

Florida Peer Network, Inc.

An independent organization of and for people who are recovering from a psychiatric disability

Conference Calls #3 & #4

Transitioning Youth to Adult Mental Health Services

Cultural Diversity

Reducing the Use of Inpatient Hospitalizations

Open Discussion About Transformation

Summary Report Statewide Teleconferences June 1 & June 13, 2006

Submitted to
Florida Department of Children & Families
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Conference Calls #3 & #4

Executive Summary

This report covers two statewide conference calls held in June 2006 among Florida Peer Network members statewide. Projects recommended for the Florida Peer Network (FPN) and recommendations for funding and resources are detailed in a matrix starting on page 26 of this report.

Introduction

Board Vice-President Patrick Hendry facilitated the first of these two statewide teleconference sponsored by the Florida Department of Children and Families (DCF) for members of the Florida Peer Network (FPN). The call took place from 6:30 pm to 8:00 pm on June 1, 2006. The second call reported here was facilitated by Board President Tom Lane and took place from 1:30 pm-3:00 pm on June 13, 2006. A total of about twenty-one Florida Peer Network members participated in the two calls:

Toni Beard - DBSA, NAMI Florida, MHAWF, Pensacola
Gayle Bluebird - Executive Director, Florida Peer Network
Babs Christy - Lehigh United Way House, Ruth Cooper Center in Fort Myers
Sally Clay - Editor, *On Our Own, Together*, Lake Placid
Dianne Côté – former Executive Director, Silver Center, Fort Lauderdale
Donald Dwyer - Project Return, Tampa, Florida
Cathy Folsom - NAMI Florida, Tallahassee
Clyde Kobayashi - Vincent House representing the Florida Clubhouse Coalition, St. Petersburg
Illene Greenberg – Executive Director, Silver Impact, Fort Lauderdale
Sharon Hamilton - Florida Health Partners, Orlando
Patrick Hendry - Vice President, Florida Peer Network; Consumer Affairs District 8
Alfred Jefferson - Canberra, Florida
Donna Jenkins – DBSA Brevard, Cocoa Beach
Tom Lane - President, Florida Peer Network, Fort Pierce
Richard Mills - Peer Specialist, Project Return, Hillsborough County
Lucy Pride - Apalachee Center Homeless Project, Tallahassee
Lexxy Revel - DBSA, Fort Walton Beach
Dawn Rix - Executive Secretary, Florida Peer Network, Hollywood
Jeffrey Ryan - Axis One, Inc., Naples
Bill Schneider - Treasurer, Florida Peer Network, & Broward Office of Consumer Affairs
Dave Shaver - Consumer Support Services, Inc., Jacksonville

Transitioning Youth to Adult Mental Health Services

Transitioning youth to adult mental health services is a hot topic around the state and around the country. The Florida Peer Network is using this teleconference to give feedback to the state on some of the changes that we would like to see happen.

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Regarding current programs for transitional youth in Florida, Tom said that the staff of New Horizons works closely with their children's program when there are kids who are ageing out of the child system. They collaborate informally with their own agency because they know there is a problem when that does not happen, and it is common sense to work together to do it.

Dave said that there should be some kind of a peer organization in each community for the age group seventeen to twenty-one. Patrick suggested that the peer role in assisting the youth in transition might be to give kids a different message than they are getting from the system as it is now.

Donna said that at Governor Bush's American Disabilities Act working group, they said that not enough services or support are given to the transitioning youth. Finding insurance, finding jobs, and so forth are the big issues.

Bill said he tied this discussion into his years of recovering when he was a youth. His symptoms such as hearing voices all started when he was between seventeen and twenty-one. He was never educated about mental health or about recovery, and his mother was told by his first psychiatrist that he would never amount to anything and that he would always be a nobody, and she believed it. That was over twenty-five years ago, and still today there are not a lot of programs in this state for transitioning youth, and the governor has cut many of DCF's transitioning programs. Bill believes in educating youth that they can be productive citizens. Productive recovering consumers can help other consumers throughout the state. He recommended the creation of a specific advocacy project for transitioning youth, along with more supports. Youth should be offered educational programs throughout the state that show that people can recover from mental illness. Bill added that if he had been educated early on, his life would have been better and he would have never had as many stumbling blocks.

Dave said that the Planning Council's statement for the federal block grant expressed a desire for insuring that schools actually do mental health instruction. School counselors should be proficient in diagnosing, and then getting students to the services they need. "We are trying to eliminate the taboo from the bottom up," he said.

Dianne said that with the national focus on Peer Specialists, the state is finally looking at this option. The seventeen to twenty-one year-olds need a way to earn a living, and they could become mentors to others like themselves, to walk in their shoes. "You know," Dianne said, "you can kill two birds with one stone. As mentors, the youth would be getting a job, and also they would be role models for their peers. We older Peer Specialists, who have been at this for awhile, can do the training." The youth do not always want to be at the mercy of the system, and a seventeen-year-old can relate better to another seventeen-year-old.

Patrick said he didn't know if there is anything in the Florida Certification Board that would prohibit a 17-year-old from being a certified Peer Specialist in Florida. Clint Rayner, the new chief of the Office of Consumer and Family Affairs, is working right now on Peer Specialist issues. There is a contract between the state and the Florida Certification Board to create certified Peer Specialist positions. The Certification Board came up with the new designation, "Certified Family Specialist," and Patrick suggested that there might be another new designation that

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targets youth. Patrick stated that perhaps this Certified Family Specialist could include a special category for Youth Specialists

Bill said that youths can start working at sixteen. As we develop a database of a good curriculum for Peer Specialists, there should be input in the certification process to include people who are seventeen to twenty one, including future funding for positions like that.

Sharon said that her only concern was that, at seventeen or eighteen, a young person is still getting a grasp on their own illness, and on how to care of themselves. She was concerned that a youth may not be ready for that at that age to work as Peer Specialist for others. She said that most of us who end up succeeding have developed a long-term support system for ourselves, but the youths will still be in the process of developing it. Still, we want to take advantage of the knowledge that these kids do have, to bring them into the process, and to help develop them as leaders. She suggested setting up outreach programs for youth in transition. Older consumers who are in recovery and working in the community could do presentations, and let people know, "Hey this is what I went through, and this is how I am using my life experience." The older Peer Specialists could let them know that they are people like them who are out there succeeding with their goals. They can make the youth aware that they can go from school and into the workforce, empowered to seek positions using their unique experiences.

Jeffrey, who has a lot of experience working with kids with emotional disturbances in the foster care system, and particularly kids, said that it is a fact that kids in foster care are dropped as soon as they reach a certain age. He has sat through countless discharge planning sessions, and most of the fifty kids that were in his house when he left wound up in jail because there was no transition. There was no professional within the system to follow them through the transition process. Many of the kids did not qualify for a diagnosis of schizophrenia, bipolar or other serious mental illness. They were only given these diagnoses so that they could be put onto Medicaid. Therefore, the system is being flooded with a lot of children who have behavioral problems, but we have no programs for mental health problems.

Jeffrey said that when children have biological or adopted parents, there is a conduit to make the transition. However, for children within the system, it will take a lot of work to rectify the problem. He said that he was currently working with two youths who two years ago were sitting in Collier County Jail for misdemeanor situations. Transitioning youth is a big problem and it's complex, and it will take lot of work to resolve the problem. The system is overwhelmed with children that are called "kiddies Axis I." Right now the first step is to target biological or adopted parents, or somebody else who has the ability to follow through the process. The second step is to teach providers in the foster care system what they need to do. All facilities throughout Florida must follow these children through, and make sure they transition. However, as the foster kids know, because of confidentiality the state will not talk about what's wrong. They won't even acknowledge that the children are in the system, so it's going to be hard even to find the kids. What is needed is to get these kids into drop-in centers or to get them somehow networked into a recovery model or even just to start such a support network.

Bill said that we need to advocate for an array of supports and services for youth. We need to advocate for outreach, mentorship, Peer Specialists. If a person age seventeen to twenty-one does not yet have life experience, they could work alongside a Peer Specialist as Assistant Peer

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Specialist. There could be another level set up in the certification process in Florida for Peer Specialist Assistant, just as in other states there are Peer Specialist-I, Peer Specialist-II, and Peer Specialist-III. The certification process has not yet been finalized, and these are great ideas that could be incorporated. Bill said that he wanted youth now in transition to have all support that he did not have.

Patrick noted that the Florida Peer Network is one group that is trying to be a voice for consumers throughout the state, and he wondered how we could help these kids to have a voice and represent the kids on a larger scale.

Clyde said that when we start talking about peers for kids of sixteen up to twenty-one, there is a larger group that these kids consider peers, and that's their friends. When he himself had trouble in school some thirty years ago, a big problem for him was that he feared his social worker for several reasons. However, he had to keep this secret because of the taboo about mental illness. Unfortunately, his friends found out, and all of a sudden he became a "retard" to them. That stigma, said Clyde, is one of the greatest stumbling blocks that we have to deal with on a community level. We have to create community awareness with a type of organization that will communicate what mental illness is to a community that lives in taboos.

Clyde said that people need to get a greater perspective, and learn to accept that a mental illness is nothing to be ashamed of, and that it's no different from having asthma or diabetes. Until we build up a great amount of community awareness, the youth will not be willing to actually go for get help from somebody like a Peer Specialist. He described how, as a youth, he did not think that he had any problems, then all of a sudden he began experiencing all hallucinations and unbelievable mood swings, for days at a time. He said that if we deal with that situation, everything else will start falling into place.

Sharon said that, whether they are in foster care or not, kids will be in the schools. The schools have to do their educational part, and to reach kids we need to be part of that educational component.

Dave suggested that schools could do some kind of anti-stigma campaign and that we could reach out to other groups who have got money. Bill said that some groups have SAMHSA grants by which they are supposed to implement certain educational components. Lexxy said that it seemed to her that one of the biggest problems we have is stigma. She wondered if anybody was doing anything like a "Stop the Stigma" campaign, and whether the Network should do something of that sort. Dave said that DCF is planning to do that next year.

Patrick asked whether anybody was up-to-date with the Eliminating Barriers Initiative (EBI). Jeffrey said that the state of Florida focused on stigma in employment, and they handed out informational packets and CDs. However, they were primarily looking at businesses, and Patrick thought the campaign needed to reach down lower on the economic ladder, not at the top. He said that he did not think the EBI program was doing anything now.

Patrick said that the EBI was a federally funded program, and it was rolled out in about seven states to create advertising campaigns to address stigma and eliminate barriers for people entering the mainstream, such as going back to work or going to school. The idea was to develop

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certain core areas of information and make it available to every state. Patrick recommended that the Peer Network should look at their material to see if we can use it in the schools.

Jeffrey said that this project was a result of the President's New Freedom Commission Report, and when the government decided to push it, they put out grants through PR firms in Washington, DC. They did not give any money to the states, although it is the states' responsibility is to carry out these policies. As a result, the states either did not have the money or did not want to spend it. "The concept was great," Jeffrey said, "but it just didn't go anyplace."

Gayle said that the Clearinghouse in Philadelphia under Joe Rogers is one focal point for the anti-stigma campaign, and for access to things that are actively being done. Susan Rogers heads up that part of things. There are materials available about things that are being done with transitional youth, for example. Gayle said that the Clearinghouse is the only place that has carried the ball, and has put some effort behind it. She added that it would be a good idea to find out if our state is continuing any effort at all.

Patrick said that he occasionally receives emails from DCF, and his district received some PSA's to send to the stations, but they never got the handbooks that were to go to the businesses. He said that he would see what he can find out, and will circulate it. He said that stigma is a big subject, and could take up many conference calls.

Cultural Diversity

Cultural diversity is an important issue because we as consumers want to make sure that we include all types of people in what we are doing. Dave said that this is not really a systemic issue—it's a cultural issue that has to start from the families, and it is part of breaking the taboos. He said that he knows the Hispanic community, and he understands why a lot of minorities do not participate in recovery efforts. One reason is that those cultures consist of tight-knit families, and people do not communicate outside of their family about issues. "We can ask all day for people of races or culture to participate," he said, "but the problem is that the taboo is still there."

Jeffrey agreed with Dave. He said that twenty years ago he went out to labor camps in Naples, Florida, and told his story with an interpreter to Hispanic groups. He said that it is true that they hold mental illness issues very close to their chest. The Hispanic groups would not admit to anything, largely because they just did not understand what was going on. Sharing this stuff, being open with it, is a big cultural issue. When somebody goes into crisis in these communities, they deal with it themselves rather than call the sheriff's department. Rather than have somebody Baker Acted, they deal with it right there. "It's a big, big, big issue."

Dianne said that it is the same with French Canadian families. She said that she has been in the mental health system for forty-three years, and her family has not spent forty-three seconds discussing this as a family. Her mother would not tell her when she had an appointment with a psychiatrist, and she would even hide her thiorazine. "I don't think that was too bad now in retrospect," Dianne added.

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Jeffrey said that a good indicator of culture is how many ICCD clubhouses exist around the world. There are really no ICCD clubhouses in the countries of romance languages. Clyde said that there are three hundred clubhouses or so worldwide, and Jeffrey clarified that he was referring to countries that use the romance languages—Italian, French, Spanish Portuguese.

Clyde said that there was another aspect besides language to consider. Those four countries all share one thing in common, which is their strong religious belief. In order to deal with the subject of community and stigma, you have to take from it a religious standpoint. He stated that in his view religious beliefs can come from one or two points of view. He said that he practices Catholicism and learned a lot from that standpoint, besides having a Buddhist attraction. (“Yeah, I love Buddha,” Tom interjected.)

Clyde continued that, from a Christian point of view, you bear a cross, and this is the gift that God gave you. The other possibility from a Jewish standpoint is the point of view is that you must have done something wrong, a sin, and that is why you have the situation of mental illness. “You need to be able to relate to the religious point of view that exists in those given areas,” Clyde said, “and wither understand that it’s a gift from God or that you or your family did something wrong and God is punishing you.” He thinks that, in a lot of cases, people in the Hispanic community are heavily impoverished and in their own way extremely religious. Often times their view would be that they must have offended God, and this is why they are suffering so much. Clyde said that it was important to understand that point of view and approach it from a perspective that the particular community can relate to.

“I think that the biggest problem,” Clyde said, “is that we talk about mental health from the standpoint of mental health. But when in Rome, you must do as the Romans do.” Clyde said that you have to communicate from a standpoint that another person or community can accept, and take it from there. Even the governor, he pointed out, does not acknowledge the fact that his mother has mental illness. “From that standpoint, there is a style of holding things back in public and not communicating openly, but communicating in a family is acceptable from their point of view. First you have to understand what that point of view is.”

Donna said that she has been diagnosed for 31 years, and only now can be out of the closet because she is not working and does not have to hide things anymore. She has spoken to many religious leaders to see how well they really understand psychiatric disorders, and she found that they do not. “Many Catholics practice exorcism to drive out the devil,” she said. She herself is of German descent, and in that tradition everything is kept secret. Therefore, she thinks we need to look at cultural traditions, and personal religious beliefs. “We need to bring families in, and we need to educate them, to let them know that it’s okay to have a psychiatric disorder because we can become stable and hopefully live in recovery down the road. I’ve had the opportunity to do that.”

Tom said that another way to educate families is a massive ad-campaign. Donna agreed, and said that self-help health groups are tremendous, as is outreach one-on-one on the telephone. Tom said that although established groups are helpful, we are talking about getting into a person’s household. Donna said that we need articles written in newspapers, and ads on radio or television, and she said that we need to go one step further and address the general topic of what is a psychiatric disorder.

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Jeffrey interjected that it has to be paid advertising. “The EBI did sixty-second or thirty-second public service announcements on television,” he said, “but they ran them at 3 o’clock in the morning. You can’t do PSAs because they run them at odd times.”

Babs suggested that we could impact the media by using something like the soaps on Spanish-speaking TV stations. “Those are one of the most popular cultural things that get into homes,” she said. “They could portray positive outcomes for mental illness, and when the system works for people. Just having people that look like me, and sound like me, and talk like me is not the only solution, but it certainly opens major doors.” Babs noted that for clients in the system who are bilingual or Spanish speaking, resistance is not just the cultural resistance of keeping things in the family, but the fact that people are terrified to use the system in any way. That is true in both the legal and the illegal population, so making access for the population that we deal with is sometimes quite complicated. “You know,” Babs said, “I’m a fat, white, 58-year-old woman, and I took over from a very attractive, dynamic black woman of Caribbean background. Now it is my face that is in the paper every week with our little column for organization, and the response to the column has changed. I work to keep that column open, but the face in the paper is not the same.” We have different definitions when we talk about culture and ethnicity, but we also need to look at the issue for people who are of different lifestyles. For example, there are a lot of people both in and out of this system who still view homosexuality as a mental illness. Success and comfort and safety are huge issues for people who are different in those ways as well.

Bill said that he was reminded of something that happened in Broward County. A woman from one of the Caribbean islands was doing a certain spiritual practice from her culture by which you pray so intensely that you become oblivious to everything else. This activity was misunderstood by every mental health professional where she was, and they Baker Acted her. When she was monitored in the psychiatric unit, however, it was discovered she was only praying. She was not hearing voices or going by internal commands. This was a legitimate act of prayer; she was not a danger to herself or others, and she had never needed to be Baker Acted. All those professionals—who all had diplomas and clinical experience—failed because they lacked the education to know the culture of that area. “If you don’t meet people where they are at,” said Bill, “you are going to lose them.”

In the United States, said Bill, we have hundreds of cultures, but it is possible to ask a person important questions about his or her culture. Yet in Florida there is no assessment that covers quality issues about the person’s culture. “This may be one of the biggest reasons why a lot of people of diverse cultures don’t want to come forward for mental health services.”

Babs said that one of the needs in terms of cultural sensitivity is to understand when someone is in conflict with their culture in their very being. That ties into the issue of addictions in mental health, because sometimes these problems get taken care of in the community and in the family. “However, sometimes it gets taken care of in ways that are neglect and abuse in any culture,” Babs said. “Whatever your culture, if you keep somebody in the basement and feed them like an animal, it’s not okay.” Wherever the culture, if people are mistreated because of their diversity within their culture, it is not okay. Babs said that mental illness is often that kind of diversity. She added that people with sexual identity issues represent an area that is not spoken of very

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much. “It does not matter if you are German, or Asian, or Hispanic, or black, or whether you are a cheerleader or high school jock, diversity in sexual identity will present a conflict.”

Patrick observed that mental illness itself develops its own culture. “As peers we have created somewhat of a culture, but we also discriminate across the boundaries of different diagnoses among our own group of people that we ostensibly are supporting.”

Reducing the Use of Inpatient Hospitalizations

As we all know, hospitals are one of the major expenses in the mental health service system. There has been a strong movement over the last few decades to move away from institutional treatment so that people can live in the communities and have a fuller life.

Dave S. said that there is a problem with having people retire in adult day treatment programs.

Alfred said that we need to look at some of the FACT teams, because he has friends with FACT teams that are not doing a good job. In Jacksonville they do not follow the model. Clyde said, “I don’t think they are following the model anywhere, actually. I know they are not doing it here.” It is a problem throughout the state. Florida started the FACT team system with the mistaken idea that it was going to replace hospitalization, but it seems that every team struggles to just stay alive. They have the highest turnover rate of employees, and they do not follow their own model.

Bill said that a coercive medical model is used in Florida, and it is not the model that is used up North. The difference is that the model that is used elsewhere is flexible, very open to consumer input and participation, and the one in Florida is the extreme opposite.

Sharon said that she has just moved here from Michigan and is still learning what’s going on in Florida. Yesterday she was approached to join the FACT team board in Osceola County. She said that she was not familiar with the original PACT or ACT model, and the FACT model here is a new concept for her. She had not been in the public mental health system in Michigan because she received treatment through a private mental health carrier. Her experience was to be put into day treatment, then go home, then return to day treatment to hospital to day treatment to home, over and over again.

Bill said that it was found in Colorado that most people who were committed to a mental hospital really did not need a fully locked-up option, whereas in Florida the first thing that happens is that the person is locked up. In fact, the locked option is the only option that is funded by DCF in Florida—people are locked up first and talked to later. The Baker Act is not a state statute, but its wording prevents DCF from putting money into alternatives to hospitalization such as respite, drop-in centers, and warm lines. More money is needed to train CIT officers to divert people from jails and hospitalizations, but funding for such alternatives is held up by the wording in the appropriations bill. It is necessary to change that wording. Bill recommended the use of respite, like the safe houses that are available up North. He also favors an unlocked Baker Act facility like the one in Boulder. The Boulder model works well—no one runs away, and the house provides intensive services with a lot of staff, including Peer Specialists, who work with people in a regular home in the community. It is a two-story house with eight bedrooms, and everybody lives there like a family, like anybody else in the neighborhood. The program does not have not an institutional mindset; it’s a natural environment.

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Dave said that his organization begins peer-run respite services on July 1st in Nassau County. He and Gayle Bluebird went up there today to see it. Basically, it will be directed by peers, and instead of the sheriff up in Nassau bringing people down to Duvall to Baker Act them, they bring them to the respite house in Nassau. The house will have a low population, perhaps five to seven people. It's a natural calm setting.

Alfred said that he was a respite worker, and he feels that a respite house would work because he has worked at a couple of respite houses himself. If a consumer in the community was in difficulty, they would go the respite house instead of the hospital, and after spending some time in there, cared for by peers, they would be able to go home.

Dave said that not everybody needs the locked option. Many times when people are Baker Acted, they are just angry. The problem is not that they are off their medication and not because of symptoms of mental illness. It is because of their anger that the police take clients to the hospital and the intake people admit them.

Sharon said that sometimes she gets upset and doesn't have brakes to stop it, but she does not threaten anybody. Since she moved to Florida she has been threatened to be jailed three times for swearing, and she has never been jailed in her life. She said that she got through forty-three years in Michigan without being Baker Acted or arrested, but down here it is the first thing that people throw at you. "It's unbelievable," she said.

Lexxy said that one of the things that has helped her is communicating well with her psychiatrist. She feels free to tell her everything, including what medicines are working and what are not, and what side effects are giving her trouble. Because she has communication with her psychiatrist, she continues to be stable. Bill recommended an article posted by Pat Deegan on her website about how to negotiate medications with your psychiatrist. If consumers are empowered to communicate with the professionals that they work with, inpatient hospitalizations will be reduced. It is especially important to be able to access your psychiatrist when you are in an emergency.

Sharon said that she was lucky to have a private psychiatrist in Michigan, and she could walk in any day without an appointment and be seen. Because of that, she did not have to go to the hospital to get treatment.

Dave said that the psychiatrist who helped him was very thorough—he could evaluate him and dig out what was happening in his life. However, he has heard from peers who are members of drop-in centers that too many psychiatrists and other clinicians are dismissive to their clients, and they continue to prescribe medications that do not work.

Alfred said that he was a member of a support group where members are allowed to express a lot that they could not say to their doctors because they did not have the time.

Sharon suggested that it would be good to have peer advocates in doctor's offices and in mental community mental health centers. A person could go to the peer advocate when in crisis even

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when the doctor is not available, and the peer advocate could talk them through whatever they are going through.

Patrick said that a number of agencies around the state now have peer advocate positions within the agency itself, and there are recovery teams with Peer Specialists around the state. The state is now in the process of certifying Peer Specialists, who can work in that sort of role. OCA chief Clint Rayner in Tallahassee is working on the process of creating certification and a uniform way of determining that someone qualifies to work as a Peer Specialist. When that is completed, we will put language in our provider contracts to require Peer Specialists.

Dave said that the problem is to convince the communities of professionals that they have to do a better job and that it is in their best interest to do so. He said, "We can get peer advocates all over the state, but there is no jurisdiction that will require the doctor to do it this way. It has to be within their community."

Patrick said that as peers we can make the alliances with other groups, such as the Florida Council that represents the provider agencies. "As we form stronger bonds with those groups, we can begin to change their philosophy, and that's when real change can take place over time."

Bill said that, as the consumer representative on the Florida Counsel, he gets discouraged because there are about forty providers in the room and only one consumer. However, something is working in terms of their accepting certification for Peer Specialists to work throughout the state and to have more roles in reducing inpatient hospitalization.

Bill said that in Arizona Peer Specialists float in and out of the emergency rooms. They help the psychiatrist to screen involuntary admissions, and they are able to avoid over 87% of the involuntary admissions, saving the system millions of dollars. They do not turn anybody away who needs help. In this process, they found that most of the time people seek involuntary admission because it's raining and thundering out there, and they are looking for housing. They come there because they totally lack resources, and all they really need is to be connected with food and clothes. In other words, most involuntary admissions are not necessary. In Arizona, the consumer is allowed to leave the hospital, but the Peer Specialists help to assure that they are connected with all they need before they leave.

Clyde said that that he was involved with a situation regarding Medicaid Shared of Cost or Medically Needy. A very strange situation exists by which to make share of cost a client has to go to day treatment. Clyde said that, in his view, all of the day treatment programs end up as a babysitting service for two-and-a-half hours. He observed that if he were put into such a situation, he would regress to where he was when he first got sick. Dave commented, "Day treatment and day treatment language in the Medicaid handbooks needs to go away."

Teleconference #4, Discussion Continued from Call #3

Open Discussion About Transformation

Transformation means different things to different people. Among the folks involved in this call are Donald, from Project Return over on the West Coast; Toni, from DBSA in Pensacola; and Cathy with the NAMI Florida Consumer Counsel. Dianne has worked with Silver Impact, meeting the needs of seniors who are an often-neglected group of self-disclosed people.

Dianne expressed concern that DCF in Broward is beginning to push the clubhouse model, and her concern is what that might do in terms of funding consumer-run programs. “In terms of recovery,” she said, “all of us do better in a peer-run program, and the clubhouse model is provider run.” She said that the distinction between drop-in centers and clubhouses is that clubhouses are modeled on Fountain House in New York—they are run by professionals and have employment connected to them. Drop-in centers are consumer run and they have choice connected to them.

Patrick wondered whether anything in the clubhouse model would keep it from being consumer run. He said that we do not need to interpret a clubhouse the way other people have; rather, if we look at the model itself, perhaps clubhouses could be run by peers. It occurred to him, in talking to some of the folks at Vincent House, that the model of a center run basically on employment principles was one that we could incorporate into our own philosophy, and have it truly consumer run, as opposed to strictly professional run. We have plenty of capable and competent consumer professionals in the state, and someone who is now running a drop-in center could probably run a clubhouse, if that’s what people in local areas want.

Sally said that one problem is that the clubhouse model is now known across the country, and people do not understand the difference between a peer run drop-in model and the clubhouse model. To try to do a clubhouse that does not fit the national model might contribute to the confusion. Dianne agreed with Sally, saying that Fountain House, as the first clubhouse, created certain guidelines that must be followed to be a clubhouse. We might have to change the guidelines to allow a peer-run program to be a clubhouse. Another issue these days, she said, is that in the desire to have people live independently, sometimes we push them into employment. She said that she is not opposed to the employment model, but is concerned about losing the option of consumer-run programs, where the only dictate is that you choose to participate in what you want. In pushing the clubhouse model, will funders now see drop-ins as less valuable, and start cutting money?

Patrick said that he would like to see clubhouses in whatever form they evolve into, but he would like to see them run by consumers and consumer organizations. They could still be employment oriented, but not at the cost of getting rid of drop-in centers—that would be a huge mistake. He was involved with a couple of drop-in centers back in the early 90’s that were doing employment programs, and a lot of drop-in centers are still doing that. Many peer-run programs do projects that are similar to clubhouse projects, but they also run a drop-in center environment. It is a matter of choice, because to him a drop-in center is a big open door with all kinds of other rooms to go into.

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Dianne pointed out that peer-run programs are also an entry to employment because consumers run the drop-in centers and hire staff who are also consumers. “At one point at the Peer Center, we had over forty employees,” she said. Patrick said that in his center back in the 90's, they had over forty employees, and they also ran businesses as part of it. “There were employment opportunities for folks, but you did not have to go that route. If you came into the drop-in center, you could choose what you wanted from the menu of activities that were available.” Dianne suggested that we need to get the Vincent House guidelines, or those of Fountain House, to see if there is anything that would preclude us from doing a consumer-operated clubhouse.

Tom said that the Peer Network board has approached Dianne Steele at Vincent House about helping us plan a statewide toll-free call specifically on the topic of clubhouses. We are now looking at the possibility of hybridizing or modifying clubhouses because this topic came up in previous calls in this series. We know there are concerns about the idea, while at the same time there are opportunities. There are also problems with the way that the Agency for Health Care Administration (AHCA) here in Florida set up the requirements for providers to generate revenue. For example, a person is required to have a bachelor's degree in order to bill for clubhouse services, and that is contrary to the standards of the International Center for Clubhouse Development (ICCD). So there are a lot of issues that need to be addressed relevant to clubhouses. Next week we may have the opportunity to again raise some of these concerns at the Recovery and Resiliency Task Force meeting. More broadly, in the context of transformation, we need to avoid reliance on any single approach, which in this case is employment. There have actually been articles written about the “Single Model Trap.”

Patrick added that we have the opportunity through this transformation process to address the language in the AHCA handbook, and to deal with the program office's push to embrace the clubhouse model using the ICCD standards. Because we are beginning to have some significant input as consumers into the changes that are taking place in the mental health system, we are now in a position to say what it really should look like. The Single Model is probably not the way to go. “There is a wide range of needs out there, and we need to be able embrace all of them.”

Tom said that choice is the fundamental value that we should really be championing as self-disclosed people. Sometimes policies come out of AHCA and DCF that are counter to what we have been saying for many years. The recent principles of recovery and resiliency that were enunciated by a panel of experts at the Center for Mental Health Services go well beyond just a consumer movement, and the principle of choice was a big part of those Principles of Recovery.

Sally reiterated the problem that people continue to be unclear about the difference between peer-run programs and programs such as clubhouses that are not consumer operated. In Broward, for example, Nine Muses and other programs may be consumer driven, and they may be successful programs, but they are not peer run. To be aware of the distinction, people need to understand the values, or common ingredients, of consumer-run programs. Sally recommended that everybody look at the book that she edited, *On Our Own, Together: Peer Programs for People with Mental Illness*. The book actually has writings from consumer leaders all over the country, who wrote about the eight different consumer-operated programs that took part in the COSP Study. The basic definition of a consumer-operated program is that it is staffed by

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consumers, and its board of directors must consist of at least a majority of consumers. The consumer-operated program must also be in charge of its own finances, and have a 501-C-3 status on its own. In other words, it must be independent from any provider agency.

The Consumer-Operated Service Program research, known as the COSP study, was conducted by SAMHSA from 1998 to 2002. The research included a qualitative study to examine the common ingredients of consumer-operated programs. This was the fidelity measure, and the research instrument used was called the COSP Fidelity Assessment Common Ingredients Tool (FACIT). A brief description of the COSP fidelity measure may be downloaded from the web at <http://www.sallyclay.net/z.together/ooo.html>.

The consumers involved in the SAMHSA Project drew up the definitions of the shared characteristics—the common ingredients—of consumer-operated programs, and these are all described in the book, *On Our Own, Together*. All of the consumer-operated groups in the study worked with a corresponding community provider agency. For example, in the Florida study, the PEER Center was compared with Henderson Mental Health Services. When the fidelity study was completed, it did find significant differences between consumer-operated and provider-operated, even though some of the peer programs were very different from each other. The consumer-run programs had different philosophies and different focuses. Some of them were drop-in's, some of them were mentoring or peer support groups, and some of them were educational programs. One of the groups was an alcohol and substance abuse treatment program. Nevertheless, all of them measured higher on the common ingredients scale than the provider agencies. The results of the fidelity study are described in Chapter 11 of *On Our Own, Together*.

Tom said that in previous discussions Network members have looked at other programs that worked very well. For example, Nine Muses is a good example of a program that has been around for a long time and is very successful. It is operated by the Mental Health Association of Broward, and when he lived down in Broward it seemed that when people chose to go there, Nine Muses helped them get better. Therefore, there are provider-operated programs that also have core principles that assist people in recovering. More subjectively, he has developed a program in New Horizons, the provider agency that he works for. It is a Learning Center that is far and away better than traditional day treatment or partial hospitalization programs. But a program such as this will by definition not be consumer-run, because it is operated in a provider setting. This brings up some dilemmas about how can we incorporate the principles and values of recovery and resiliency as defined by self-disclosed people in the context of transformation. How can we apply those values of independent consumer-operated programs in the community and in provider settings?

Lucy said that she still needed some clarity on whether a program such as a drop-in is run by professionals or by consumers. Who is able to run that type of model? Sally said that there is a lot of “in-between” in this issue, because it's not always black and white. A completely peer-run center is very difficult to run, because it needs a lot of very dedicated people to make it come off properly. On the other hand, some programs may have peer support groups that are lead by consumers even though the larger program is provider run. Such a program may hire consumers, and consumers may have a great part in running the organization and may have a lot of input into how the program's policies. Where the line is drawn between consumer run and provider run is whether the consumers can hire and fire their own staff, and whether they have their own 501C3

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and control how their money is spent. The board of directors, the decision-making body of a consumer-run program, consists of a majority of consumers. Ultimately, the members of a provider-run program usually cannot not hire and fire staff, and cannot make the final decisions about how money is allocated. Those factors are what separate a completely peer-run program from an agency that might have programs within it that are run by consumers.

Sally added that consumer-operated programs are independent of any pass-through agency, and they are based on two principles. The first is the Peer Principle, which means that the people who run the program have walked in the shoes of the people using the program, and they therefore understand each other. The second principle is the Helper Principle, which means that by helping others who are your peers, you end up helping yourself.

Tom said that certainly a clubhouse could be run by self-disclosed people. The real issue is how to pay for such a program under the current AHCA structure. In terms of Medicaid, first of all you have got to be a Medicaid provider, and then you have got to meet all the standards of treatment planning. This means that you are required to have a clinician, among many other guidelines that are very much driven by the medical model approach to service. In the case of Vincent House, they have chosen not to be a Medicaid provider. The issue of Medicaid requirements would be an important question to raise at the next Recovery and Resiliency Task Force meeting. Nevertheless, on principle there certainly is not a deficit of skill sets in the Florida consumer community that would keep a group of consumers who chose to run a clubhouse from running it. The question becomes how do you pay for a clubhouse, and how do you sustain it? The national standards, which are the guiding principles of a clubhouse, are available at the website for the International Center for Clubhouse Development, at <http://www.iccd.org>.

Patrick said that, of the clubhouses that are now active in the state, there is only one that is actually billing Medicaid, and that is the Peace River House. So far Vincent House, which is probably the most vital and successful clubhouse model in Florida, is choosing not to do Medicaid billing. One of the reasons for this is that they feel by billing Medicaid they would lose some of their independence, as well as their ability to evolve as they go along. Basically a clubhouse is an employment-oriented model, and the barriers to its being peer operated, as opposed to being operated by a typical traditional provider agency, are not insurmountable. We can, if we choose to, do that kind of thing. We could choose to come out with some sort of hybrid that we can operate either way, and if it is not dependent on traditional Medicaid funding, then we have got a lot more directions to go in.

Lucy said that most consumer-run programs are opposed to Medicaid funding because then they would have to jump through all the government hoops. Many of the other participants on the call agreed with this statement. "It all depends on how our funding comes through," said one. Toni said that her group was going to try to build some clubhouses in Pensacola, and they want them to be mainly consumer run. However, they do want to be affiliated with a medical system, and the medical system is working with them.

Sally said that she would like to add to what Toni was saying by going back to the topic of transformation. She thinks we have a real opportunity here in Florida to get things off on the right foot by getting recognition and support from the medical system for peer-run philosophies

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and techniques. Dianne added that because peer-run programs have gone through SAMHSA research, hopefully they will soon be acknowledged as a best practice. She pointed out that recently she had to write a county grant, and the first question they asked was, “Are you involved in some sort of best practice, and if not how soon do you plan to become a best practice?”

Tom said that there is a huge body of evidence that points to consumer-operated services as an emerging best practice. He thinks that CMHS is working on an implementation tool kit, and that there is a lot of work out there that bolsters that idea. He suggested that the Peer Network could put this kind of information on our website, with links to documents in the public domain, including work at the University of Pennsylvania School of Social Work and at the University of Illinois in Chicago. He asked Cathy to talk about how she perceives the NAMI Florida Consumer Council within the context of transformation in Florida.

Cathy said that the Council is in the process of starting more activities and getting more participation from consumers. This is the topic of an upcoming teleconference, where they will brainstorm how to get more involved in their communities, doing community service and so forth.

Tom said that another topic from previous teleconferences that has come up again on this call is the need for, and benefit of, peer support. He emphasized that there is a distinction between simple peer support and peer-operated services, because a lot of communities have the experience of informal peer support.

Toni said that right now DBSA’s main role in the context of transformation in Florida is to push the Certified Peer Specialist Program. It is a very successful program in many states, and Florida right now is going by the Georgia model. A lot of emphasis is being given to either mentoring or job support. DBSA hopes that sometime this year they can organize a “train the trainer” program. Right now that program is just in Pensacola, but they are trying spread it throughout the whole state.

Toni said that for communities that don’t have capacity for structure, DBSA that has a connection back to a national organization for support groups, just as there are different types of NAMI support groups. Tom mentioned that within his local community there is a DBSA affiliate in the Stuart and Martin County area, but there are deficits in other places.

Toni said, “It’s actually fairly easy to start a peer support group. I have started up three DBSA support groups, and really all it takes is people willing to start a group.” She said that usually you want to have at least a small core of about three people for startup paperwork, but national DBSA dues are very reasonable, about \$60 a year for the whole group. Starting the peer support group mainly involves advertising and finding a place to meet on a regular basis once you find some people who want to get together on a regular basis.

Tom said that two kinds of peer support groups—structured ones, based on national or recognized models, or just informal ones—relate to transformation and building capacity for self-help in the state. Peer support groups may be informal groups or groups like DBSA or NAMI support groups. There is also Schizophrenics Anonymous, which, although it does not use not person-first language, is a twelve-step program similar to other twelve-step models.

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Toni said that she has been dealing with peer support groups for about eight years, and the ones that always work best are those where the group's idea is fairly informal. Each community builds its own model. They just have a regular meeting time and allow people to socialize. "It's not group therapy," said Toni. "We stress to people that if you need group therapy, you need to go see a therapist and go to group therapy." She said that a lot of people use peer support to work on their problem-solving or coping skills, to figure out how to do things better in life, how to deal with their relatives little bit better, how to build better relationships with people. Her group also does some educational programs; for example, they will invite a professional such as a police officer to visit the group and tell them about other services that are in the community. They also do a lot of creative things; for example, once they had a Reiki healer come in to explain all Reiki therapy.

Sally said that she would be interested to know to what extent groups in Florida are operating from the kind of principles that were developed in the COSP Consumer Advisory Panel. She noted that it is hard to talk about values when you are seeking administrative funds to operate a program. Nevertheless, the key to every successful peer-run service that she has known is a feeling of friendship. That is a spiritual value that is awkward to talk about it. Nevertheless, one of the common ingredients that were developed in COSP project was that the peer-run environment allows comfort for people as part of the accessibility issue. You need to have a place that that is relatively informal, and where you feel at ease with the people you are with. That is sometimes one of the big differences between a peer-run program and a provider-run program. Does that make any sense?

Donald said that everybody else was saying what he was actually thinking. He said that he can only go from his own best experiences, and he believes it is best just to keep things simple. He said, "You guys are talking about advanced stuff here, and you are using a lot of fancy terminology, but we need to remember where the people are coming from, if we are talking about peer support groups." Sally said, "I agree with you Donald, I am glad you said that. That's right on."

Lucy said that her experience was with her peer support group where she is working with the homeless population of mentally ill. There is a need for that kind of support, she said, when people are in transition from homelessness into temporary transitional living and other kinds of housing. Because she noticed that there was a need, they created a peer support program that meets twice monthly in her area. They network with people who are in transition and living in temporary housing. She has been motivated to help them to understand what they need to know about going from homelessness to housing. "I know that's a great need," Lucy said, "and they need all the support that they can get. The foundation for all we are trying to do is to support each other."

Patrick said that another reason that about peer support groups are essential is that they are the fundamental way that we bring people into this whole process. "Many consumer leaders like us, who are involved in a high level of advocacy, began through support groups. We first start meeting with other people who have similar experiences, and we share our experiences—what works and what doesn't. Then we start to talk about it in broader terms, and we move on to dealing with things outside of our own lives. Any way that the state can support the formation of

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these groups is an important part of transformation. When we talk about transformation, we are looking for programs that we can implement and that will move us from the traditional model of mental health into something that actually lends towards recovery. Peer support groups are proven to be a major part of that.”

Yet, there is very little support on a statewide level for peer support groups. Patrick pointed out that in his district the program office contracts very heavily with a NAMI organization, which receives almost a million dollars a year to provide their educational classes as well as NAMI support groups, information and referral services, and so forth. What the Peer Network asks is that peer-run services be included in this funding. Transformation support groups have to be a part of this process, and they have to be something that the state recognizes enough to support financially. “Although sometimes people may feel that the purity of peer support is diluted if the state pays for it, sometimes that is the only way to grow.”

Sally enthusiastically agreed with Patrick’s remarks. She said that because the state is now actively going after transformation, this is consumers’ big opportunity to discuss what we are really about, and what peer support is. This should include the Peer Principle and the Helpers Principle that Dianne talked about. These two principles are core values that do not come up in lot of the talk of funding and operations. When talking about transformation and recovery, for example, we may talk about transportation and get into a lot of fancy terminology. In that way, in emphasizing material plans, we may lose the whole peer concept. The whole idea of the Peer Principle is to helping people who have been through similar experiences and keeping it simple. The idea behind the Helpers Principle is that by helping others you help yourself.

Dianne said that we often forget that the leaders also need a peer support group. She recommended that the Network could create a support group of leaders who could support one another and bounce ideas off each other. In Broward County Peer Specialists say that they are burning out because they do not have a Peer Specialist support group. Another problem is that support groups can sometimes be monopolized by one person and end up not being a mutual support group. She said that using the Native American counsel method for a support group, everybody gets their turn. That can be followed by going to a diner or restaurant to socialize. With this approach, there are two aspects to a peer support group—support and socialization.

Tom said that the board of the Florida Peer Network has discussed how they can help facilitate that “after the meeting” thing, such as going out to the diner. One of their thoughts was to try to have a telephone support group, since we have a conferencing service that allows us to offer toll-free calls for people in the absence of any other mechanism to provide support for leadership around the state. “The Network has some phenomenally effective people,” Tom said, “but it does take a toll when people go to the same person for anything that happens in a community.” In addition to the teleconference strategy, other activities that are often used are list serves and chat rooms and the like. “It’s the human touch that we are talking about.”

Sally said, “You need to be able to see the person, and then you can relate to their experience.” She said that a lot of people have trouble connecting with the Internet, and hearing other voices might be almost as good as it seeing other people. In any case, speaking on the telephone would allow for more direct human contact. She also pointed out the plans that are already under way to certify and train Peer Specialists. “Isn’t one of the values of being a Peer Specialist is that you

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are available to receive and give support at a very human basic level?” Sally said that we need to publicize these values, and stick to their importance. Sometimes we trapped in the use of fancy rhetoric, but the Peer Principle and the Helper Principle are actually what peer work is all about. Peer-run services are a critical part of transformation, and there are other types of services that are lacking in this state. All over the state there are pockets of things that work and things that don't work. In talking about transformation, we want to move towards services that really encourage and enhance recovery. What is it that works that we are not doing on a regular basis?

Tom said that people must have access to the services. For example, in many communities a person has to wait and wait and wait before they get into to see a doctor. Toni said that in Pensacola they have three large institutions close by that provide mental health services, but often when people go to one of these centers to get service, they are told that they can't see a psychiatrist for three months. “Well, that doesn't help you if you are in a crisis and need medicine,” Toni said.

Patrick mentioned the need for community-based programs, where services come to the person, and are built around the person's individual needs as opposed to fitting the person into the program. Sally said that that was exactly what Peer Specialists should be all about. Toni agreed that Peer Specialists could definitely assist in areas where there are not enough professionals to do a FACT team. The services now being offered fit too few of the people who need them. Patrick remarked that even though FACT is somewhat based on community services, it still primarily follows the medical model. “It's not recovery oriented,” he said, “it's maintenance oriented.”

We need to make some major changes so that the fundamental services we offer in the state are truly recovery oriented. There are other models besides FACT, such as supportive living, that are more based on the individual's needs rather than fitting the person into the program. There are some good models for supported employment, supported living, and other programs that the state has not supported. Those are the kind of changes that we have got to make if we are going to transform the system.

Florida does not have a very good rating when it comes to funding. Other states—California, for example—have had legislation over the past few years that has infused a large amount of money into their public mental health systems. The fact is that Florida is really cheap about this, incredibly cheap. This year the state had a three-billion-dollar surplus, yet those of us who work in mental health for the Department or for a provider have had less money this year than last year. Where's that money going?

Fundamentally, consumer-run programs should have access to a certain amount of the block grant. The American College of Mental Health Administrators under Neil Adam's leadership, a few years back advocated that 5% of the federal block grant monies should be earmarked for consumer-operated programs by the year 2005. That is not an insignificant amount of money, even in a state like Florida that does not fund things very well. By those means the Department could set aside an existing level of funding for programs that are not funded well now. Certainly folks on this call are leaders in terms of developing and operating consumer-run programs, as well as actually participating in research on consumer-operated programs. We believe that certified Peer Specialists could meet needs that are not now being met.

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The Florida Commission on Mental Health found that only 25% of the adults with serious mental illness were being served by DCF, and this is similar to data from the national scene. It makes you wonder where the other 75% of people get services, if they get services at all. Patrick said that his own hunch is that a lot of people choose to go to drop-in centers instead of Community Mental Health Centers, and a lot of people could have their needs met to a large extent in settings such as drop-in centers.

Sally said that she agreed, and just wished we could educate the public about those facts. “We all know how valuable peer support is, and how really helpful it is to feel that you belong, and you are not a freak—that other people have been through similar situations. Just realizing that one small fact can be very empowering.”

In terms of transformation in the state, we are all working very hard to make a philosophical shift towards recovery. Yet at the same time the state is making the opposite shift in how mental health services are funded. We are moving toward recovery services on the philosophical side, but we are moving away from recovery on the funding side, especially in Medicaid. In the changes that Medicaid will go through over the next couple years, our community mental health centers will have to cut all kinds of community-based supports. The same situation applies with peer-run services. We know what works, and we talk about what works, and we talk about wanting to shift to that, but we are not supporting it. The state has a large surplus, but decreases funding for mental health. Even in general revenue, although we have small incremental raises in money available for mental health, they do not meet the growing need. The population of Florida is growing tremendously faster than the amount of money in our mental health budget. “We are the people who should be saying how it should be,” Patrick said. “Right now we have got a chance to be a voice, and we need to make that voice loud and clear.”

Dianne said that in transforming the mental health system, there should be some a way to look at the number of people needing services in a county, and the money allotted should be fit that number of people. She noted that a big county like Broward does not get its share relative to the people they serve, while a smaller county that serves fewer people gets equal or more money. “That does not make any sense at all,” she said. “We need to change the system so that where there is a higher population, there is a higher funding.”

Patrick said that one problem is that we are too far away from Tallahassee, and also that we have a tremendous shift or variance in the use of hospitalization from district to district. Inpatient hospitalizations take up a tremendous amount of money, and it is much cheaper to reduce hospitalizations and put in community supports. We do not need to put so many people in hospitals where they do not need to be. Hospitals should be the exception, not the rule. We have made some big changes in the state; for example, a few years ago there were around 10,000 mental health patients in Florida hospitals, and now there are about 1400 people. However, the hospitalization rate is still very high in certain districts where they have not implemented the recovery-based services that would keep people in the community and make their lives better.

Dianne said that another thing that hinders consumers from using services in the community, including consumer-run services, is the barrier of transportation. For example, members of the Silver Center in Broward could not there independently, so the Center had to purchase a bus.

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In rural areas like Highlands County there is no bus; there is not even a taxi. Many districts are like that, and it is a huge problem.

Tom said that when she first got to District 15, she believed that there was a way for a consumer-operated program to be a Medicaid transportation provider. She quickly discovered that there was a counsel on aging had a statewide contract, and they subcontracted from that. She wanted to somehow broker this out so that the consumer-operated programs could in fact become transportation providers. There is a lot of business planning involved in this, but it is likely that some consumer-operated programs throughout the state could actually break even with such a plan, and then address some of the unmet needs. However, they would have to be able to bill Medicaid.

Tom said that the issue was billing Medicaid. He said that at New Horizons, because of the inefficiency of the Medicaid transportation system, there are people who miss appointments because they cannot get there on time. Medicaid transportation is scheduled in such a way that there are people who wait two to three hours to be picked up when their appointment is over. Consumers could operate such a service, and we could do it better. We could do a better job, and possibly return a profit, if we address some of these transportation issues. In the process we would create employment opportunities for people, as well as opportunities for people to get better and have better self-esteem.

Patrick said that they have been talking about it in his district for number of years, but they keep running up against the same obstacles—basically the Medicaid standards. Dealing with Medicaid on any level, and being able to bill Medicaid, is still a big mystery. It is convoluted, and the number of hoops you have jump through are too huge. A good outcome of transformation—and of prepaid plans and HMO's—might be that it becomes simpler to deal with Medicaid as a provider. Perhaps that is where the Network should be right at the forefront.

Tom requested input about how the Peer Network can get the level of participation that we had promised the state. He found that Patrick, Dawn, Donald, Sally, Lucy, Dianne, and Toni were still present on the call. The Network's membership is growing steadily as a result of outreach to drop-in centers, and we have enrolled about 225 members. We have not worked on our membership drive to the extent that we planned because we have been so involved with this teleconference series, which is deliverable for the state. The BOD and Gayle want to get more participation from the steering committee. The Peer Network really wants input, and the state does, too. How we can get more people on the calls, and what can we do better? Sally asked how soon can the Network could have a statewide conference, so that people can actually go some place and see other people. "That is the way things got going in other states and nationally," she said. "At a conference, you get directly to people, and this also happens when people take part in local activities at drop-in centers. Real participation isn't going to happen to a large extent until people really get that "aha" experience—'this is about me' and that sort of thing."

Patrick said that the Network plans two activities that will help with that. In October we will hold a mini-conference with the Florida Council for Community Mental Health (FCCMH), who have provided us with twenty-five hotel rooms. We will bring together people from each district to this small leadership institute. In addition to the conference we will do one-on-one advocacy to help develop leaders throughout the state. Secondly, we hope to have a statewide conference as

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soon as February, and we are starting to look for funding for that. It is true that we need to have a powerful event that really kicks this thing off.

Tom said that the conference that the Network has planned with the Florida Council is designed to be a newcomer's event. We hope that this will create an entry for us with the district programs so that they will begin to support Florida Peer Network events. The BOD actually plans to have the Florida Peer Network sponsor a call with the district program offices, rather than vice versa. Instead of always having our hand out and being needy, we have got to acquire a small amount of discretionary resources and to develop some new leadership. We are concerned about diversity, as any organization should be, and we plan to work on that in collaboration with the Florida Council. We drawing up a funding wish list that we will send to the state, and the list will include funding for the statewide conference. Sally and Tom have also been talking about a hard copy newsletter that will add value to membership.

Sally said that another thing that would work—although DCF wouldn't be very happy with us—would be to do something splashy such as having a protest or creating a little stir about something. Patrick said that about ten years ago consumers used to have a big get-together in Tallahassee once or twice a year, especially during the Legislative Days.

Sally said that the Peer Network now has couple hundred members, but what does it mean to be a member? She said that she had a handful of people Highlands County who have joined the Network, but they can't really seem to connect. They need to feel that they actually belong to something. How do we contact and stay in touch with our members, and make them feel like they are part of this effort—even if they don't have Internet capabilities or are not connected into this system in some way already?

Dianne said that participants in the COSP program were all over the country, but the PEER Center office had a speakerphone that looked like something out of Star Wars. Twenty-five people could gather around a table and all be part of the teleconference, and this worked very well. She recommended that the Network find out how many providers or DCF county offices have such a speakerphone and could have consumers bring their support groups to teleconferences. If local people could take part, they would learn about the Network and who we are, so that when they come to a statewide conference they would already have some clue.

The speakerphone is one of the items on the Peer Network funding wish list. We have asked for \$30,000 for technology grants for peer-run programs that meet the definition of consumer-operated programs. There would need to be a large number of mini grants and four \$2500 grants. In Gayle's travels we were surprised to find that very few drop-in centers even have telephones. Of those that have telephones, some do not have speakerphones, some do not have fax machines, and some do not have desktop computers or Internet access.

Among other things that require funding is for a statewide conference, at about \$60,000. We are asking for funds to operate a statewide Technical Assistance Center modeled after the nationally funded TA centers such as CONTAC, NEC, and the National Mental Health Consumer Self-Help Clearinghouse. From our perspective there is a huge unmet need for technical assistance, this project would be very sustainable. The Florida Peer Network would cover operations for the

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TA Center and have funding to pay for a fulltime executive director. Until now the Advocacy Center has funded both Dawn's time and Gayle Bluebird's time, and that's going to go away.

Tom said that the Peer Network has also asked for funding to develop the educational curriculum and the Peer Specialist trainings that are needed. In his interactions with the people served by New Horizons, he was appalled at the low level of awareness people have about their rights, and this lack of awareness is similar in other areas.

The Network has asked for funding to provide feedback on policy issues to the Advocacy Center. Funds are requested to hold a series of round-table dialogues throughout the state to follow up on what we are doing here. The Network would bring in consumers, family members, and provider agencies, and we will conduct a meaningful dialogue between the groups about what works and what doesn't—what problems do we see and what are the solutions to these problems. Another thing that the state is interested in are outcomes from the mental health system statewide. They want indicators that their mental health services work successfully and move people towards recovery. Right now there are no effective statewide indicators—all that we have is the traditional consumer satisfaction survey. The Network is now looking at available indicators to implement as a consumer tool to decide whether or not the system is working.

Our total funding wish list amounts to \$293,000. Patrick said that was a very do-able number, and Sally remarked that it is really a rather low figure. Patrick said that if the state contracts with just with one NAMI for nearly a million dollars for education and information referral, then that could be done on a statewide level.

Patrick, Gayle, and Tom are meeting with Dave Shern and Pat Robinson at the Florida Mental Health Institute this week about possible opportunities with FMHI. Dana Farmer from the Advocacy Center will be also participating. Dave Shern has accepted the executive director position at the National Mental Health Association, and to his credit he asked to have this meeting before he leaves. This is a relationship that Gayle and Patrick have been developing for awhile. The Florida Peer Network board is using the same document for discussion with any potential funder, because any one organization may not be able to fund completely a given part of the project, and if we are consistent in what we request it will send the right signals. We are trying to do a lot because we recognize that there is lot that is needed in Florida. We favor working with district program offices directly rather than relying on Tallahassee for our projects.

We are still just about a year old, and we are still waiting for our 501C3 status. We are getting ready to involve our local legislative representatives in helping us move that along, because we have got to have that before we can get any of these monies. We need to look at those areas of the state that do not have any consumer-run presence at all, and our hope is that when our technical assistance capacity is funded, we will be able to increase that presence. We will be able to tap into some of the expertise from our leadership within the Florida Peer Network.

Some of the ideas that people have suggested on these calls about how to reach out to our members clearly validate many of the issues the board has talked about. This series of teleconferences done in collaboration with the state is concluded with this call. Now we will have a chance to focus on some of the other efforts that we need to put forth. Sally commented that she deeply admires all the work that the Florida Peer Network board of directors has been

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doing. “All of the ideas you just have been talking about are like very well thought out, and I hope we can make them come to pass.”

Patrick said that the key to our success is that the state has become very interested in our organization, and particularly now that we have Clint Rayner up in Tallahassee as OCA. Clint supports and stands up for us every day. “Now that we are in a position to actually offer things to the state,” he said, “we just have to make sure that we come through with them, that we do what we say we can do, and that we are effective, efficient, and timely. We are in the best position we have been in since I have been doing this work, anyway.”

Tom said that there are now two schools of thought in Tallahassee. One is a perception that, although the Florida Peer Network is the statewide consumer network, we cannot do the scope of work that, for example, DBSA Florida does. But that is not our purpose. We are not a drop-in center, we are not the Peer Center, and we are not the NAMI Florida Consumer Counsel. We are the statewide network. The second school of thought questions how representative we are—how many people do we speak for in the state? Of course, the BOD’s concern is to grow our membership, and we are exploring the feasibility of dual membership within any of our partner organizations.

Lucy said she feels that the Florida Peer Network represents a far more visible community of people who will be able to know where they can find and get assistance when needed. She recommended checking advertisements for places to meet in various communities, because such places are very much needed. “What I have learned with homelessness,” Lucy said, “is that people do need support because many of them don’t have families. Giving them that extra support and help from consumers makes a difference in their being empowered to move back into life.” Tom asked Lucy whether her organization might be able to partner with the Network to schedule and set up activities in Tallahassee. He said that in regard to having more visibility, it was a great suggestion to have a community partner like Lucy, and it is important for the Network to make that happen. He would like to talk further with her about making that happen.

Sally said that it is extremely important to keep the support aspect going, and to be really there for people who need the support. Lucy added that we can include other agencies in a county that may want to be involved. Her organization holds a monthly meeting with all agencies that they partner with throughout the county. “The other agencies have issues as well,” she said, “because they know that support is what’s needed for people.”

Lucy said to let her know if she is needed to set up her location or to select a larger site in town—churches, a library, whatever is feasible and needed. Tom said that the Florida Peer Network website has a membership form that people are encouraged to download. Some of the folks who get services from Lucy might want to become members. Patrick suggested that Gayle Bluebird could come to her drop-in center at the Homeless Project in the next week or two. Sally asked for Lucy’s email address and said she would write.

Dianne said that we finally have an opportunity to transform or have some influence on how the state of Florida does things. “This is long, long overdue compared to much smaller states like Maine. But we have really need to make sure we don’t miss the important dates, times and opportunities.”

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Patrick said that these teleconferences have been very good, even though we have not had as large a group as we would have liked. All the input has been very useful, and Sally is editing the transcripts to make sense of it all for us. This is good input for the state to hear. Sally said that sometimes it's good for the movers and shakers to put a foundation together, and she did not think it's all bad that it was a small group today.

Tom said that Florida's community colleges are known for having a phenomenal technology, and he recently facilitated a retreat for the sheriff's Department of Public Defenders office. He plans to pursue whether their technology center could assist us in doing a web cast. He said that it would entail a lot of planning to put together a live web cast that could be archived as is done for some organizations like the Consumer Center in SAMHSA. If the community college is willing to commit to do the technology part of it, the Peer Network can put together get a planning committee, perhaps with the folks who have been active on these calls as well as the steering committee. We could put together a one-hour webcast that folks could view, including people from the department and providers, and market it as a big event. Dianne suggested that we could put it on DVD's too, and Tom said that he would look into all of that. "You know," he said, "we need to have that 'aha' type of advantage. A DVD doesn't carry the same magnitude that a day-and-a-half or two-day conference does—when people get to network and shake hands and go to workshops—but you know it certainly wouldn't hurt."

Conclusions

The topic of transformation is how we started these calls, and overall we have talked about various subjects, including certified Peer Specialists, peer support, consumer-operated programs, youths in transition, access to services, and reducing hospitalization. Our conversations have ranged broadly, and we have collected a lot of really good information. We are sending detailed reports back to the DCF, and we will post those all on our website. OCA Chief Clint Rayner wants everybody in Tallahassee to follow up on this information. Sally has agreed to edit and produce the reports for us.

Sally Clay is the editor of the book *On Our Own, Together*, and it is recommended that everyone get a copy. Patrick mentioned that the Recovery and Resiliency taskforce meets next week in Tallahassee. We are always looking for other people who might want to attend these statewide meetings of people who want to have input into the transformation of the mental health system in Florida.

"In previous conversations the idea of peer support was a broad topic of discussion," Tom concluded, "and it happened that over the course of these calls we enjoyed de facto peer support by just talking about our perspectives in terms of what the mental health system needs now."

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Recommendations — The table below represents current resources, challenges, and unmet needs.

Issues/Concerns	Current Resources /System Capacity	Challenges/ Needed Resources	Recommendations
	<p>There are not a lot of programs in this state for transitioning youth.</p> <p>There is a lack of professionals to follow youth through the transition process.</p>	<p>The governor cut transitioning programs. Kids in foster care are dropped as soon as they reach a certain age. Youth wind up homeless or in jail</p> <p>“Kiddies Axis I” - Youths are diagnosed inappropriately to qualify for Medicaid.</p> <p>Parents and schools need to be involved in follow-up for youth. Providers in the foster care system should be trained.</p>	<p>FPN recommends an advocacy project for transitioning youth, along with supports and recovery-oriented educational programs.</p> <p>FPN recommends insuring that schools conduct required mental health instruction. School counselors should be trained in diagnosing youth and getting students to needed services.</p>
	<p>The state supports training and certifying Peer Specialists.</p>	<p>Youths need to earn a living, but need more life experience before becoming full Peer Specialists.</p> <p>Youths need a peer support group in each community for age group seventeen to twenty-one.</p>	<p>FPN recommends including youths in Peer Specialist training, hiring them as Peer Specialist Assistants</p> <p>FPN recommends consumer outreach to youth. Peer Specialists could mentor youth and conduct trainings.</p>
	<p>Some organizations collaborate informally with their own agency.</p>	<p>Because of confidentiality the state will not even acknowledge that the children are in the system.</p>	<p>FPN recommends starting a peer support network for youth.</p> <p>FPN will participate in anti-stigma campaigns.</p>
	<p>Eliminating Barriers Initiative focused on stigma in employment.</p> <p>Self-Help Clearinghouse has anti-stigma campaign</p>	<p>EBI is ineffectual; was national program but did not send funding to states.</p> <p>DCF provided PSA’s, but did not provide handbooks for businesses.</p>	<p>Peer Network should study EBI material to see if we can use it.</p> <p>FPN will request materials from Clearinghouse on transitioning youth.</p>

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Issues/Concerns	Current Resources /System Capacity	Challenges/ Needed Resources	Recommendations
<p>2. Cultural Diversity</p>	<p>Mental health system does not outreach to families.</p> <p>People are Baker-Acted for culturally based religious practices.</p> <p>EBI did sixty-second or thirty-second public service announcements on television.</p>	<p>Diversity is not a systemic issue—it’s a cultural issue that originates from families and cultural taboos.</p> <p>Cultures consist of tight-knit families that do not communicate about their problems outside of their family</p> <p>Religious beliefs have strong influence, especially in romance-language cultures.</p> <p>An unrecognized source of stigma is diversity in sexual identity: homosexuality viewed as a mental illness.</p> <p>Persons in conflict with their own culture are sometimes treated in ways that are neglect and abuse in any culture.</p> <p>Mental illness itself is a kind of cultural diversity even within its own community where consumers discriminate by diagnosis.</p> <p>Free PSA’s do not work because they are aired in the middle of the night.</p>	<p>FPN recommends addressing fear of participation from a religious or family standpoint rather than medical perspective.</p> <p>“Just having people that look like me, and sound like me, and talk like me is not the only solution, but it certainly opens major doors.”</p> <p>FPN recommends more public education about psychiatric disorders and anti-stigma campaigns for families and the public.</p>

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Issues/Concerns	Current Resources /System Capacity	Challenges/ Needed Resources	Recommendations
<p>3. Reducing the Use of Inpatient Hospitalizations</p>	<p>FACT teams started in some areas to replace hospitalization.</p>	<p>FACT teams in Florida are medical model and use coercion, unlike the national model.</p> <p>Inpatient hospitalizations are expensive; it is much cheaper to fund community supports.</p>	<p>FPN recommends alternatives—respite, drop-in centers, and warm lines.</p> <p>Peer support groups should be funded in all local communities.</p>
	<p>Baker Act is used to commit people involuntarily in locked facilities.</p> <p>Peer-run respite house in Nassau County is an alternative to Baker Act & hospitalization.</p>	<p>Baker Act wording prevents funding of recovery-based programs. Locked units are the only ones funded.</p> <p>Baker Act is employed as a threat and inappropriately used for behavior problems.</p> <p>Crisis intervention teams (CIT) are needed to divert people from jails and hospitals.</p>	<p>Revise language in Medicaid handbooks with FPN input. Change wording to allow unlocked options and alternatives.</p> <p>Develop respite house model for Baker Act commitment.</p> <p>Fund more CIT training and programs. Involve consumers.</p>
	<p>Florida is certifying Peer Specialists.</p> <p>Arizona Peer Specialists help to screen admissions & avoid involuntary admissions, saving millions of dollars.</p>	<p>Peer-run programs and Peer Specialists empower consumers to communicate with caregivers, reducing the need for hospitalization.</p>	<p>FPN recommends that the state fund peer initiatives that empower people to manage their own treatment.</p> <p>Certify more Peer Specialists and require hiring consumers in language of provider contracts.</p>
		<p>People are forced to retire in adult day treatment programs and ALF's.</p> <p>Psychiatrists and other clinicians are dismissive to their clients, and prescribe medications inappropriately.</p>	<p>Provide easier access to psychiatrists and services.</p> <p>Provide peer advocates in doctor's offices, community mental health centers, and recovery teams.</p>

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<p>4. Open Discussion About Transformation</p>	<p>DCF is committed to transformation as defined by SAMHSA.</p> <p>A key to transformation is consumer input at all levels of policies and programs.</p>	<p>Some AHCA and DCF policies are counter to consumer values and to CMHS/SAMHSA principles of recovery and resiliency.</p> <p>Consumers and providers make a philosophical shift towards recovery, yet at the same time the state makes the opposite shift in funding.</p> <p>This year the state had a three-billion-dollar surplus, yet persons who work in mental health received less money this year than last year.</p> <p>Changes in Medicaid threaten to reduce community-based supports and peer-run services.</p> <p>The lack of transportation is an ongoing barrier.</p>	<p>Models such as supportive living, supported employment, drop-ins, and other programs are based on individual recovery, but the state has not supported these.</p> <p>Peer Specialists facilitate access to clinical services and provide community-based programs that come to the person and are built around the person's individual needs.</p> <p>FPN recommends forming partnerships between providers and peer-run services that support philosophy of recovery & resiliency.</p> <p>Peer-run programs could be transportation providers, if they could bill Medicaid</p>
	<p>DCF promotes the clubhouse model.</p> <p>The most successful clubhouse in Florida is Vincent House.</p>	<p>The current clubhouse model is provider-run, not peer-run. Clubhouses emphasize employment and generally require Medicaid billing and a medical-model approach</p> <p>Vincent House declines Medicaid billing to protect the integrity of their program.</p> <p>AHCA has restrictive billing requirements bill clubhouses that are contrary to ICCD standards.</p> <p>Preference for funding clubhouses might result in the "Single Model Trap" and less funding for drop-in centers.</p>	<p>FPN proposes a statewide teleconference on the topic of clubhouses.</p> <p>FPN to address clubhouse issues at Recovery & Resilience Task Force</p> <p>FPN recommends revising language of AHCA Handbook, especially billing requirements. Require consumer input in this process.</p> <p>FPN recommends a clubhouse structure not dependent on traditional Medicaid funding.</p>

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Issues/Concerns	Current Resources /System Capacity	Challenges/ Needed Resources	Recommendations
<p>4. Transformation (continued)</p>	<p>Consumer-operated programs are based on the foundation of peer support, described by the Peer Principle and the Helper Principle.</p> <p>Consumer-operated services are an emerging best practice.</p> <p>Transformation includes training and employing Peer Specialists.</p> <p>DBSA plans to organize a “train the trainer” program for Peer Specialists and spread it throughout the state.</p>	<p>The public and providers do not understand the difference between provider operated and consumer operated.</p> <p>Some provider-operated programs also have core principles for people in recovery.</p> <p>The issue is how to pay for programs under current AHCA and Medicaid structure.</p> <p>At community mental health centers, people are told that they can’t see a psychiatrist for three months.</p> <p>A large county like Broward does not get its share relative to the people they serve, while a smaller county gets equal or more money.</p>	<p>FPN recommends developing a hybrid model—a consumer-operated clubhouse. Consumers already skilled in running drop-in centers could operate employment programs.</p> <p>Drop-ins incorporate a choice of activities, including employment.</p> <p>FPN to publish on website info on consumer-operated services as a best practice.</p> <p>Funding is requested to develop Peer Specialist educational curriculum and trainings.</p>
	<p>The COSP study included a fidelity measure to examine common ingredients of peer-run programs, & <i>On Our Own, Together</i> describes that instrument.</p>	<p>Definition of a peer-run program: it is staffed by consumers, and its board is chosen by consumers. The program controls its own finances, and has 501-c-3 status.</p> <p>Peer-run services measure higher on common ingredients scale than provider agencies.</p>	<p>To achieve transformation, FPN recommends incorporating CMHS principles and values of recovery and resilience.</p> <p>Study Chapter 11 of <i>On Our Own, Together: Peer Programs for People with Mental Illness</i>.</p>

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Issues/Concerns	Current Resources /System Capacity	Challenges/ Needed Resources	Recommendations
5. Conclusions & Florida Peer Network Wish List	FPN to hold leadership institute in October funded by FCCMH	Need to get more participation in FPN.	<p>FPN plans a statewide conference in February 2007 and seeks \$60,000 for the statewide conference,</p> <p>FPN will do one-on-one advocacy to develop leaders statewide. We are exploring dual membership within our partner organizations.</p> <p>Funding is requested to develop Peer Specialist educational curriculum and trainings.</p>
	FPN FUNDING WISHLIST totals \$293,000	Many consumers do not have Internet capabilities or are not connected into mental health networks. Existing groups need technical assistance.	<p>FPN will seek discretionary resources from district program offices, funding opportunities with FMHI, and funding from other sources.</p> <p>FPN recommends that peer-run programs receive 5% of federal block grant monies.</p> <p>FPN seeks \$30,000 for a TA Center to benefit peer programs statewide with several technology grants and mini-grants. We will ask community colleges to help with a webcast.</p> <p>FPN will publish a hard copy newsletter.</p>
	FPN will send detailed reports of teleconferences to DCF, and will post them on our website.	<p>OCA Chief Clint Rayner will follow up on these reports with officials in Tallahassee.</p> <p>FPN needs to maintain focus on peer support as the foundation for consumer organization and recovery.</p>	<p>FPN will help develop a consumer tool to indicate whether the system is working.</p> <p>Funding needed to conduct a series of round-table dialogues statewide to provide feedback on policy issues to Advocacy Center.</p>