

I'm [name] and I am presenting "Consumer Roles in Inpatient Settings" today.

This module has been created by three individuals: myself, Tom Lane and Joyce Jorgenson and you're going to notice in the module that some of the slides have changed. Each one of us does our presentation a little bit differently. Originally, Tom Lane was going to do this presentation and I'm actually filling in for him. You won't have all of the slides but if you would like them we'd be glad to provide them to you later.

One of the things that we always do in our introductions is to talk about ourselves as a consumer and it might be helpful also to know well, what is a consumer? A consumer is a person who has been diagnosed with a serious and persistent mental illness; generally a person who has a current or former recipient of mental health services; frequently we think of persons that have been hospitalized. It might include other things like receiving benefits or receiving other kinds of services. It occurred to me to think also that our definition may be changing because we're hospitalizing less and less and so people are being served in a variety of different ways. But the one distinction is that it's not a person who has just received counseling; it's a person who, or the worried well as we sometimes put it; it is a person who shares a severe mental illness and has had a variety of experiences as part of that and also chooses to share those experiences.

I also know that I'm in the company of other people that are consumers in the audience and I would really like to acknowledge them at this time. So for those of you that identify as self-disclosed consumer/survivors and are working in our system would you please stand up. Thank you. It's also my thought or my goal to go through my presentation and be able to have a little time at the end to include some of them as part of our presentations.

Any work used from this document should be referenced as follows:

"National Executive Training Institute (NETI). (2005). Training curriculum for reduction of seclusion and restraint. Draft curriculum manual. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD), National Technical Assistance Center for State Mental Health Planning (NTAC)"

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Consumer Roles in Inpatient Settings: Consumer Movement History

■ 1970's

Radical Liberation Movement—
Demonstrations/Conferences/Newsletters

■ 1980's

Movement received attention from Federal Government—

First Alternatives' Conference Drop-In Centers developed

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I'm going to start off with something that I think is real important to see in context is the grass roots, the historical perspective, of how consumers have come to be as involved as we are. In the 1970's, we had what we called our radical liberation movement. Sometimes today we refer to ourselves as being part of a consumer movement. At that time it was clearly people who were very, very angry at the system; groups of people that formed in different parts of the country and banded together in their protest and demonstrations against a mental health system that they felt was harmful.

In California there was a group called Network Against Psychiatric Assault. This was something that I joined up with at that time. They put out a newsletter called *Madness Network News*; all that fits, that's news to print; all that fits, that's news to print. That was their byline on the newsletter.

One of the significant things that happened was a month long sit-in that happened in the governor's office, Jerry Brown at that time, where demands were made for conditions to change. Shock treatment was a big issue; restraint and seclusion was also talked about and deaths in institutions. At the same time that people were angry they also started to talk about self-help alternatives. Sally Zinman was one of the people that took the lead on this and the beginning of drop-in centers started to happen in the 1980's. One of the first drop-in centers was On Our Own of Maryland that began in 1982.

First Alternatives' Conference took place in the 80s. We think with about 300 people and at that time the word "consumer" was agreed on. Everybody coming at this conference and coming from different perspectives had different ideas of how they wanted to define themselves. And the word consumer was finally agreed upon but not popular really; not popular then, not popular today, but it definitely was the word that seemed to provide the most consensus.

But for those people that were not happy with that they added the word "survivor". Other people wanted to just call themselves ex-patients. So sometimes we are referred to as c/s/exr's, as consumer/survivors. Still others call themselves other things and in Florida, Harold Maio, who is certainly a person who talks about language, that's his big issue and he doesn't feel that we should ever have a label at all and thinks we should only be people or persons. So in the Baker Act in Florida for the first time, all of the words "patients" were taken out and changed to "persons". So that was a nice thing.

Consumer Roles in Inpatient Settings: Consumer Movement History

■ 1990's

Recognition of peer roles, demonstration projects and recovery orientation

■ Now:

Consumer roles have become more accepted and integrated in all areas of mental health

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In the '90's was the beginning of the recognition of peer roles. There were demonstration projects on drop in centers. The word recovery and the meanings of recovery and even research around the meanings of recovery through the efforts and writings of Ruth Ralph and others. Dr. Dan Fisher in Massachusetts has written an awful lot about recovery and did a very nice article about recovery, "Healing and Recovery in Mental Health Settings".

Now, what we have is a much more acceptance of consumer roles. And I think we are at a point where we have a position, a staff position that I think will continue in part of the settings of mental health or credit the culture of mental health is the role of peer specialists, and not only are peer specialist being hired in a variety of mental health settings, they're also being trained and certified and there's some research being done on peer specialists.

Consumer Roles in Inpatient Settings: Surgeon General's Reports and Peer Supports

• Mental Health: A Report of the Surgeon General (US DHHS, 1999) recognized self-help as an important adjunct to traditional mental health services and concluded that self-help activities serve as powerful agents for change in service programs and policy.

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In 1999 the report of the Surgeon General recognized self-help as an important adjunct to traditional mental health services and concluded that self-help activities serve as powerful agents for change in service programs and policies. So we started to be included in some of the national and federal guidelines.

Consumer Roles in Inpatient Settings: Peer Supports: an Emerging New Practice

- Peer-run support services holds promise for improved outcomes for a public mental health system that:
 - is under-funded
 - fails to reach the majority of those with mental illnesses
 - often delivers services that are ineffective

(Campbell & Leaver, 2003)

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In 2003 there was a meeting, a National Experts Meeting that was sponsored by NASMHPD. Jean Campbell, Ann Leaver concluded that peer-run support services hold promise for improved outcomes for a public mental health system and we can all agree that this is under-funded, fails to reach the majority of those with mental illnesses and often delivers services that are ineffective.

One of the things about drop-in centers is that frequently they serve people that do not enter the system at all and so they become an effective part of the array of services and a very important part of where consumers go. We also have a lot of different types of services that are offered that are self-help and are in the community and provide different services than are provided by the inpatient and outpatient mental health services.

Consumer Roles in Inpatient Settings: Involving Those You Serve

- Integrate consumer choices at every opportunity
- Promote cultural change through inclusion:
 - Service delivery systems reform
 - Policy development & revision
 - Program design/re-design
 - Environment & physical design changes

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This frame relates to integrating consumer choices at every opportunity and yesterday I think we heard about how people that are being served can also be utilized through the system to help in mental health systems reform and policy development and revision; program design and redesign and environmental and physical design changes. Really people have a lot of ideas and concerns about what it is that's helpful to them. The questions can be asked what do people want. Even children; we have done a lot of focus groups with children and adolescents in residential facilities and when you ask the questions about what they think is helpful, frequently it's not the groups that they're going to or the support groups, but other things like the arts and different types of topics that they would like to pursue other than what is being offered at that time.

They're also helping to change the physical designs and when we talk about comfort rooms, people that are going to use them are participating in helping to develop them and choosing what colors and what goes into those rooms.

Consumer Roles in Inpatient Settings: Why Hire Consumers?

 Utilize unique benefits of 'experiential knowledge' through peer advocates, peer mentors, and peer support

(*Borkman*, 1975)

- Peers serve as role models, communicators, mediators, advocates, teachers, and legal protectors
- Peers provide support from a perspective of experiential rather than professional authority
- First hand experiences provide unique insights and analyses

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You hear a lot of talk about experiential knowledge and consumers are people that because of their experiences have special knowledge about the kind of services and what the experience of other people is like and can offer that experience. Sometimes it's a very intuitive or an innate kind of communication that is able to be offered to somebody else.

Peers can serve as role models, communicators, mediators, advocates, teachers and legal protectors. So there's a difference I think between professional authority and the way peers provide support to each other and part of that is because it's an equal experience that we are able to share with each other on a more equal level than somebody that's in a clinical position.

Consumer Roles in Inpatient Settings: Why Hire Consumers?

 Self-help, peer support, and self-advocacy are being recognized as components of wellness, recovery, and even treatment

(*Curtis & Hodge*, 1995)

- Peers understand the need for reform and often have the initiative to begin the task of creating new approaches to care
- Persons in recovery hired as staff at all levels, promote movement towards organizational culture shift!

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Self-help, peer support and self-advocacy are being recognized as components of wellness recovery and even treatment. This was Laurie Curtis and Martha Hodge who are two very frequent speakers and have talked a lot about this for a number of years, about the inclusion of self-help and self-support.

Peers are able to understand the need for reform and often have the initiative to begin the task of creating new approaches to care. In addition to initiative, I would also add tenacity and the energy. Consumers frequently work long and hard and we almost live our lives doing what we think is important to make changes for others and to change the mental health system.

Sometimes it's hard to get us to stop and take some time for ourselves because we're always busy and always intensely involved in what we do. Also, our friends, our friends frequently become other consumer/survivor activists and advocates that are in the country. So when we get together at conferences that's when we share what we're doing and learn from each other. Persons in recovery are being hired at staff at all levels which does create an organizational culture shift.

Consumer Roles in Inpatient Settings: Delivering Services Differently

- First hand experiences dealing with psychiatric disabilities equip peers with extensive practical knowledge and information in a way professional training cannot.
- Peer relationships often incorporate friendship and encouragement; hope for recovery!

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First hand experiences dealing with psychiatric disabilities; equip peers with extensive practical knowledge and information in a way that professional training cannot. I think also because of our experiences we do acquire a lot of practical knowledge and some of the ways I can think of that is that consumers have learned how to negotiate changes in their medications. So we do a lot of teaching with people that are in hospitals how it is that they can talk with doctors and get changes made in their medications rather than just demanding for those changes. We help to train them on their rights and how they can negotiate rather than just refuse treatment and what their rights are in terms of reading their records and other types of rights that frequently are denied to them.

Peers also or consumers also know frequently where to go for services. We have a pretty good idea of where things are in the community that will be helpful; where the drop-in centers are; frequently that the other staff providers may not know those things. Or even things about housing. There was always the thought that people would like to live in congregate living or in with other peers, whereas I think consumers always knew that most of us would rather live in our own apartments and live independently. Peer relationships often incorporate friendship and encouragement; help for recovery.

Consumer Roles in Inpatient Settings: Delivering Services Differently Peer providers may have greater tolerance for unusual behaviors and are less hampered by the need for "professional distance" Peer providers can help to implement creative

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I think this is an important point. Peer providers may have greater tolerance for unusual behaviors and are less hampered by the need for professional distance.

strategies.

There's a lot of writing that we're doing. Pat Degan has written articles about hallucinations and whether or not hallucinations don't represent something different than what is usually thought of clinically; that they are an extension of our experiences and can be used in a positive way if we think of it in that way.

I think, frequently, that there's a whole issue of women and others and men also that are cutters and there's historically been the idea that this may be a suicidal attempt; not quite understanding why it is that people would cut. So now we're beginning to understand that from a trauma perspective that it is not just a mechanism of getting attention but it's a way of feeling ones body. It's something that is done as part of letting go of earlier traumatic experiences.

We're also not as concerned about professional distance. On the other hand, the training that people are receiving as peer specialists talks a lot about what are the boundaries that we need to be concerned about. Whereas we may not be as concerned with the same boundaries that professionals have with persons that they're serving, we still have to be concerned about forming relationships with people we are working with. So I think there's a lot of time being spent on how we also have to be concerned about some professional distance, even though that's not something we like to think about a whole lot.

Consumer Roles in Inpatient Settings: Core Values

- Trusting relationships
- Founded in philosophy of empowerment and recovery
- Self disclosure is central to all consumer roles!
- Mutual Self-Help; the "Helper's Principle"

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Peer providers can help to implement creative strategies. We know a lot about what people like to do; the personal safety plans or the de-escalation forms get filled out. What I find is a lot of time they are stuffed in the back of the chart; nobody ever looks at them; nobody uses them. I think we as peer providers, as consumer providers, would take the information from those forms and know that that's very important information. What a person's hobbies are; how we can enhance what people like to do, for example, the arts and other things.

Some of our core values: trusting relationships; founded in philosophy of empowerment and recovery; self-disclosure is central to all consumer roles. So what do we mean by self-disclosure? It's a person who openly and intentionally discloses their history of having received mental health services or having been diagnosed with a psychiatric history. This crucial element is the key that allows for the exchange of experiential knowledge between the consumer employee and the person receiving services.

We've had, a number of years ago in Broward County and I was working for the Department of Children and Families, we basically asked all of the agencies, all of the community mental health centers to hire consumers or to have them on our advisory boards. So most of the agencies were cooperative and understood the value and the meaning of those. One agency on the other hand wrote us a long letter and explained that they had a lot of consumers on their staff and they didn't need to go hiring other people or including other people, so they really did not get it. There are people on staff in any agency or in any hospital, people that have a history of being a patient, but it's this key component of self-disclosure and the willingness and the incentive always to use that as part of the experience of our roles.

The other thing that gets talked about is the helper principle; mutual self-help and what this means is again, this kind of equal relationship in which two people exchange. One of them may be in a position of needing help; the other person might be the helper person but that those roles can interchange. And even the thought sometimes of how we're receiving and giving is different from looking at a person that is sick or the needy person but that always knowing that those roles can change and that we don't necessarily think of a person I don't think as being sick, so much as how it is that we can help them where they're at to move to a better place.

The second thing that happens in this exchange of mutual self-help is that while a person is helping somebody, they're also helping themselves and it's therapeutic; it's self-therapeutic for ourselves to be giving to another person.

State Offices of Consumer Affairs—

Expands the consumer voice in policy making, planning and practices:

Policy and Regulation Development

Program Planning

Evaluation and Monitoring

Training

Contract Management

Complaints and Grievances

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Some of the roles that have been established, the first role that I think of is the State Offices of Consumer Affairs. The mission for the Offices of Consumer Affairs is to serve and improve state mental health systems by working to support and expand the consumer voice within mental health policymaking, planning and practices. So a director in the Office of Consumer Affairs would be engaged in policy development, program planning, evaluation and monitoring, training, contract management, complaints and grievances.

What isn't on here is another very big part of this role is to network with consumers in their state. Frequently there is a conference that's held annually, a state-wide consumer conference that this particular office would help to sponsor. They also might be the contract manager for drop-in centers and to evaluate them and monitor those drop-in centers.

Consumer Roles in Inpatient Settings: Specific Roles - Advocacy Services - The "eyes and ears" - Complaint resolution - Attends treatment team meetings at patient's request - Protects patients' rights

Another role for consumers is the role of a resident advocate and when Kevin was talking about the role that I had years ago at South Florida State Hospital, my role was as a resident advocate. One of the things that Bob Quam, who was the administrator at that time always talked about was the eyes and ears. Sometimes we talk about staff being the eyes and ears but this role also the resident advocate is frequently somebody who goes out, who sees situations or sees problem areas and can bring that back and it's very important that somebody in this position report to top level administration and get their support because it can be a very difficult role.

One of the roles then is complaint resolutions; frequently to serve as a mediator between the patient and staff or clinical providers. They attend treatment meetings at patient's request and protect patient's rights.

- Advocacy Services (cont.)
 - Serves on key hospital committees (Ethics, Performance Improvement, Risk Management)
 - Participate in development and refinement of hospital policies and procedures
 - Conducts focus groups & workgroups
 - Reports to top-level hospital administration

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Other roles for resident advocate is serving on key hospital committees such as the ethics committee, performance improvement, risk management; helping to develop and refine hospital policies and procedures; conducting focus groups and work groups. I love to do focus groups and I find that going out and listening to people's concerns is a really good way to find out satisfaction; to find out what things they might like changed or just what some of the problems that they're having are.

One of the things that we've developed as part of how we measure satisfaction in Broward County in Florida is actually to do focus group dialogues. Going out and doing these on a regular basis at all of the community mental health agencies and hospitals.

So I've made the point about hospital administration and reporting to top level. I think that any of our positions, it's very important, particularly the role of somebody in a position of authority, that they do report to top level administration whether it be the Offices of Consumer Affairs or the advocate positions.

- Peer Specialists
 - Participation in treatment team meetings
 - Facilitate peer support group meetings
 - Provide individual peer supports
 - Assist with discharge transition
 - Teach community adjustment and coping skills

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Peer specialists have become a very common term and a role that is becoming very familiar. Georgia I think takes the lead in developing the first peer specialist training program and certification. They have a cooperative agreement with I think Boston University and have several other research projects that are following this training over a period of time and to develop it as a best practice.

Peer specialists are kind of service related whereas the advocacy position is more rights oriented. Peer specialists are more service oriented and they do a variety of things depending on what the setting is. They may be in a community mental health center; they may be in a hospital, so the role would be somewhat different as to what the setting is. Most frequently they would participate in treatment team meetings, facilitate peer support group meetings, provide individual peer supports, assist with discharge transition and teach community adjustment and coping skills.

- Drop In Center Director
 - Develop drop in center on grounds to enhance socialization and recreational opportunities; safety valve
 - Assist with orientation for newly admitted persons
 - Facilitate monthly consumer affairs meetings, support unit government development and design
 - Administer consumer satisfaction surveys.
 - Coordinate peer specialist initiative

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We talked a little bit about drop-in centers. In Florida we have two state hospitals that do have drop-in centers: one, by consumer advocates and also with staff that are consumers. The drop-in center is basically a place for people to get recreational, socialization, to kind of hangout whereas all the other programs are more structured, the drop-in center is a place where nobody is telling them what to do and they can choose themselves if they want to play pool, if they want to watch TV, play a game or just interact with their peers.

One of the things about the drop-in center and we've had the drop-in center at South Florida State Hospital for quite a number of years and it's always been a popular place. I've never heard of an incident occurring. I've asked whether or not we've had people that have escalated in their behaviors or problems and this is probably one of the few areas where that generally never happens. People are always happy to go. They're always wanting to go to the drop-in center and they're wanting their grounds privileges to be able to go.

The drop-in center in Florida also provides other kinds of services, so they assist with orientation for newly admitted patients. They facilitate monthly consumer affairs meeting, so this is where the government meeting takes place in the drop-in center. All of the units are then represented. They administer consumer satisfaction surveys and coordinate peer specialist initiative.

- Peer Bridger, and other Peer Mentoring Programs
 - Provides support to individuals in institutions
 3-5 months prior to discharge and 6 month to a year afterward in person's homes
 - Provides intensive support through a balance of social, recreational, and skills teaching
 - Establishes linkages to community-based services and natural supports

(Mead, 2002)

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Peer Bridger program; I think there's several in the country. The one I'm most familiar with is in New York and this is a specific role in which people are given support prior to discharge from the state institution three to five months, and then six months afterwards in their home settings. So these are kind of bridging between the hospitalization and community integration experience.

They work I think individually and probably in groups settings to develop, to teach skills so that people will be able to live successfully in the community when they're discharged, and they also establish linkages and take them to probably help them to use the bus and how to do their checkbook and all those kind of skills things that people frequently don't know how to do or haven't done in a while.

Consumer Roles in Inpatient Settings: Using Community Resources

- Integrating consumers from the community in volunteer capacities
 - Self-help groups facilitate coping skills subsequent to stress
 (Silverman, 1985)
 - Peer 'inreach' from community-based peer run service and support agencies to provide selfhelp, self-advocacy, and integration of peer support group models (e.g. Schizophrenics Anonymous, Double Trouble in Recovery)
 - Examples: Copeland's WRAP; NAMI Peer to Peer Training (Mead, 2002)

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The other role that's a very common role would be what Tom Lane calls the "inreach" of community programs that can be brought into hospital settings and these might be things like AA groups, double trouble in recovery, all kinds of self-help groups.

Another popular program is Maryellen Copeland's WRAP program. Probably some of you have heard of Maryellen Copeland and she's written a number of books; she has workbooks, videos, constantly creating new tools for consumers that will help them in their recovery. The other popular program is NAMI's Peer-to-Peer training that is done by consumers with consumers.

Consumer Roles in Inpatient Settings: Emerging Roles New Specialized Areas of Practice: Trauma Specialist Debriefing Role Art & Creativity Documentary & Story Development Crisis Prevention and Intervention

Some of the new areas of practice that are being created and that I know about are the role of a trauma specialist. There are people serving now in the areas of relating to people that have trauma histories, specifically with providing support to these individuals, peer support, and understanding of the issue of trauma, sharing those issues.

In Massachusetts I recently talked to somebody who I think has the first role. She calls her role a "debriefing" role and she's serving two different state hospitals; one in Tewksbury and one in Wooster, whereby she works with every individual who has been secluded or restrained or with other types of sentinel events, and she is one of the first people to work with individuals when they come out of restraints, talk to them, tries to find out what might have been done differently and is able to translate that then to the treatment team. I talked to her several times because I think it's a very powerful role that she's playing. She herself is a trauma survivor so she's sharing those kinds of experiences with the people that she's working with. She talked about one woman who had been a very frequent user and was frequently in restraints and when she started sharing the fact the she herself had been in restraints and had issues around trauma and as well as self-abuse behaviors that she had experienced, this woman just immediately felt a compassion and a rapport and that this I think was a very changing moment for this woman because she stopped needing or requiring to be in seclusion and was later discharged. She also was able to continue her support and relationship with this woman.

Story development narratives: there's a lot of emphasis now on collecting person's stories, publishing person's stories. There's several states I think that have EBI, elimination of barriers initiatives, and a lot of things that are happening with this are the publishing or the collecting of people's stories and we're using them in a variety of ways.

Crisis prevention and intervention: there's now some new programs, particularly in the state of Arizona where peers are actually running crisis units, parts of crisis units. I was able to visit one of these in Phoenix, Arizona that's operated under META Services, Inc. and 24 hours a day, consumer/survivors are the staff of six to eight patient units, on a crisis unit. What was impressive about this is that the setting for these was totally different than any crisis unit that you would imagine. They actually called them living rooms; they looked like living rooms; they're comfortable places. People are able to use the little kitchen areas for the snacks or for cooking or getting what they need.

The other thing that was very interesting to me is that people do not watch television. They watch Maryellen Copeland's recovery videos and other types of videos that relate to their recovery and I think that this is something that we could, in all settings, could begin to model after.

Another thing that they do that I think is unique is that part of the therapy of people being there is to work on their story narratives. So instead of charting on somebody, they will be developing their own narratives and charting their own progress in support of and working with the staff. Very, very unique project.

Consumer Roles in Inpatient Settings: Guidelines for Hiring

- Preparation for job hiring is important from consumer and provider perspective
- Gaining the education and training is necessary for peers to be qualified
- Hospitals need to refine organizational structures and practices to accommodate peers providers
- Hospital staff needs to understand the importance of the consumer role
- Support mechanism needs to be put in place.

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Some of the guidelines for hiring: preparation for job hiring is very important from the consumer and provider perspective. Training is one of the keys. In the past a lot of times consumers have been put into roles that they were not prepared for and sometimes these roles or these situations were not successful. Now that we're establishing training, that people are being certified, that's going to make a very big difference in the success for both the person and the provider.

Hospitals need to refine their organizational structures and practices to accommodate peer providers. Also staff in hospitals need to be prepared for people coming into these roles, so there needs to be training not only on the side of the consumer, for the consumer working to be placed in these roles, but also for the providers. And support mechanisms need to be put into place. In Georgia I know they have several people with positions as mediators and as people are placed in the positions and sometimes have conflicts or have difficulties in these roles, the mediators are accessible and make frequent contact; go to the agencies and talk with both the consumer to help them as well as the providers.

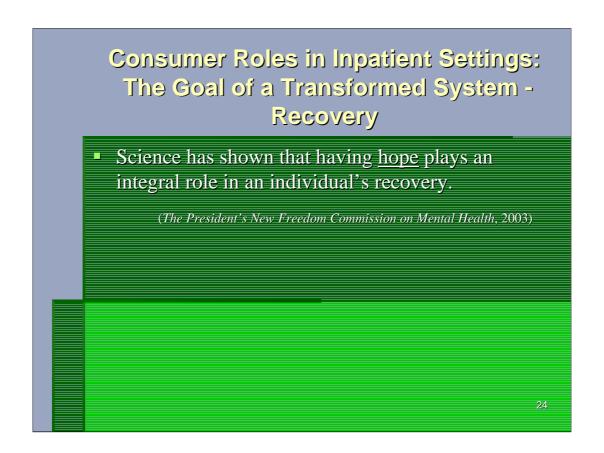
Consumer Roles in Inpatient Settings: Cultural Change

In 2003, The President's New Freedom commission on Mental Health recommended in its 2003 report a "transformation" of the system and identification of "recovery as its legitimate goal. It called for the complete inclusion of consumers and family members as providers, advocates, policymakers, and full partners in creating their own plans of care.

(The President's New Freedom Commission on Mental Health, 2003)

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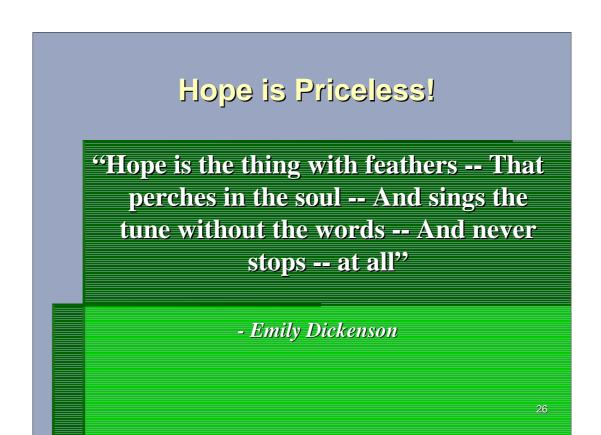
Again, the President's New Freedom Commission is frequently used as a support for all of our new efforts and for transformation of our system. It calls for a complete inclusion of consumers and family members as providers, advocates, policymakers and full partners in creating their own plans of care. So we are quoting this and as we develop some of our new initiatives as well as other people doing it the same.



Science has shown that having hope, this word hope, plays an integral role in an individual's recovery and I think it's very important that we not only talk about what recovery means but we really emphasize this ability for all of us to have hope; that we can recover and that hope is something we can foster in each other. The hope instilled in people recovering from mental illnesses through the dynamic exchange of peer support has the potential to foster hope and change for the mental health system.

Consumer Roles in Inpatient Settings: Hope, Transformation, & Recovery The hope instilled in people recovering from mental illnesses through the dynamic exchange of peer support has the potential to foster hope and change for the mental health system. (Campbell & Leaver, 2003)

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This concludes my presentation.