

The Recovery Vision: New paradigm, New questions, New answers

**Mental Health: Stop Exclusion, Dare to Care,
World Health Day 2001**



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Presenters

Dr. Courtenay Harding, Ph.D.
Director
Institute for the Study of Human Resilience

Dr. William Anthony, Ph.D.
Executive Director
Center for Psychiatric Rehabilitation

Judi Chamberlin
Senior Consultant on Survivor Perspectives
Center for Psychiatric Rehabilitation
Senior Associate, National Empowerment Center
Lawrence, MA

Dr. Marianne Farkas, Sc.D.
Director
World Health Organization Collaborating Center

[?]Introduction - by Dr. Marianne Farkas

Welcome to today's broadcast, ladies and gentlemen. My name is Marianne Farkas and I am the director of the World Health Organization - PAHO, Collaborating Center in Psychiatric Rehabilitation here at Boston University. We are holding today's webcast to celebrate World Health Organization's World Health Day 2001. For the first time in its history, World Health Day will be devoted to mental health to draw global attention to both the magnitude of suffering and discrimination experienced by some 400 million people around the world - and we would add, the reasons for hopefulness in the 21st century.

"Stop exclusion, dare to care" is the World Health Organization's call for action. There are many events planned to celebrate this event around the globe. Two events that we would like to draw your attention to are the webcasts being conducted by the Center for Mental Health Services. The first one is Open Minds, Open Doors and it was broadcast immediately before this webcast this morning. Information about how to access it can be located at www.mentalhealth.org. The second one, which is a chat with Dr. Bernard Arons, the director of CMHS, will occur following this broadcast at 2:00 p.m., Eastern standard time.

Today's web broadcast is entitled "The Recovery Vision: New paradigm, new questions, new answers." And the format for today's webcast will be four speakers

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Courtenay Harding, William Anthony, Judi Chamberlin and myself. Dr. Harding will review the evidence for recovery and its implications. Dr. Harding is, of course, known for her groundbreaking work in research in the area of recovery. Dr. Anthony will discuss how this research must change the paradigm for our field and Dr. Anthony is a leading pioneer in the field of recovery oriented psychiatric rehabilitation. Judi Chamberlin will discuss the roles of consumers and non-consumers, in the on-going development of the field of recovery and Judi is an internationally known psychiatric survivor and advocate. And I will end the broadcast by briefly outlining some of the implications– for development of recovery-oriented systems. If you want more information on each of these speakers, it can be found on this speaker profile located in the description of the webcast at our website. And so now, without further ado, I'd like to introduce Dr. Courtenay Harding, who will give our first presentation.

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Evidence for Recovery and its Implications - Dr. Courtenay Harding

Hello. I have entitled this presentation, “Long Term Outcome for Rehabilitated Psychiatric Patients: Reasons for Optimism.” The plan this morning is to look at recovery and the evidence for it among people with very serious mental illness. Let us look at some things that we've learned about rehabilitation and also a little bit about resilience. I'm going to present seven of the ten world studies this morning, and slide that's next that actually gives the evidence. What I'd like you to observe, on the right

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hand side of the screen, the congruence of findings between these seven studies from all over the world. Now, when we talk about subjects who are recovered, we're talking about no medication, no symptoms, being able to work, relating to other people well, living in the community, and behaving in a way that you would never know that they had had a serious psychiatric disorder. And if you have heard of that the old belief that one third get better, one third get worse and one third stay the same, we found that it was not true. In the Vermont Longitudinal Study, we took the bottom third of this population and found that two-thirds of them also turned around. So that our old views of schizophrenia are considerably different than they have been for the last hundred years. What I'd like to do is go through this table a little bit and talk about these studies and then tell you what exactly these investigators had to say when they got through.

The first study was done by Manfred Bleuler, whose father Eugene Bleuler, renamed dementia praecox and studied schizophrenia. And his son, Manfred, took over the hospital at Burgholzli in Zurich, Switzerland and he did what his father did not. He followed 208 people for 23 years and found that 53-68% of his subjects significantly improved or recovered.

Gerd Huber and colleagues in Germany followed 502 for 22 years after their episode of schizophrenia found 57% significantly improved or recovered.

Luc Ciompi and Christian Muller in Lausanne investigations in a medium-sized city in Lausanne found 289 people followed 37 years. They're actually the longest study of schizophrenia in the world. They go up to 64 years after first admission and they found 53% significantly improved or recovered.[?]

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Ming Tsuang and the Iowa 500 study had the strictest criteria for schizophrenia but found 46% improved after 35-year average. Using the DSM III diagnosis, we found 62-68%. Dr. Ogawa et al. in Japan found 57% and Michael DeSisto in Maine found 49%.

Let me tell you what these gentlemen had to say about the long-term course of schizophrenia. Manfred Bleuler said that, “I have found the prognosis of schizophrenia to be more hopeful than it has long considered to be.”

In the Lausanne investigations, Christian Muller and Luc Ciompi wrote, “The long-term evolution of schizophrenia is much more variable and considerably better than heretofore admitted.”

In our Vermont study, we found with two-thirds of these most chronic patients ever studied in the world literature. I said with John Strauss, one of my colleagues, “We have gathered some evidence that the course of schizophrenia is a more complex dynamic and heterogeneous process than has heretofore been appreciated or predicted by diagnostic specificity.”

And the quote I like best is from Gerd Huber in Germany, “Schizophrenia does not seem to be a disease of slow progressive deterioration. Even in the second and third decades of illness, there is still the potential for full or partial recovery.”

So that, ladies and gentlemen, is substantial evidence for recovery. There are also many myths about schizophrenia, which have been challenged by all of these studies. “Once a schizophrenic, always a schizophrenic” has been significantly challenged now. The reality is improvement and recovery for most patients. “The same treatment for all”

is a myth. We've found that individualized treatment is much more successful because there's wide heterogeneity of function, interest, and capacities within each person.

There's a myth that says, "You only do rehab afterwards..." after the symptoms settle down. It turns out you need to do rehab starting on day one. Rehab is actually treatment. Rehab can reduce symptoms. Getting somebody a job can reduce symptoms. Getting them stable housing can reduce symptoms. Getting them social support system wrapped around someone reduces symptoms. So why wait until the symptoms subside with medications when we have strategies to do something about it? There's a myth that says, "No psychotherapy for these patients." But our patients tell us that they need supportive psychotherapy and that they need somebody to talk with about the process that they're going through.

There's another myth that says, "We need to be on medications all our life." There's absolutely no evidence in the world literature that says that that's true. There may be a few people who might need it all their lives, but certainly most people do not. Over time, most patients begin to titrate off their medication.

There's a myth that "people can only do low levels of work" and in reality, people can do all levels of work. It depends on their education. I got telephone calls from all over the country, when I was on National Public Radio a while ago. People who were physicians, professors, high school teachers, nurses, engineers who called to say thank you for telling our story because we don't tell anybody because of the stigma.[?]

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[?] And the last myth, one of the most insidious, is that “families are the cause of it all.” When you work with families, they can be collaborators and very helpful.

Does all of this mean that you don't bother with treatment if there is a natural healing capacity? One of the things that we've been proposing in the literature is, and no surprise to neurologists is that the brain is the most plastic organ we have in our body. It is in constant interaction with the external and internal environment. We've also found that getting older is a wonderful thing for people with schizophrenia. Thank goodness it's great for somebody! It turns out that there is a subgroup who may have too much dopamine and not enough serotonin for instance and these are neurochemicals. It turns out that when you hit about age 40-50, you drop the levels of dopamine naturally and your serotonin levels rise. That's exactly what someone with schizophrenia needs.

We also found terrific sex differences between men and women. It's not just John Gray with his Venus and Mars, but it turns out that there are huge differences that are too complex for me to go into but we're finally paying attention to them. The genetic studies are proceeding and they show it will probably be multiple genes causing some kind of psychotic process. It's not much different than response to stress for high blood pressure, cancer or heart disease. We all have these genetic predispositions of one kind or another.

We've learned to pay attention to where someone is in the course of a disorder because for schizophrenia particularly, it can be quite virulent early on and then it can taper off. We've learned that vulnerability isn't a concrete, permanent thing. There's probably variability in your vulnerability – that's a big change from previous thinking. Some of the smartest people I know in the business think the word schizophrenia is

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actually like the word “fever” and that it means that there are many etiologies that go into a final common pathway. As we learn more and more about what’s going wrong in individual brains that we can chunk it off and call it something else and within 25 years, we may not have something that we call “schizophrenia.” Most people forget that the person who named the disorder, Eugene Bleuler, called it a group of schizophrenias with an “s” on it. And we’re beginning to think that he was probably smarter than we thought.

With this kind of complexity about natural healing capacities over time, does that mean we just don’t bother with treatment and just let Mother Nature take her course? And the answer is absolutely “NO.”

So what roles do rehabilitation efforts play? I want to tell you about a story where the name rehabilitation might come from. And it may be an apocryphal story; maybe it’s a true story.

The French Foreign Legion has many traditions. One of the biggest traditions is that when you become a member of the corps. You have to stand in front of the whole corps and you’re given your fancy epaulettes, which you can see on this picture, and your gold buttons and your white hat and that is called *habille*, which is to be “dressed.” And if you dishonor yourself in any way and are drummed out of the corps, they stand you again in front of the Legion, and they take a sword from the commandant and they cut off your buttons and your epaulettes and that’s called *deshabille*. And if you reinstate yourself with appropriate behavior[?] then it’s called *rehabille* and it seemed to me that this kind of process is often what our patients have to go through in order to become members of our society again.

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Now I've already talked about rehab as treatment – that it can reduce signs of symptoms of illness, that there are many many new strategies – cognitive rehab, cognitive remediation, social skills training, relearning social cues, going back to work in a train/place model or place/train model. And there are many areas in the world that are pockets of excellence such as Trieste, a town north of Helsinki, in Bogotá and in Long Beach, California. Pockets of excellence worldwide and certainly here at Boston University in Bill Anthony's group that has been working for many many years to develop rehab strategies. My pleading with people is "Please don't throw the baby out with the bath water." (This looks like my granddaughter so I was particularly pleased to put it in here.)

What I'm mostly afraid with research is that it clusters people together who have different kinds of forms of the illness, different lengths of course, different problems to solve and then declares that a program works or doesn't work. We all have to be aware of this hidden heterogeneity. What may be lost is that a program it might work for certain groups but not for others, I'm hoping that researchers will pay attention to those things. We literally have known how [?]to help this process of recovery since the 1950s and we have only applied this knowledge on scattered places across the world. But most often, we don't apply what we know helps and many many people are left languishing in hospitals and community mental health centers. Unfortunately, most Community mental health centers have become just as sturdy institutions as the state hospitals used to be.

Given our frustration with these languishing patients, I wanted to you show you that we've devised a multidisciplinary algorithm for the assessment of persons with

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schizophrenia. A bunch of post docs in public psychology – June Hicks, Chad Morris, Linda Roswell and I have put this together. It covers all five helping professions and we ask a few critical questions within each field. We select the best practice instrument to get the information. It takes 60-90 minutes per discipline. Once you get the answer to these questions and what to put on the treatment plan, we're hoping that with such a structured format maybe people will get a much clearer assessment

I wanted to talk with you about resilience. We've tried to learn to define resilience although we're just beginning to figure it out. It may be the ability to recover from a life challenge such as serious illness or trauma, natural urge towards health, promoting the healing process, taking control back and reinventing oneself. We have an institute here called the Institute for the Study of Human Resilience and our vision is that people, who are challenged with serious life challenges are resilient, and can significantly improve and often recover when they have access to knowledge self help resources, skilled professionals, sustaining environments and social justice. We hope to do this with research and practical applications over findings and interactive sharing of people, information with people and their families, the professions and policy makers.

And we want to apply several approaches. First, we definitely believe in a bio-psychosocial-spiritual approach. We want to be a research center and a learning community. We want to read the literature from across all kinds of fields that have studied resilience but have stayed in their silos of knowledge and not shared across fields. We want to learn about lived experience. We want recovery oriented self-help tools, leadership training, qualitative and quantitative combined strategies for research. [?] We

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want to add theoretical basis to empirically derived practices. We want recovery based best practices and policy initiatives and multimedia approaches. So we have a lot of work ahead of us.

I wanted to show you, since we're just beginning to build this institute brick by brick, that we're putting together a logo, which is being un-loaded at the moment. In this logo we try to show what a resilient person is. The person is shown with his or her head down sort of sitting on a curb. Then halfway up, and then all the way up with hands reached high. People, who've seen it, really get it, just like that. While I was wandering around with this logo in the Xerox room, Dr. Su-Ting Hsu saw it, and she's a psychiatrist in training here from Taiwan. She brought me this lovely Chinese proverb, which says, "The way to growth and development is to plant both feet firmly in the ground, raise your hand to the sky and then push the sky up so you have room to grow." I thought it was wonderful.

The last item that I want to say to you, were two sayings that I found recently on a wall. One was on the wall of an apartment building of a colleague who trained at Albert Einstein. This wonderful poster was painting of Maimonides, who was a 12th century scholar and physician. It quotes him saying, "Teach Thy Tongue to Say I Do Not Know and Though Shalt Progress." That's what we need to do with resilience and the new questions that Dr. Anthony's going to talk about, the new paradigms. Then the last quote is a Latin phrase that really has to do with Hippocrates and says "Vis medicatrix naturae" or loosely translated means, "Honor Mother Nature's Healing Capacities."

So thank you very much.

Changing the Paradigm by Dr. William A. Anthony

Thank you Courtenay. My name is Bill Anthony and I want to talk about the kind of the implications of what Dr. Harding, or Courtenay, has just described from the literature. Because she's talked about some facts that we haven't really operated on in this field and if you combine Dr. Harding's facts about recovery with the writings of consumers, who've written a long time about their own recoveries, just that professionals haven't chosen to[?] listen to what they've been writing and saying, I would commend the Psychiatric Rehabilitation Journal for one of the first journals to start to publish consumer accounts of their own recovery. And we find that obviously, they drive with the facts. People do recover, we have the data to show it and we have the people to show it. So while we have a recovery process going on, and the facts and the people talking about it, what we've developed now is a new vision for this field. We've developed a new vision for this field - so that we no longer think of deterioration, we no longer think of just maintenance. We think of recovery as a vision for this field. The thing to remember is that our whole field has been based on the fact that people don't recover. All our systems, all our institutions, our training programs, everything in this field has been based on the fact that deterioration is the typical course. So I am talking about a vision here that consumers have suggested that we need a whole new vision for what can happen in this field and we've named it recovery for the time being. Maybe a better word will come around for it at some time, but right now, I think we're talking about recovery and we

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have a working definition of recovery that's based on the consumer literature and the literature of Dr. Harding, and what we talk about is the development of new meaning and purpose in one's life as one grows beyond the catastrophe of mental illness – an earlier working definition now but something that we can all grab into.

Now I said that this new vision changes everything and professionals have a word for it - they call it a “paradigm shift.” Good luck spelling it. It was one of the first words that I had to learn how to spell when I got in this field. We have a paradigm shift and by that I mean the simple explanation of that is – recovery vision has forced us to put on new glasses when we look at this field. We have new lenses through which we're looking at this field of mental health. And it's similar to me, well, I thought, “What's a metaphor here that can explain a paradigm shift?” I think the simplest metaphor is, that maybe translates all over the world, is that at one time we thought the world was flat. And because we thought the world was flat, we had a lot of questions about the world that turned out to be dumb questions, like, “How far do I sail before I fall off the end of the world?” “What's at the end of the earth?” “What's underneath the end of the earth?” “Monster[?] Dinosaurs? What's under there?” Because I remember in the fourth grade, a picture of a sailing boat sailing along the flat earth and there are monsters at the end of it – that's what people were talking about apparently when they thought the earth was flat.

Well now we know it's more round-like than flat, and it's changed the questions. We no longer ask questions – when's the last time you heard someone say, “What happens when you fall off the end of the earth?” We don't ask that question anymore. “Are there dinosaurs under there?” We don't ask that question anymore.

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I would say that recovery vision is going to have to change the questions we ask ourselves as we move onto this next century. I have listed a few questions, just to give you some examples of some old questions that we asked before the recovery vision and maybe new questions that we should be asking, or as I call them, “Earth is flat questions and Earth is round questions.” So let me give you some examples of the Earth is flat question and Earth is round question.

For example, here’s one that I certainly hear all the time when I go out and give a lecture anywhere and I think that maybe I’m hearing less of it but it’s an Earth is flat question. It’s essentially this, “What do we do with our unmotivated clients?” That’s yesterday’s question. That’s an Earth is flat question. What is the new question now that we know[?] that people do and can recover? The new question is, what do we do with our unappealing programs? Because we use to think that when we were asking what do we do with out unmotivated clients that we were making a diagnosis of the client, we’re actually making a diagnosis of our program because if we have a number of “unmotivated clients,” it says something about our unappealing program. That’s where the challenge is for us. How do we develop programs that don’t demean and infantilize the person for trying to help? How do we come up with words that are different from non-compliance and talk about collaboration? How do we get rid of words like family burden and talk about increase family responsibility? We have all these words that are inherent in our questions that we need to change. So that’s one example. Let me give a couple of other examples of some flat Earth questions.

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Another flat earth question: What credentials do we need to practice in this field? I mean, how many times have you been to a planning meeting or assistant planning meeting, and folks start to talk about, “Well we need 2.3 psychiatrists,” I’ve never seen a 2.3 psychiatrist – maybe I have – “We need 1.2 social workers, .7 psychologists.” Like when we mix them all together, somehow we’re going to get some type of outcome. Those are really yesterday’s questions.

What is the new question? It’s really the Earth is round question is “What characteristics make a person helpful to another person?” That’s what we have to build our team around. We have to look at - independent of credentials except for obviously, when you have to do prescriptions and legal implications and so forth - but aside for that we have to look for what makes people helpful. And if you ask people, what makes a person helpful, they will tell you how skilled they are interpersonally, they will tell you that they’re good teachers, coaches, mentors, models, they can negotiate with people that need to be negotiated with. ³It’s those type of skills – they don’t say, “The person has a PhD, MD.” That’s not what makes a person helpful. So we need to build our teams that way, a very different way to look at teams. So when I hear somebody say, “This team has to have this level of credentials,” I want to translate that into, “What characteristics are part of that team that are making people helpful?”

Pat Spencer, who is a student in our program here, who also is recovering from a severe mental illness, wrote an article—I think it was in the CAMI Journal at the time – and said essentially that there were two things she’d look for when she was receiving help and that was, “Is the person confident and is the person caring?” And that was it

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with Pat. She wanted a confident person and a caring person and competence for her did not translate into credentials, it translated into some of those characteristics I just talked about. And caring of course, “Is the person treating me with dignity, with respect – does the person listen to what I’m saying?” Those are the type of things that to her defined caring.

And I think really in this field, with our new recovery vision, we know some of the things I won’t get into that but that bring about recovery, somebody out there has to be a caring person. Why not some of the professionals who’ve been trained? Makes sense to me. And[?] I know that there’s a lot about this field and about mental illness that I don’t understand but there’s no excuse – so there’s maybe an excuse for lack of understanding at times because sometimes it’s so mysterious - but there’s no excuse for not caring. There really isn’t. How can you have a recovery-oriented system and programs and people in it who are unappealing and uninspiring? So that’s another type of earth is round, earth is flat type question.

I’ll go with a couple of more. This one, when we first started talking about the importance of consumer-survivors being allowed to set their own goals and really it’s almost being allowed to set their own goals, people would say an earth is flat question to me, they would say, “What happens if consumers don’t achieve their goals?” And I would look at them and say, have you achieved all your goals? “Well no, but the consumers will fall apart and just won’t be able to take it.” Well, that’s a far piece from the truth. I think the earth is round question is, “What happens if you don’t have a goal?” That is really the most important thing because it’s really the experience of having

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options and choices, which helps us move towards the recovery perspective. It's not necessarily achieving your first goal or your first option. Most of us don't; we explore through other options and other choices and move along but if you don't have a goal, it's a very different feeling in your life than if you do have a goal or goals. So the real question becomes, "How do we help people develop a goals?"

I want to read a quote – I don't usually read quotes this long, but this seems to me such a nice one. It speaks of this whole idea of goals and it was – I think this person was an educator - Benjamin Maze wasn't in the mental health field, but he said this, "It must be borne in mind that the tragedy of life doesn't lie in not reaching your goal, the tragedy lies in having no goals to reach. It isn't a calamity to die with dreams unfulfilled, but it is a calamity not to dream. It is not a disgrace to not reach the stars, but it is a disgrace to have no stars to reach for."

And we have to be aware of that thinking as we build our recovery-oriented programs and systems and train our personnel. It's fashionable in this field right now to say things about – "Well, patients are dying with their rights on." This is the whole compliance-forced treatment issue and here this, "Patients are dying with their rights on." Well I think we need to rephrase that a little bit, too and I think it's also worth noting that people are living with their dreams turned off and that may be a bigger dilemma for this mental health system.

I'll go with one more here (I haven't gotten the high sign yet.) So I'll try another one. Alright. Earth is flat, "How do we get the person to change so the person can

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achieve their goals?” I say that’s half a question. People do change. But I think the Earth is round question is, “How do we get the environment and the person to change to achieve their goals?” Often it’s just changing the environment, making some accommodations to treating people decently, doing a lot of other things in the environment. And all of a sudden, the person is working, living more independently, going back to school, etc. In rehabilitation, we had a focus initially, on skill development and I used to go out and present and people would say, “Oh you’re about building skills.” I said, No, we’re about a lot more than that. Rehab is a lot more than that. It’s about arranging supports, and helping the environment be more facilitative and not getting in the way of people. It’s more than just building skills. It’s skills and support. Sometimes we focus so much on trying to change the person and that’s really bad when you’re trying to change the person who doesn’t want to be changed in a particular way to set a particular goal. But so often we’re so focused on that as opposed to rearranging the support system. I think[?]it’s the environment and Dr. Harding’s research has implied this and it’s the environment, which sometimes encourages chronicity or long-term illness or long-term disability. And environment again that discriminates, an environment that often sinks people into poverty. Those are some of the biggest barriers to recovery, not the person who has the diagnosis.

So let me try to wrap up here, if I may. What I’m trying to say is that everything should be changed. I remember there was a car commercial that says somewhere, “This changes everything,” with the announcer saying it very dramatically. Well I think a recovery vision or the idea that people grow and move and develop meaning and purpose

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in their lives, even if they had been diagnosed with a mental illness, it sounds so strange sometimes to say it, but that's the way our field was built. On deterioration, on maintenance, on control, a very different field we're moving into the next century and if we're moving in that field, then things are going to have to change. And now, somebody might say to me, "Well, Bill, it's a little Pollyannaish here, that we're not even close to that." I understand that. There's a big gap between our vision right now and our reality. The whole idea of a vision is to pull us into the future. A vision means that you're not there. It means that's the way you're going. And I think that's what the recovery vision is doing for us. It's trying to pull us into the future. There is a gap between vision and reality. You drive a bus to it, but you can look at that gap in two ways. And I like the way Thomas Edison looked at it. [?] Again, not a mental health person, but he had something interesting to say about opportunity that has always stuck with me.

"When opportunity is knocking at your door, it's often dress in overalls and disguised as hard work." Well, I think if we're going to move from reality to a vision of recovery, there's a lot of hard work to do. We best take off our coats and ties and put on overalls. Thank you very much.

Role of Consumer and Non-consumer in the Field by Ms. Judi Chamberlin

Hello, my name is Judi Chamberlin and unlike the two previous speakers, I am not a mental health professional. I was a person labeled with a serious mental health

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illness – I was diagnosed with schizophrenia when I was 21 years old, and I’m a person who’s recovered. So I’m an example of what we’re talking about today. And I think it’s very important to recognize that recovery is not something that happens to a few exceptional, privileged or lucky people, but as building on what Courtenay and Bill have said, recovery is possible for everyone who’s been diagnosed with a major mental illness.

Being told that you have schizophrenia is a devastating experience. Especially, when I was told this, I was also told that I would always be ill, I was always going to need treatment and it was terrifying. It was – this happened in a time of my life when lots of things were going wrong and to be told that they[?] weren’t going to get better, that they weren’t – that things weren’t going to come together for me, was taking away hope at a time when I needed, more than anything else, people believing in me. And I needed support, I needed someone to say there are ways out of this morass you find yourself in and I wasn’t hearing that. And what compounded it was that these people were the experts. They were the ones who were supposed to have the answers. So it was a terrible blow to be told by these professionals that I was never going to get better.

At the same time, and I’ve heard this from many many people over the years who’ve been through this, there was always a part of me who didn’t believe it. There was one part of me that was saying, Well these people are the experts, they know what they’re talking about and another part of me was really inside me screaming, No no no I cannot believe that my life is over at the age of twenty-one. I had all kinds of hopes and dreams

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about the future, like other people, and to be told that there wasn't any point in dreaming them, just didn't make any sense to me. I needed to hold onto my dreams.

I had gone into the mental health system because I believed that there were people there, with the right kinds of training and knowledge and expertise that would help me to figure out what had gone wrong in my life and that they would be helpful in getting my life back on track. Instead I found out, in addition to all the other problems that had brought me to that point, I now had to fight the mental health system and that's really what I did.

I've written an article, called "Confessions of a non-compliant patient" and I really believe that it's those of us who were considered the most ill, the most non-compliant, the most trouble, we're the ones who have the fastest track really on getting better because there's always that part of us saying, No no no, I'm not going to take your vision of what my life is going to be, I'm going to stick to my own vision of what my life is going to be. At that point in my life, I thought maybe I was the only person who felt like that. I didn't know that there were [?]other people – I hoped there were, I believed there were, I used to have a dream that sustained me that somehow I'd find other people who'd been through the same kinds of experiences and that we'd join together and do something about it. But it took me five years after I got out of the hospital to find that there was, in fact, a group of former patients that had started meeting in New York City - this was the early 70s –and it was only when I became involved in the self-help movement and self-help and advocacy movement that I found what I had been looking for in the mental health system but never found there and that was people who were

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willing to listen, willing to accept my experiences; take me at face value, not start labeling my feelings and my thoughts as symptoms and that we can do this for one another, that it was a very mutual activity – it was mutual support.

So I've been very involved in the ex-patients, consumer-survivor movement for thirty years now and I've seen this movement grow and develop and really pioneer a lot of the concepts that professionals are now beginning to talk about – particularly the idea that we can and do get better. What a lot of us have learned in the mental health system is what has been termed in literature as learned helplessness. And when you have learned to be helpless, you are not, I really can relate to the things that Dr. Anthony was saying, you've had your dreams taken away from you.

The term recovery has a little bit of, I'm not sure if it's a word that a lot of us feel comfortable with because a lot of us don't feel that we had an illness at all – we feel that we had a catastrophe in our lives – a catastrophe that was in many cases compounded by the experiences that we had in the mental health system.

So let me talk a little bit about terminology here. I'd like to talk about the terms that we used to describe people who get diagnosed as mentally ill. Because a term that a lot of professionals seem to use is a term that a lot of us don't feel comfortable with and that's the term "consumer" or as it's used in other parts of the world, "user," user of psychiatric services. And when we say consumer or user, it implies that we are purchasing a good or a service – and that's not the experience most of us have had in the mental health system. We've had a lot of things shoved down our throats – that we didn't

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have any choice in deciding that those were the things that we wanted. So I always feel a little uncomfortable with the term consumer.

Another term that we used a lot especially in the early development of our movement, which was “ex-patient,” which implies a movement, a process of development from having been a patient to no longer having been a patient, but it still accepts the idea of patienthood and illness. So a lot of us have moved on to using the term “survivor.” We survived quite a bit actually. We survived all the disastrous experiences that led us to the point where our lives felt like they were falling apart – that’s the point where you get diagnosed with a mental illness. And for many of us, we also survived some treatments that really were not terribly helpful, were in many cases obstacles to our regaining of our sense of who we were and what we were capable of. So a lot of times, you’ll hear the term as³Marianne Farkas used, “consumer-survivor,” so that we kind of encompass people who used different terminologies to describe themselves.

And I’d also like to talk a little bit about this term “recovery.” Because it does carry within it the connotation that we got better from something and I like Dr. Harding’s term, “resilience” – that this capacity was within us all the time and we just have to find ways to nurturing and encouraging it.

So the consumer-survivor, ex-patient-user movement is a worldwide movement of people that developed in many many countries in the early 70s. It’s really interesting as I’ve learned more and more in my travels, to see how many different groups got started independently of one another, not knowing about other groups in other countries at about the same time – the early 70s. And we saw this very much as a civil rights movement – it

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was modeled on other movements that were very active at that time in history. The struggles of in this country, black people, and the struggles of racial minorities and ethnic minorities around the world - women's rights, disability rights and the movement of sexual minorities, and we also see this as a civil rights movement. This is not merely about improving treatment; this is about improving our lives by gaining or regaining the civil rights that we lose when we diagnosed with mental illness. So like other groups that have been oppressed and have seen their selfhood defined by other people, we're trying to reclaim our right to speak for ourselves, to make our own decisions and to determine our own future and that drives very well with the paradigm shift that Bill Anthony was talking about – moving from giving people goals to letting them find their own goals.

And you can't really give anyone a goal. I gave a talk once at a large conference that was mental health professionals and mental health recipients together and at the end of the talk, somebody asked a question. One of the "consumer-survivor" asked a question, she said, "What do you do if you don't like your goals?" and I was kind of taken aback for a moment. And what I answered her after trying to put together a quick answer, I said, I don't know what those things are that you were apparently handed, but whatever they are, they're not your goals. They're a set of expectations that somebody else has for you. But only you can determine your goals and the look on her face as this little light bulb went on over her head is something I'm never going to forget. So we now see within the professional community or at least in some segments of the professional community, that this paradigm shift is occurring, that more and more professionals are talking about recovery, about resilience, that they are confirming something that we've

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always believed – that recovery is real and possible for anyone who’s been diagnosed with a serious mental illness. And what this implies for professionals is that there’s going to have to be an extreme shift in how they practice because for many people in the mental health system, professionals present themselves as the person with the answers and the person who has the diagnosis is presented as someone who needs to be led, needs to be told what to do, needs to be controlled, needs to be curbed in many ways because their own impulses are so wrong.

So as we move into a recovery paradigm, professionals are going to have to shift their attitudes about who they are, what they do and what they practice. They’re going to have to be very conscious about the messages they give out – as I started out by saying my own initial diagnosis carried with us this enormous message of hopelessness and professionals are going to have to re-examine carefully what they do so that instead they are carrying the message of hope, that they are letting people know that yes, that in this point of your life, things are really pretty bad, ‘you’re not able to do the things that you want to do, but I’m here to tell you that this is not a permanent state and you can move on from this state and that’s going to require a lot of retraining or as I like to think about it, unlearning.

Professionals are going to have to start thinking of their clients as active participants, not passive recipients. They are not just there to be filled up with some, “Here’s some treatment” and then just fill them up with it. They’re there to work in a collaborative relationship where it’s the client who sets the path and the professional who then tries to move things along. So there’s going to have to be much more of a

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collaborative, interactive effort through all phases of treatment - that means there shouldn't be meetings at which everybody but the client is present to decide what's going to happen to the client, that there have to be serious discussions in which the client says, "Here's where I think I am and here's where I want to go" and the professionals then think up of strategies on how to get there. And there certainly has to be the recognition that the role of the ill person, the role of the mental patient is a temporary condition, not a lifelong one. This paradigm shift is⁷ very important and it's particularly important to make sure that we don't just change what we call things, that we actually change how we do things because it's much easier to change the words than to change the actions behind the words but unless we really do change the actions behind the words, it's not really a paradigm shift at all.

When Courtenay was winding up her talk and she quoted something that she'd seen posted somewhere, it made me think of something I found a year or two ago, posted on the wall of a drop-in center near Vancouver, Canada – a Client-run Drop-In Center and it's a poem by e.e. cummings. And I'd like to close with that because to me it just captured what this experience of being defined as mentally ill and struggling against it is all about. And this is the poem: "to be nobody but yourself, in a world which is doing its best, night and day, to make you everybody else, means to fight the hardest battle, which any human can fight, and never stop fighting.

Thank you.

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²Effect on Mental Health & Rehabilitation Systems by Dr. Marianne Farkas

Thank you Judi. I'm going to spend a few minutes now trying to talk about the implications of all this for the implementation of the recovery ideal at a systems level. A system that can support people's recovery has a recovery culture. It has a strong commitment to recovery and the capacity to support recovery. In the few minutes that I have now, I will give you a few examples that are drawn from what the three speakers before me have already emphasized so eloquently. First of all, the recovery culture is one in which that the system as a whole believes in recovery, in other words, it talks and walks recovery. While I fully acknowledge that there is still much to define in this field, I'd like to suggest some system features that would reflect such a culture. First of all, the mission and policies of any system state what its overall purpose, its expected outcomes and its basic values are.

So, in a culture of recovery, there would naturally be the idea of recovery as the overall purpose of the system, tying all of its services together, rather than the usual mission, which is to provide the services of treatment or rehabilitation or case management to population X within cache area Y. A policy statement, based on recovery values might be for example, every person with a psychiatric disability or long term psychiatric experience, as some people have told me is a better phrase, has the right to determine his or her own goals and future. That might be a policy statement that reflects recovery culture.

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The second example of a recovery culture might be, and my apologies to Judi here, the system fully expects to involve consumers or consumer-survivors or consumer-survivors-ex-patients at all levels of the system, not just accepts consumers in the system. So those are two examples of what I would think would reflect a recovery culture. Now a system has to demonstrate not only a culture but its commitment, as Judi said before to actually changing that more than just the words. So a system that demonstrates its commitment to recovery will use recovery outcome measures to honestly evaluate whether or not it implemented to the mission that it stated. Such measures might be for example, the number of system clients, who have gained or regained the valued roles that they prefer in society. It might be the number of system clients who report experiencing meaningful lives as a result of the services that have been delivered. And when I say honestly evaluate, I mean that administrators change the system, that based on what the evaluation data reveals[?]; otherwise, what usually happens is that evaluations are done and then the evaluation report is stored in the drawer for the annual meeting and that's about the impact of it. When you honestly use these measures to evaluate your system, the implication is a promise that you're going to do something to change the system based on what you evaluate.

The second example of system commitment to recovery is that you have consumer-survivors active in planning, developing, implementing and evaluating the service system. Token seats on councils and boards are not real mechanisms for participation. Making sure that no phase of the system development from planning for evaluation is done without consumer-survivors. Consumers who are organized to provide

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direction, decisions, feedback is the hallmark of a system that is committed to implementing recovery. As Judi Chamberlin once told me, “Nothing about us, without us.”

Third example of system commitment to recovery is that the system funds services whose procedures and⁷ practices demonstrate recovery values, such as the value of self-determination, the right to make choices, a belief in people’s growth-potential, the hopefulness issue and individual uniqueness, going back to what Courtenay had said originally about heterogeneity. We are all individuals. So recovery oriented systems use their funding mechanisms to encourage all provider services whether it be treatment services, rehabilitation, case management, basic support services, for example, to show how their activities support client choices. How does this treatment service demonstrate that activity support client choices? To show how their procedures and record-keeping ensure that each individual strengths, talents and deficits are assessed and planned for; to show how their services result in consumer survivors in a variety of living, working, educational roles. For example, are there opportunities for people to go to everything from supportive housing to owning their own flat? From working as a farmer to working as this CEO of a large corporation? Or a professor in a University? From being a student in a vocational course to a doctoral student at a University - rather than what usually happens, which is limiting clients to what people in the system feel is appropriate, and usually this involves entry-level positions, group homes or day treatment learning classes.

I wanted to give you an example of this issue of systems capacity for the delivery of recovery services. So it’s one thing to have a culture of recovery, it’s another thing to

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have commitment to a recovery vision, but you also have to have the capacity to delivery that vision in the actual way in which people interact and we heard some things already from this morning and I'm going to summarize them.

So whether systems staff are consumer-survivors or non consumer-survivors, training and development must have ways to teach staff for example, how to be there in a way that clients experience as trustworthy and supportive rather than as controlling and interfering. Yes, it's a characteristic, but it's also a skill and people need to be able to know how to do that since clients have told us that that's what people find helpful. People have to be taught how to help people develop their own goals and we've heard a lot about that this morning rather than adapting themselves to goals that others believe they should have. Learning how to help clients to figure out what their own strengths and deficits are rather than what their label is. Learning how to promote hopefulness in clients, significant others and general society for that matter, rather than accepting or promoting resignation and despair[?]. A skilled workforce needs to be able to do these things and much more than what I've mentioned.

Developing a recovery-oriented system requires that all services and structures have incorporated the culture that the on-going commitment is demonstrated in concrete terms, and that system providers at all levels have the knowledge, the attitudes and the skills necessary to delivery on the promise of recovery. The culture commitment and capacity of a system to delivery services that contribute to recovery as much more complex than this brief overview will allow. Indeed, there is much, as we've said over and over again, that we have yet to learn about what it does mean to create such a system.

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Helping people to live meaningful lives rather than existing on the margins of society, helping people to do what they want to do rather than what others feel that they are able to do, helping people to be with their friends and neighbors rather than being with only the ones who are paid to be there, helping people to fully live, learn and work in the communities that they value and prefer as citizens of those communities is our task for the 21st century. It is truly time to do so. Creating these systems that honor and support recovery is an enormous task, but by working together, researchers and non-researchers, consumer-survivors and non consumer-survivors, professionals and non-professionals across the globe, we can make it a reality. And thank you for your attention.[?]

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