like me, who have been stuck in a mental illness story that is not of their own choice or making. I want to find out whether, through dialogue, we might be able to re-define ourselves and our experiences along the lines of my experience with the trauma survivors band..

I start making calls. I find that there is interest at the state level in developing what are called "peer support programs." I talk to the Director of what's called the Office of Consumer Affairs and tell him about my experience with the women at the domestic violence center. I tell him how their abuse stories get lost –how they go into a mental health agency to

get help with their experience of being abused and come out instead with a diagnosis of mental illness and a bagful of medication. I tell him how this leads to more and more psychiatric involvement and less and less community involvement. I confide in him my conviction that services are turning survivors into patients!

What, I ask him, are the resources for people who have gotten stuck in this situation? To my surprise, he tells me there is some seed money available for peer support. He explains that peer support is support provided by people who have been consumers of mental health services who want to support others in a similar situation--a bit like AA. He hopes that there will be enough interest to start a program that would provide an alternative to traditional services.

I tell him that this **SOUNDS AMAZING!**

It's not long before I take the job as director of this project. I have two missions:

1. Keep people out of psychiatric hospitals
2. Continue to work with women who have experienced past violence to keep them from seeing their experience as illness

This is when I learn about "drop-in centers." I learn these are places where people who have learned to describe themselves, or are described by others, as seriously mentally ill spend their days under the supervision of staff. The program consists of a basement room with a pool table and a coffee pot. Thought of as an innovative way to help people with mental illness to have some meaningful interaction back in the community, these

centers don't seem much better to me than the institutions people have been released from.

I go and have dinner with the members and try to find out if they are interested in developing a new program. It takes a while to wade through the medication haze clouding out most semblance of their motivation. Nevertheless, there are a few people who say they would like to help.

I feel good about this. Hopeful. We might really go somewhere. This could lead to real change.

Then I ask the group what they envision, and I get my next eye-opener. I'm expecting them to say: We want to work together for better housing, education, jobs, respect, an end to discrimination, to stop being treated like children. Instead, I get responses like, "I want you to take us to the beach, I want you to cook for us."

I want, I want, I want. I am taken aback. How did we get like this? Again, my mind returns to our stories. First to my story, then to the story that my logic and my intuition working together imagine them to have based on my story. How does this dependency make sense? Where did it come from? Where do we go from here? —Because, having raised 3 kids, I'll be damned if I'm carting grown adults off to the beach.

It takes me some time, a lot of self-reflection. Eventually, I realize that we have learned to be this way. It is part of our role as a good mental patient. We are incapable & therefore receive help, they are the capable and therefore give help. . That is the implicit social contract— of the one way service relationships that freeze us in a never-ending incompetent role: we are never allowed to give the help, only to be the ones who "get" the help.

It is then that we begin to really talk about ourselves. Not the people who we are now –the incompetent incapable ones with medication haze and the gimme parrots squawking from their perch on our shoulders. But ourselves –the people we were before the doctors, the hospitals, the labels, diagnoses and medications that de-invented us—the people with dreams and families and talents and relationships that meant something—something important—on both sides.

I tell them I once was the lead guitar player in a rock and roll band. They laugh, but it seems to spark a different conversation nonetheless. I find out all kinds of things. One person had studied geology and knows a lot about rock formations. One person has been in the military and travelled all over the world, and one woman used to be an ER nurse.

We begin to recover the parts of ourselves we learned to forget –that we were taught to forget, were socialized out of in learning to play our reassigned role as incompetent, incapable, incurable mental patients.

We start building a new program slowly. Since it is Thanksgiving time and I am not in the hospital for the first time in several years, we decide to put on a potluck thanksgiving dinner. It's a bit of a fiasco because most of us have never cooked anything other than with a microwave. We have been conditioned to think about ourselves as “unsafe,” and therefore in need of constant monitoring. But after a while everyone puts their best foot forward and says they will bring or do something. We end up having one big turkey, my salad, and 13 boxes of microwaveable stove top stuffing.

Well this is the most fun any of us have had in a long time. There is lots of conversation that isn't about our symptoms, and there is lots of new found energy -- quite a change from the old "thorazine shuffle." We begin to realize that we aren't as "sick" as we thought. In fact, we begin to realize, much of what we understood as symptoms are simply reactions to things that make us uncomfortable.

It is at that point that we start to have very different conversations. The questions become less cautious, more daring, even seemingly outrageous: What if we can move on with our lives?, Do something other than be mental patients?, Start our own support network? Replace the whole hospital system?.

We start reading? the word "recovery" in some of the other peer support literature and get curious. Then excited. Then inspired. Soon we begin to tell our case managers and our doctors that we want real friends rather than paid "friends," choices rather than decisions made for us, and most importantly a sense of hope.

It is not long before we turn to each other rather than calling emergency services when we're feeling frightened or really down. It's much nicer being listened to by a friend rather than asked about our safety. As our confidence builds we even decide to start our own alternative to psychiatric hospitalization. Quite a shift in the status quo -- patients running the asylum!

In our crisis alternative program, people can come in when they're worried they might get hospitalized, and instead of assessing each other we simply talk. Unafraid that we'll be hospitalized, we're freer to talk about things like suicidal feelings and find that most of us have felt that way at one time or another.

A young man comes to us and says he wants to use our respite bed. He is hearing voices and is afraid. Prior to this he has had many long hospitalizations, lost jobs, been heavily medicated. He feels disconnected from everyone and everything. He just wants to make some sense out of his experience, he says. And so he comes and just talks...for 4 days he is up talking to people, explaining what he's going through, getting each person's take, comparing experiences, and then he sleeps. Instead of 3 months of being forced to take medications that make him forget, he has had a week of conversations that allow him to feel more fully alive and aware. He's made friends with people he can call on down the track and he decides to write about his experience for a graduate program in eco-psychology.

No one in the medical field believes us. We must be wrong. There is no way to achieve this result with someone who is a "true psychotic."

We ignore them. Continue on. We know the power of our work together –have seen and experienced it in our own lives.

We face down problem after problem. Turn lived experience into solutions. Engage in honest dialogue about what works and what doesn't.

We start new groups, try new approaches, as old stories are re-examined and new stories are tried out. Our members with trauma tell us that their talk therapy groups don't work. They tell us they end up feeling worse when they leave than when they went in –with the added insult having to pay for the privilege. They think the problem is the

horrific stories they are forced to recount --one survivor after another--the purported therapeutic purpose of “dealing with the abuse.”

So we start a new group. It involves music. We use music as a way of communicating. And, instead of telling horror stories, we are finding our voices through music, putting them together and feeling the energy and power of what we can create.

So what is it that’s happening that has contributed to so much change in the culture of people who have historically been marginalized, voiceless and contained? And I realize that it’s quite simple: We are interacting differently. We no longer talk with or about each other in ways that define us by our problems or deficits. Instead we are communicating through our strengths and possibilities.

As we continue to play with new assumptions and beliefs, we are writing ourselves a new reality. We are creating community, and we are challenging the secrecy of what has conversations that lead to new behavior.

This isn’t rocket science. **But it’s certainly different from what we’ve been told to expect.** Which, happily--as we are learning to get new results through challenging old assumptions-- is both the process and the product of our efforts.

And so I wonder what your stories are...When did you learn to be a “mental patient?” When and with whom do you tell different stories. It is an important discussion.

And what are some of the things that get in the way of doing something differently? How will you know? What are the things telling you you’re going in possibly the wrong direction?

The first thing you may notice is that you're dying to "help." Now help is not necessarily a bad thing at all but when you are out for your own satisfaction, help can turn into control. Remember the times when you've heard people say things, like "I'm only doing this for your own good, etc.?" Is that necessarily true or did they do it so they wouldn't have to feel so uncomfortable watching while you did things your own way, however painful it might have been? Help can become a double edged sword if it's used to be coercive, controlling, is fear based or is just done to make the helper feel better about having done something.

Let's think of an example. Someone you know seems to be really self destructive, is always doing things that seem to take him/her away from what she seems to want? For example, your friend says she want to "get better," to work on her recovery etc but you see her doing things that get in the way, like having a second glass of wine, like not exercising, like sitting around reading all day when he/she could have been out looking for a job. You say to yourself, If I really wanted to "get better," to recover, I would be doing everything people told me to do. But maybe this is not the way your friend learns or gets things done. Or maybe he she learns differently than I do.

And that is the key, Right there, learning. What happens if we take the time to learn a little more about our friend? What if that second glass of wine loosens her up enough to go to the interview she is dreading? What if not exercising but sitting around reading all day is exactly what he/she needs to do to get up the next day and go to the interview? And this is the lesson for us. Our assumptions about what others need is not always/if ever accurate. Our assumptions are based on our perspective, our "worldview." They are there because

they belong to us and to our way of knowing, but try and impose them on someone else and you may find that you are not only not helpful, but losing a friend at the same time.  
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And so we talk about learning together vs. helping. Let's think about this for a minute. What's different about learning rather than helping? Learning implies a curiosity, an inquisitiveness about the other, their way of knowing, their way of making sense of the world whereas helping often implies that you already have the answers, that you know better, that you can come in and tell someone what to do, and if they do it, everything will work out the way it did for you when you were in their shoes. Well maybe and maybe not, but one thing is for certain, helping based on what's worked for you can also be tremendously damaging.

The next principle to remember is to focus on the relationship rather than on the individual. As in Help, when we pay attention exclusively to the individual, we can easily fall into the kind of "help" we talked about before. Where all my time and focus goes into to you and what you need rather than into our process of relating.

When we pay attention to the relationship, it is quite different. Then we are paying attention to what is going on between us. In other words we focus on the "space" between us, what is happening right here, right now that can either move us forward or back.

Let's take another example. I come to "help" you and all my attention is on you and what's wrong, then I'm not going to necessarily factor myself and my actions into the equation. But what happens if we're not communicating well, what happens when something I do pisses you off and I simply

take it as a sign of your further incapacity. Do you see where this is going?

But if I pay attention to our relationship and to our communication, I can see that something I'm doing really pisses you off and I can apologize, stop doing it, or try and figure out what it's about with you.

When I pay attention to what's going on between us, it opens up a line of communication that supports honesty, safety, and integrity and ultimately changes. The very direction I had wanted to go without you. In other words when I was paying attention to you and your changes, nothing that I did factored into it, but when I put myself into it, I realized that yours and my interaction was just that, an interaction that might go anywhere. There is no predictability, rather just a seeming randomness. This randomness, this unpredictability is exactly what we are striving for in peer support, not the linear outcomes we've come to think of as success.

Finally, the third thing (and perhaps the hardest) to remember is to not react out of fear but to try out new ways of relating based on hope and possibility.

Now this is easier said than done. When we're afraid we often just want things to go back to the way they were before, to settle down, to become more "stable." And yet "stability" may not be the goal here. Think of a time when things seemed really out of control for you, yet you had a sense of what you needed and wanted even if others around you said things like they knew better. Chances are things happened that were out of your control, perhaps even slowing your process. This may have led you into dependence on someone else's experience of the "problem. In other words, you may have become reliant on someone else's interpretation of your experience. This happens simply when someone says to you, "that doesn't hurt, don't cry

over spilt milk etc.” and you wonder why you’re making a big deal out of something that others don’t think is. Or the opposite, when what you’re doing doesn’t affect you at all and someone else is scared that you’re going to get hurt. And they continuously say, “be careful,” Pretty soon you’re terrified of something bad happening and you’re reacting to their fear. This leads to complicated dynamics where one person’s emotions drive the reaction of the other person. This is too often what happens in mental health services when they tell us we are helpless, etc. We have learned to be that way based on their fear.

And so today, I put out a bit of a warning...that its quite easy to “do what’s been done to us.” And for all the right reasons. We just want to help, we care about the other person and we are afraid for them..or really are we afraid for ourselves. What might be the consequences of this person’s actions? Will we be seen to have failed them?

This leads to complicated dynamics where one person’s emotions drive the reaction of the other person. This is too often what happens in mental health services when they tell us we are helpless, etc. We have learned to be that way based on their fear.

And so we go into doing peer support with a focus on learning rather than helping, with an attention to the relationship rather than on the individual and onto creating opportunities for hope and possibility rather than fear and power and control...or at least we try. And although it sounds like a lot of hard work (and it is) it’s also fun, rewarding, simply about having good relationships that promote health in all our relationships. If we can do this, we can quite literally change the world.

Thank you