

Expert Panel Discusses Workforce Issues in the Face of a Recovery-Based Care Transformation

By all accounts, system transformation requires a skilled and dedicated workforce that is willing to be flexible while enabling change. For state mental health agency administrators, the workforce provides both a source of daily challenges, and the answers to the system's ills. Whether consumer or non-consumer, psychiatrist or nurse, the workforce is the engine that makes the current system run. This NASMHPD/NTAC e-Report features a panel of three experts on recovery-based care issues discussing the status of a public mental health workforce on the verge of system transformation.

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1) What can the public mental health system workforce (clinical and administrative) do to become more informed about recovery-based care?

Deegan: I think the number one thing is to listen to consumer/survivor/ex-patients in the mental health system about what helps and what hinders recovery. We need to urge staff to get beyond the assumption that people with psychiatric disabilities can't speak on their own behalf. Pay attention to people who work as advocates, especially those with first-hand experience of the system. Include consumer/survivor advocates at all levels of the mental health system to make sure that we are there in a real presence, represented in all our diversity. There is an error that is often made that we all think the same way, that if you have one consumer on the committee, that makes it an integrated committee. Also, don't just listen to satisfaction questionnaires. These can be misleading because what the survey shows is a person's level of satisfaction with the services, as if the services themselves are an end point. One of the keys to understanding recovery is that services should be a means to an end—living a full and meaningful life in the community, with relationships enmeshed with the world of commerce, employment, and education. To me, rehabilitation is about services, technologies, professionals, advisors, or experts that people with psychiatric disabilities can consult with, can receive guidance from, can involve themselves with about shared decision making. Recovery is a person-centered phenomenon. You can't 'do recovery' to someone. You can't 'do services' that will force someone to recover. Recovery-based services will always be one small part or one small ingredient for a person with psychiatric disabilities to achieve a meaningful life in the community.

Jensen: In terms of ideas I have heard from the field, one idea is to make it mandatory that all current and new professionals take some sort of psychosocial rehabilitation certification course so that they know about rehabilitation. Another idea is to promote self-education. What is recovery? What is recovery-based care? Start this process by inviting people into hospitals and clinics to tell their own recovery stories as people with lived experience, and to convey what

works and doesn't work. Another way would be to host short, on-site, mini-recovery conferences on topics selected by persons with lived experience: patients, clients, consumers. Another idea is to become involved through their local peer-review board, in order to connect their local board to efforts such as the Annapolis Coalition on Behavioral Health Workforce Competencies and their efforts. A sub-item on that would be to support the efforts of coalition groups such as the Annapolis group to develop across discipline and across provider competencies in order to ensure that recovery-based services are being delivered. Another way is to apply for federal, state, or private grants to provide recovery-based education and program development.

Knight: There are four rehabilitation or recovery packages for the workforce. I agree with Pat Deegan that recovery is the lived experience of rehabilitation. I think that the skills training approach and the strength-based approach are what's needed, rather than the "psychology of adjustment" approach. The psychology of adjustment attempts to adjust *you* to a baseline that is usually your lowest functioning level with a mental illness. Everything else you attempt to do is seen as delusional. A psychology of respect would be based on strengths and teaching skills, rather than trying to adjust you to your mental illness. The packages are 1) from University of Kansas – a strengths-based case management approach, which has recently been thoroughly updated by Priscilla Ridgway in a book called *Pathways to Recovery*; 2) Bob Lieberman of UCLA [the Clinical Research Center for Schizophrenia and Psychiatric Rehabilitation] has a set of skills packages that is very good; 3) Eli Lily has the Team Solutions rehabilitation package [in conjunction with the University of Medicine and Dentistry of New Jersey (UMDNJ)]; and of course there is 4) the Boston University technology—probably the most extensive of the technologies. They recently came out with a package of 68 skills [*Practitioner Tools for Achieving Valued Roles (Compendium Version)*] that can help people regain the skills they've lost during institutionalization, either in the community or in the hospital. Institutionalization "de-skills" people. It's a result of being institutionalized and having things done for you, and being repeatedly told that you have to adjust to a situation where you can't expect anything out of life, a.k.a. the psychology of adjustment. You can't expect to have normal social relationships, jobs, or a car. These four rehabilitation packages are all out, they are available for purchase, and you can get some training on them.

2) Can you provide some detail on how consumer/survivors can help mental health professionals facilitate the system's transformation to recovery-based care?

Deegan: Nothing about us without us. We want to be involved at every level of decision making, we don't want to be just relegated to an advisory board. Also, we want to be represented in large enough numbers that reflect the diversity of opinion within our community. Systems need to work with consumers to see how health systems can support resilience in all consumer/survivors rather than treating deficits. The workforce should learn that persons with disabilities do not have special needs. I have the same needs as you. My needs are for community, companionship, decent, affordable housing, the right to say what I want to do with my life, and the resources I need to achieve that end. When my needs are converted into special needs, then somehow it becomes the prerogative of specialists to address my special needs. Then we are talking about specialized placement. I don't want to live out my life in the netherworld of 'human service land.' I want to live out my life in the real world with all of the stress and struggles and the wonder and complexity of it all. We've got to get off organizing models of service and instead

start talking about supports for living real life. I think consumers can provide an enormous help because I don't believe that systems can care. Some systems throw up roadblocks and impediments to recovery. There are also marvelous models of innovation in person-centered recovery that show us how to get rid of those obstacles so we actually have support. In a transformed system, it will be the establishment of our humanity as a common ground from which all work and all care can possibly emerge.

Jensen: Consumer/survivors can help mental health professionals facilitate the transformation in several ways. From my informal survey of consumers, they say that if consumers could be volunteers in state hospitals, working with the patients on recovery issues, then the staff would be able to see positive changes. Additional ideas would be to become partners with academics, professionals, researchers, and mental health service organizations in order to co-develop, co-lead, and co-author efforts. An example of this from Illinois would be the Recovery Assessment Scale. This scale looked at perception of recovery from the service user's point of view. It was a partnered effort by researchers, administrators, and mental health consumers. Other ways would be for consumers to seek inclusion on boards of mental health service organizations, local chambers of commerce, church boards, library boards, etc. to promote education in the area of mental health recovery. Another way is to seek to learn and lead recovery education groups, such as Mary Ellen Copeland's Wellness Recovery Action Plan [WRAP], and try to change the culture from within. Another idea is to use that same WRAP approach through organization development, and this could be also be co-lead by people with lived experience and organizational experience. Another idea is to create groups to provide services to peers. This could be a non-profit group for educating, or it could be a support group, transportation assistance, companionship – there are all kinds of ways to develop peer services. Also by providing peer crisis services, and peer hostel services, peer hospice services, or peer support services. The next item would be to learn how to break the silence, which Pat Deegan talks about, whenever disrespect occurs, to come to the aid of people who need it rather than being silent. People can influence micro-aggression [*Editor's note: see Deegan's answer under #3*] right where services are being delivered. Consumers can learn how to break the silence about macro-problems in this micro way. They can break the silence about how restraint and seclusion occur.

Knight: I think that receiving a serious mental health diagnosis is what Andrew Phelps calls, a "social death sentence." I think the workforce should listen to consumers very carefully so consumers can present the social death sentences they've received, and also present what's been helpful in overcoming these sentences and regaining meaning and purpose. We as consumer/survivors have kept recovery on the agenda, and our political clout has been great, enough to keep it on the agenda. There have been a number of attempts to move recovery from the agenda, including the narrowly defined evidence-based practice movement. I emphasize *narrowly defined* if you actually look at the evidence. RAND Corporation did a review and found one best practice—ACT teams. I don't think most ACT teams are recovery-oriented, they are maintenance-oriented, although I do know of some examples where ACT teams use a recovery approach. I think a much broader definition of evidence-based practice needs to be created, and if you use this [broader] definition, than self-help becomes a best-practice. It doesn't have a number of random assignment studies behind it, but then neither do other best practices

that are being promoted. I think that the consumer/survivor movement needs to keep up the political pressure to keep recovery on the agenda.

3) What can academia do to instill the philosophy of recovery into the next generation of mental health professionals?

Deegan: I believe that we need to be extremely conscious of language. I did a brief survey of staff and clients from a very typical mental health service setting. I asked for examples of times when you heard someone who was being disrespected, or a time when you were being respected. These weren't evil staff and they weren't particularly awful clients. They were just typical. Their answers included words and phrases like: crazy, nut, psycho, retarded, whacko, nutjob, stupid, sick, creepy, screwy, back-to-the-nut-house, child, drama queen, time-for-the-rubber-room, lazy, get-a-life, substance abuser, loser, for-a-schitzo-you're-doing-very-well, my-taxes-pay-for-your-SSI, [etc.]. These are just some examples of micro-aggression. This is the kind of stuff that is going on daily in programs. Over time, this begins to wear down people and their hope. It creates a culture of hopelessness and despair. In terms of educating people on language and other aspects, we need to begin to operationalize the recovery-based approaches. We need to come down from the principles and talk concretely about personal choice. We need to rethink professional boundaries. We need to rethink approaches to psychiatric medications. We need to create opportunities for mental health workers and students in the profession to have a 'disability internship,' to live in an SRO on \$562 month, using day treatment, using public transportation in rural settings. And this is not to impose any suffering on these students, but to let them feel how profoundly disabling poverty is when there is no way out.

Jensen: From the consumer input I have heard, we need to start in the junior high schools, before people even get into professional schools with educational efforts. As a recent grad of an MSW program told me, consumers should come and speak and tell recovery stories. They could discuss what is good and not good about the existing system's services. Other ideas include having persons with lived experience lead discussions, and to have required courses in recovery competencies. Another idea is to have academics who are also in clinical practice to educate themselves. The concept of recovery is so foreign to how today's professionals are educated, except for a few isolated departments, that it's very hard to find information on recovery. It's more than instilling the philosophy; it's teaching research-based and recovery-based best practice models in the core curriculum. Things such as strength-based approaches to depression, such as case management, or therapy, or professional conduct between physicians and patients. Another example of a model is implementing WRAP as a model of co-collaboration between patients and providers.

Knight: The field of psychology generally teaches a "psychology of respect" for people without problems and for people with minor problems such as mild depression, and it teaches a "psychology of adjustment" for [people with SMI]. The field of psychiatry is the same. Although, at the University of Colorado Medical School, I get invited in to talk about recovery. Other consumer/survivors have told me that some universities invite them in to talk as well. Judith Cook and the University of Illinois, Boston University, UCLA, University of Kansas – they all have some recovery orientation. One of the most important things to do is to look at the evidence on recovery from schizophrenia that Courtenay Harding has put together. Look at her

body of work; look at the work around recovery from bipolar illness. Some of these studies of longer than 12 years show a 75%-or-better recovery rate. From that body of evidence, you can develop a platform from which to begin to approach recovery. The next most important thing is for universities to invite in their local consumer/survivors to speak about recovery. They are eloquent about discussing what hinders and helps their own recovery. Next, universities should hire some staff from the four or five institutions that are teaching recovery to be on their faculty. They can also improve the research agenda at universities, which flows from NIH and NIMH. They are not very open to recovery studies themselves. We have a series of article we've written on a research grant and the methodology is excellent. It's top-notch research, and we are having trouble finding journals to accept our articles that are oriented toward consumer issues. The fact that NIMH almost always does research based on diagnosis, rather cross-diagnosis research, is not very helpful for recovery. Most research done on mutual support and cross-diagnosis, such as Double Trouble and Recovery, has been studied by the National Institute of Drug Abuse. This all relates to academia, and the flow of ideas has to follow the flow of money. As long as NIMH has their priorities where they are, you won't see much inroad into academia for recovery research.

4) What are the two largest workforce-related obstacles to implementing Recovery-based care in existing systems and settings, and how can they be addressed?

Deegan: The creation of service models, and the organizing of services around models, as opposed to encouraging individualized supports with individual budgets for living in the community. This is the biggest obstacle to having true, recovery-based care. The corollary to this is in the workforce itself. The workforce is trained to offer services according to models—and being accountable to agencies which are also organized around such models—instead of service workers being accountable and paid by the person with the psychiatric disability, via an individual budget and as negotiated with a fiscal intermediary. In a transformed mental health system, we see more about person-centered planning and person-centered budgets. We see a different sensibility regarding tax dollars. These dollars are not owned by social service vendors, but rather, through the aid of fiscal intermediaries, these dollars go into personal accounts for individual support and are then spent in a planned way by the person with psychiatric disabilities who has developed a personal recovery plan and an individualized budget. The person has a plan to be accountable for the expenditure of those dollars, to maximize the value of those public dollars, by working with a public intermediary. This is the future we are looking at when we talk about the future of recovery care.

Jensen: I think from the consumer input I have heard that stigma is a significant obstacle. Further, consumers say that the stigma and ignorance is so bad that providers think they already are providing recovery-based care. In the United States, we have no central system of regulation that is in place that has been helpful in other countries such as in England, Australia or New Zealand, as they are moving toward cross-discipline services. We don't have some sort of overarching system to provide an umbrella for core competencies across disciplines that are the same, and then people can add their own discipline-based competencies. This is one of the things that the Annapolis Coalition is looking to address. What happens is that the language—kind of like the tower of Babel—needs development. Recovery in mental health is not the same as recovery in substance abuse. The core of the matter is that the words needs to be useful across age groups, disciplines, cultures, service provision areas, and so we have a Tower of Babel

situation where we may be talking about the same thing, but we can not come to the table to come up with the words. So what's happened is that whether you are a provider, or a family member, or even a consumer, people still think that they can decide whether recovery exists or not. Fortunately, there are accounts of recovery for hundreds of years. Recovery has nothing to do with whether they believe it or not. But, the criss-cross of language gets us bogged down in the idea that 'it can't possibly be true.'

Knight: I think the largest obstacle is the funding mechanisms, the fee for service mechanism—this promotes that if you are paid by the hour, you keep on doing more and more by the hour. This method of funding promotes dependencies and a psychology of adjustment. If *properly done*, capitation can promote recovery. The promotion of recovery through alternative funding mechanisms is not through fee-for-service, but through some form of capitation. You can talk about case rates, for example, or other capitation mechanisms like block grants with outcomes tied to the grant. Those kinds of mechanisms can promote recovery. While we continue with funding fee-for-service, there is more and more dependency created. I think that consumer services, when they are funded that way, will eventually promote dependency. This is why there has been so much controversy about Medicaid funding of consumer services. If you are paid by the hour, you will be driven to do more by the hour—even consumer providers. It's a simple survival mechanism. This tradition of funding mechanism helps create the psychology of adjustment culture. This culture has a set of roles and identities that professionals and other staff members occupy. They are essentially caretaking roles, not recovery roles, and so you'll find professionals forming their social identities around taking care of a group of people they think are totally hopeless. The second large obstacle is the culture being built around a psychology of adjustment versus a psychology of respect. The phrase "psychology of respect" is credited to Andrew Phelps, with the Accountability Caucus in California. These two obstacles can be addressed by: changing the funding mechanisms to some form of capitation, and as for the culture and identity issue, this is best changed through dialogues with consumer/survivors about what helps and hinders recovery, and through training.

5) From your interactions with the public mental health system workforce, is there more hope for recovery from mental illness today than there was ten years ago?

Deegan: I'd like to take a longer look back. As you know there are seven longitudinal studies in modern times that show recovery rates of one-half to two-thirds of people diagnosed with schizophrenia and other major mental disorders go on to significant or full recovery. Those studies span from the 1940s to the 1990s. But, there was a longitudinal study done at Worcester State Hospital in Massachusetts that was started in 1881. They looked at 211 patients who had been discharged as recovered between 1833-1840. The superintendent [in 1881] found that 51% of those discharged as recovered had remained well for as long as they lived. Between 1881-1893, the hospital sent letters to families of those who had been discharged from the hospital, and they looked at a total of 984 people discharged, and they found that 568 people remained well for the rest of their lives, or for as many as 40 years after discharge. They found that recovery rates between 1840-1893 were 58%. I know the danger of making a comparison between unmatched samples. However, the homogeneity of these rates with today's studies is striking. What can this homogeneity of data mean? Some might say it says something about the treatment, yet, the treatment has changed dramatically and recovery rates are about the same.

When we are talking about recovery, we need to start thinking about recovery as a type of resilience, a drive to wellness, a self-righting capacity, a resourcefulness that people who were historically seen as vulnerable and afflicted can somehow bring to bear on their own recovery. This begins to change the human services landscape. Currently, we live in a time of unique opportunity. We have at the federal judiciary level the Olmstead Act in 1999, saying it is a form of illegal segregation to keep people in institutions longer than they need to be there. We have the legislature—the Americans with Disabilities Act—saying that people have the right to accessible voting, transportation, communication, mobility, and equal opportunity to work. Now we have the executive branch with the President’s New Freedom Commission. So we have these three major things converging and it opens a unique window of opportunity. The grave danger of this time is - are we going to look at transformation as a matter of rearranging the chairs on the deck of the Titanic? Change is no guarantee of progress. If there is going to be one thing that each state does to bring about real mental health system transformation, let’s get at least one demonstration project of self-directed care up and running in each of the states and territories.

Jensen: The short answer is absolutely and absolutely not. The first part of my answer is absolutely. There are individuals with life experience who are hired by everyone from the federal government to local agencies, and they are hired to do peer services, organizational change, education on recovery, and this is where change happens on the front lines. For most individuals doing this sort of work, such as a development specialist, or consumer specialist, this is isolated work. Even though I have my professional license and I have had my license for 25 years, I am no longer a nurse as a disclosed person. As a disclosed person, I am not necessarily a part of the staff from the point of view of everyone on the staff who is non-disclosed or a non-consumer. But, on the other hand, I am someone who does not have the court of peers, because I am a provider. It’s like I’m on an island in the river, with the river going by on both sides. There is hope in other ways, though. There is research, there are best practices, there’s self-help, there’s partnered collaborations that are already in existence that are supportable, fundable, and they are in demand. Further, there is the President’s New Freedom Commission to bring a vision of recovery into being. Further, there are people with lived experience working in the system all over the country. Maybe there’ll be a time when more people will become more recovery-oriented. Our current system is disease oriented, in that it is based in the disease model. Our system is still entrenched in that model. Perhaps there will come a time when self-disclosure will not be hazardous to your career, your professional health. There are more and more people self-educating about recovery who become people who can influence organizations in greater and greater ways. Many have started with GEDs and now they have PhDs. They are still living with symptoms, and are still recovering people. Further, there is more and more information that is carried on from person to person, to share concrete ways to make recovery possible. It’s done primarily by word of mouth from people with lived experience. The answer to the question is absolutely. To answer the question in another way, the caution is that this is kind of like trying to water ski behind a six-masted, ruddered tall ship. They don’t go fast, they don’t turn fast, and they don’t make waves. And if they make wakes, you have to get out of them. We are trying to get up on the water, but they don’t go fast enough. Where it’s bogged down is when people equate hope for recovery with that tall ship. Instead, you’ve got to equate it with the water skier who can swim faster than the ship. Maybe the water skier can succeed by finding an island, or

they could find a way to get faster, maybe a motorboat. We need to change our perspective on this effort.

Knight: Because of the consumer/survivor movement, there is more hope now. We have pushed the notion of recovery, and we have pushed the notion of consumer-run and consumer-driven services in the field. I know of examples, some tragic examples, in some states and counties where there has been direct competition between consumer programs and day treatment programs run by the county. The consumer-run program was doing so much better than the day treatment programs, that the county took away the funding for the consumer-run program. This left an impact on people's minds. People indeed did better and preferred the service of a clubhouse over a day treatment program. I think the work that Larry Fricks has done in Georgia is great, and the work of Mary Ellen Copeland, and Joe Rogers from Southeastern Pennsylvania. Mary Ann Long of Meta Services in Phoenix. The work of Andrew Phelps, John Delman and Moira Armstrong in Massachusetts, the work of Howie Vogel with Double Trouble, the work of Bonnie Pate of South Carolina—all these various people—I am leaving out a lot of people. All of these modalities have pushed the system, nationwide. Most of these people have been noticed nationally in places where consumers do and teach recovery. Those kinds of outposts of recovery have been extremely important. All of these people have influenced the local and national scene.