

Florida Peer Network Retreat

DECEMBER 8-10, 2005

Dayspring Conference Center
Parrish, FL

Meeting Summary

Prepared by Jim Winarski, MSW

*Louis De La Parte Florida Mental Health Institute
University of South Florida*

Introduction

On December 8-10, 2005, the Florida Peer Network conducted its second meeting at the Dayspring Conference Center in Parrish, Florida (near Bradenton/Sarasota) to continue the process of developing a statewide organization to represent the interests Florida citizens who are mental health services consumers. The Florida Peer Network, Inc. (FPN) is an independent organization of and for persons with psychiatric disabilities. FPN's mission is to promote recovery, quality of life, advocacy, education, mutual support, peer directed services, and participation in mental health policy design for consumers throughout the state of Florida. The purpose of this meeting was to organize efforts related to organizational development; to develop strategies for responding to issues that are of critical importance to persons with mental illnesses in the state of Florida, and to have opportunity for peaceful reflection and meaningful dialogue.

Gayle Bluebird, of the Advocacy Center, led the planning for this meeting and served as facilitator for the proceedings.

Thursday December 8, 2005

7:00 – 10:00 PM

Showing of Videos
Networking and sharing

Friday December 9, 2005

Welcome and Introductions

All of the participants were welcomed to the second retreat of the Florida Peer Network (FPN) (see attached attendee list). Participants were given the opportunity to introduce themselves and to share their hopes for the meeting. Participants were asked to focus on accomplishments and plans that will translate to action, and to take the opportunity to get to know each other better and enjoy each other's company.

A folder was distributed that included the agenda, meeting guidelines, FPN press conference remarks regarding the Medicaid Waiver Proposal, FPN Position Statement regarding Florida Agency for Health Care Administration's Proposed Medicaid Waiver Application, Position Description for the Office of Consumer Affairs Coordinator's position, an example of advocacy by a state level organization, an AARP article on Florida Medicaid's shift to managed care, and the summary from the July 2005 retreat.

Guidelines for Participation

The agenda was reviewed for the retreat. The group agreed to follow the following set of guidelines that had been developed for the retreat to provide a structure for achieving meaningful goals:

- All presentations should be limited to 10 minutes
- Discussions should be held in workshops rather than asking questions or making comments after each presentation. (Reason: the presentations are food for thought; the discussions and work go into the work groups.)
- If you have any questions or concerns of a personal nature, please save them for networking times.
- A timekeeper will be our friend. We are here to walk away with concrete steps; consequently timekeeping will be most helpful.
- Every workgroup should focus on how we play a role in each area.
- What is the issue? Then ask; what do we do to impact the issue? We should walk away with a group plan as well as an individual plan.
- The meeting is not about vocabulary or definitions.
- The meeting is about action.
- The Florida Peer Network is you.
- Transformation of the system needs us.
- "Nothing About Us, Without Us" has meaning – it is not just words.

FPN Incorporation Status

Tom Lane provided an update on the status of FPN process of incorporation. Tom sent application and payment for process of incorporation and IRS application for 5013c status. He also submitted the FPN bylaws to Neil Bush's attorney as part of this application. Cost is 1,000 for incorporation, including all of the fees. He expects FPN to be incorporated in Florida and have IRS submission completed by the end of December 2005. His hope is to schedule an election for a board that will serve the terms that are described in the by-laws.

Executive Director's Report: Gayle Bluebird

The following update was provided:

- Membership cards and letters of welcome are prepared and ready for review.

- Gayle, Tom, and Patrick, have attended meetings with SAMH Corp. and Rod Hall of the Department of Children and Families (DCF) on separate occasions re OCA development.
- FPN was asked to provide consumer participants to attend the Medicaid quarterly meetings, but was not able to accommodate the request because expenses for travel were not provided. This has been an on going problem that has created barriers to consumer participation at many important state meetings.
- A power point presentation will be created for membership drive and recovery orientation that will be used for FPN presentations and also be posted on the web site.
- Thus far there have been 74 applications for FPN membership received from different areas of the state.

Gayle expressed her thanks to Dana Farmer (Advocacy Center) and to Pat Robinson/Florida Mental Health Institute (FMHI) for funding each of the retreats.

Special Visitor's Report

*Jim Winarski - University of South Florida/Florida Mental Health Institute (FMHI)
Update on State Mental Health Transformation*

Jim provided a summary of planning activities being conducted by the SAMH Corp and DCF, including a discussion of the first meeting of the Transformation Work group in October. Two FPN members represented FPN at that meeting. Jim indicated that these early stages of planning are critical for success and explained that consumer (FPN) participation is necessary for an authentic transformation. FPN should begin to think strategically about how it wants to become involved in the planning process in order to have the greatest positive impact for mental health consumers throughout the state.

*Dana Farmer – Advocacy Center
Update on Advocacy Center Involvement with FPN*

The Advocacy Center is federally funded and is able to support FPN as part of its focus on self-determination. There has been some concern among board members about the Center's continuing ability to provide financial support to the FPN. There is a general feeling that FPN has the best chance of developing a viable statewide consumer group and that it has done a good job of creating a positive public profile. FPN is starting to be recognized in Tallahassee as a viable statewide consumer voice. However, current support is being provided by carry-over funds that will soon be running out. FPN should place a high priority on seeking alternative sources of financial support. This issue will be especially critical after Gayle leaves the Advocacy Center in early 2006. Sally Clay indicated that FPN should consider writing grants.

Tom Lane expressed appreciation for the support of the Center and acknowledged that FPN's role is to speak for other groups that have done a broad range of important work. However, he emphasized the urgent need for an entity to organize the all of the groups

and to speak with a unified voice. Tom acknowledged the challenge of FPN walking a fine line between intruding on the work of other independent consumer organizations and FPN but stated that the goal of FPN is to be a representative group composed of all organizations and individuals in the state in order to present a unified voice.

There was consensus among the group that between now and 9/06, much work needs to be done to build a financial base for FPN.

*Pat Robinson – University of South Florida/Florida Mental Health Institute (FMHI)
FMHI Update – Future Connection with FPN.*

Pat described FMHI's continued interest in developing a strong partnership with FPN. FMHI is a college of the university. This has special significance in developing a partnership with FPN because, as a college, much FMHI's activities are targeted in the community. However, FMHI is a training and research facility and its capacity to distribute money is very limited. It will be especially important for FPN to become incorporated and self-supporting in the near future.

Both FMHI and FPN stand to benefit from collaborating. FPN has a wealth of expertise and FMHI is positioned to provide support that is unique to the university. FMHI needs to orient its staff/faculty to recovery and is taking steps to provide education. This is an area in which FPN could provide invaluable support. FMHI can collaborate with and provide compensation to FPN on activities in the areas of training, research, and work force development. The development and implementation of evidenced based practices such as supported employment and education also provide ideal areas for partnership. FMHI is committed to developing a strong partnership.

*Ann Rollyson
DCF/Office of Consumer Affairs (OCA) Update*

Documents for the OCA position have been posted on the florida.com web site. Copies are available. DCF intends to do a national search, but requested that FPN members use all networks available to get the word out – word of mouth will be an important part of advertising the position. The OCA position has the support of secretary and senior DCF staff. The position will be posted until January 13.

Gayle Bluebird stated that three weeks is not enough time to post the job and that this time frame was not consistent with practices in other states. Patrick Hendry stated that posting the position on the web (People First) does not provide enough exposure to attract a wide range of qualified people. This is not the type of position that people would necessarily be looking for in state listings unless they have heard about it somewhere else. Therefore, it is extremely important that we get the word out through the various organizations and websites that serve consumers. FPN members should use every available network available to inform potential candidates.

*Pat Glenn – Medicaid Field Office Manager for Area 6
Medicaid Reform Presentation*

Pat made a PowerPoint presentation to the group on Medicaid reform and the potential implications for persons with mental illnesses (PowerPoint Presentation available at the Florida Peer Network Office upon request). The reform will initially focus on Broward and Duvall counties, and may eventually be implemented statewide.

Tom Lane announced changes in agenda for afternoon session.

There will be four work groups: Transformation, Peer Specialists, Medicaid/Medicare D, and Web Site E-News. Break out sessions for each group will last one hour, then groups will report back for 5-10 minutes, and then facilitate dialogue and develop a work group action plans, with wrap-up by 4:15.

Summaries from Afternoon Work Groups

Transformation: Patrick Hendry & Jim Winarski – Facilitators

Members: Gayle Bluebird, Tom Lane, Michael Stevenson, Pat Robinson, and Dana Farmer

The group discussed the complexities of organizing statewide transformation efforts and reviewed recent planning activities currently directed by DCF. There was some discussion regarding the process for applying for the last federal Transformation Grant led by SAMH Corp. The group decided that FPN needed to have a strategy for working with the newly formed Transformation Work Group. The group also recommended that a group with broader statewide responsibilities such as SAMH Corp should be the lead agency for Transformation, rather than DCF. In addition, the need for leadership training was identified as a priority to enhance the effectiveness of FPN in interactions with government and the community.

RECOMMENDATIONS:

- Peer network needs to define leadership role in state transformation work group.
- The State provides important leadership but should not be the only driver.
- SAMH Corporation should be the lead agency for transformation.
- FPN will write a letter to Ken DeCerchio and Ellen Peikalkiewicz recommending that SAMH Corp. should be lead for transformation (see attached letter).
- Tom Lane will schedule conference call to coordinate the efforts of FPN members who participate in the transformation work.
- FPN should develop plan for leadership development.
- Request can be made to NASMHPD in Alexandria, VA, for a speaker/consultant we identify to provide technical assistance.

Peer Specialist Certification Ad Hoc Committee Meeting

Committee members: Clint Rayner, Heather DeLoach, Steve Estes, Jean McPhaden, John Massolio, Sherri Trahin, Susan Lang, Toni Beard, Neil Bush and Jana Spalding (absent).

Guest: Neal McGarry, Florida Certification Board

A short presentation was given on the Depression/Bipolar Support Alliance's peer specialist training program that has had success in Florida. Up to this point there has been little success in efforts to get peer specialist training in the state.

There was a handout and discussion about how closely the DBSA training fit the Georgia peer specialist certification model; the acknowledged leader in this area. Georgia was one of the first states to fully implement the CPS program. They went beyond the traditional involvement of consumers by using this certification as the tool to bring them into the formal mental health system.

The Certified Peer Specialists in Georgia were brought on board as full-time employees and professionals of the Department of Mental Health. They were dispersed throughout the system as state employees and worked side by side with the other mental health professionals. Larry Fricks was the motivating force behind this move and has since been involved in taking the certification process both nationally and internationally. He serves on many national Boards and Organizations, one of which is the Depression Bipolar Support Alliance (DBSA), the federally funded organization used to implement the CPS program. In fact, Larry was one of the five trainers for the first CPS program held in Florida during September, 2005 in Pensacola Beach, Fla., District One of DCF.

The program is a very intense week long (40 hour) training program and the curriculum is exactly that of the Georgia program. This means that those first consumers certified at this meeting are now qualified to move to other states and receive professional status. This training meets evidence based criteria and requires a very intense and difficult post test for certification.

A discussion with McGarry followed. Some points included: a "role delineation" study would be needed to determine the "scope of practice" for peer specialists and the "core competencies" on which to base a program; the committee may want to consider that other entities may want to become training providers; CEU's should be a part of recertification; the FPN would be the responsible party for determining the criteria for persons seeking certification; the FPN would be the responsible party for creating the peer specialist certification exam (with professional input), but the exam would be administered by the FCB; a governing board would need to be established from FPN members of not more than 11 persons, said governing board would report to the FCB Board of Directors.

All members present were in agreement that a partnership with FCB would lend much-needed legitimization, statewide standardization and professionalism to a Peer Specialist certification.

ACTION ITEMS

- Clint will email committee members and FPN Board of Directors members a copy of the Georgia training program manual.
- Clint will call Larry Fricks (Georgia model) to inform him of our progress and seek further counsel on proceeding.
- Neal McGarry will bring the proposed partnership to his Board of Directors for approval. Pending said approval, Neal will contact leaders in the mental health field that he knows for information on funding initial start-up expenses and later training costs.
- The decision was generally approved to meet again with McGarry to pursue developing a credential program for a Peer Specialist in the state of Florida.

Medicaid reimbursement for peer specialists' services was mentioned as a future goal.

Medicare/Medicaid

Reported by Bill Schneider.

The Medicare Part D/Medicaid Workgroup was attended by 5 people, one whom which was the District 9 Florida Representative for the Agency for Healthcare Administration (AHCA), which regulates Medicaid in Florida. The main points of discussion are summed up below.

Best Practices of Medicaid HMO's: Some best practices were discussed, especially Dr. Ruth Ralph's ideas of spilling over profits from Medicaid HMO's into funding consumer recovery initiatives. The representative from AHCA was open to these ideas, and said that further discussions on higher levels could result in this happening in Florida, that AHCA is open to new ideas for the system. The representative from AHCA mentioned that he is willing to be a contact person for the Florida Peer Network for assisting with facilitating consumer input from our organization to others in AHCA and encouraged partnering with the FPN to assist in this area.

Medicaid HMO's and the Agency for Healthcare Administration (AHCA). Based on the presentation and further discussions from the representative from AHCA in the group, the following was found out about AHCA and Medicaid Managed Care Implementation for Florida that AHCA is:

- Inviting consumers for their input to meetings
- Has in their plan for "Choice Counselors" for consumers to be assisted in navigating the system and making their choices for their healthcare
- They are developing personal outcomes, which they can welcome consumer input to the development of. (Some advocacy is needed here for the consumer input to this development).
- Medicaid Managed Care in Florida is heavily concentrating on prevention and is open to future ideas of what will work re: preventions of hospitalizations, crisis, etc.

- Local District meetings need to be attended with consumer representation, as well as the statewide meetings
- The statewide AHCA Medicaid HMO Help line that is intended to assist consumers is missing a data base of mental health agencies. The AHCA rep. will be looking into this.

The FPN members in the meeting advocated specific points of importance and brought up concerns/opportunities for advocacy:

- *Consumer input* at all meetings
- *Flexibility* for recipients to be able to see their treatment professionals, PRN, as opposed to only certain number of times per year.
- *The importance of unlimited outpatient services*, so this can do the most to prevent crisis, hospitalizations, etc.
- The need for consumers to have *funding to go to the meetings*, for AHCA to accommodate consumers for input
- The hiring of *Choice Counselors*
- *That AHCA has more sensitivity/understanding* that consumers have thought disorders and that there needs to be accommodations for this, especially when consumers need to make decisions about their healthcare plans and services.
- That all communications with consumers be more clear, simplistic, better ways of informing consumers, timeframes were discussed about the notification to consumers of requirements, and *the need for overall improvement of communications and information dissemination.*
- The high concern *that consumers are being disenrolled away from mental health services and their ancillary services that they use to receive from their community mental health agency*

Medicare Part D: Much discussion ensued in this area. People all felt that the current distribution of information to consumers was too complex, difficult, government websites not user friendly, consumer friendly, unable to easily navigate to find simple answers to simple questions and concerns. There were brought up concerns of people being automatically enrolled into HMO Drug Coverage Plans that cost more money than some other plans being offered. The AARP Guide to Understanding Medicare Part D was commented as most helpful and that this should be distributed statewide for consumers to access.

The representative from AHCA expressed that people who are dually eligible are automatically enrolled into Medicare D and that if someone is going to dis-enroll, that they may jeopardize their benefits. He suggested caution when enrolling into different plans.

*Web-E-News – Sally Clay Facilitator/Recorder
Present: Gayle, Dawn, Elvira, and David .*

The committee agreed that an online newsletter, along with a comprehensive website, is the best way to achieve transformation of the mental health system in Florida. The newsletter will represent what consumers want and need, presented in their own words, and it will be capable of disseminating that information far and wide both to consumers and the general public.

The working name of the newsletter is “*FpeN*,” which stands for Florida Peer Electronic News. It is recommended that the newsletter employ the services of Constant Contact, an online mailing list service. *FpeN* would be emailed to subscribers on a weekly basis. A sample of how the newsletter will appear was emailed to all members of the Steering Committee before the retreat. Mike Hourihan of Constant Contact estimated that one year’s mailings to 500 subscribers would cost \$126. The following are the action steps necessary to begin publication of *FpeN*:

- Approve use of Constant Contact mailing list service (BOD)
- Arrange for payment to Constant Contact and send proof of nonprofit status (Dawn)
- Create an Advocacy Center email address for newsletter editor (Keith)
- Establish process to send subscribers’ email addresses to the editor (Dawn)
- Establish channels of communication for newsletter and webpage coordinators (BOD)
- Establish process for newsletter editor to directly receive and edit manuscripts (manuscripts should be edited before being posted)
- Establish way for authors, committee, and Board of Directors to approve content of newsletter (BOD)
- Establish way for editor to arrange for quick upload of manuscripts to the webpage (Keith)
- Formalize e-news committee (see below for current members)

"Sally Clay" <zangmo@sallyclay.net> - Central Florida

"Angela Vickers" <angvickers@aol.com> - Jacksonville/Gainesville area

"Clint Rayner" <clinrayner@bellsouth.net> - Panhandle/Pensacola area

"David Money" <DavidM@advocacycenter.org> - Tallahassee (website)

"Gayle Bluebird" <gayleb@advocacycenter.org> - Broward/Miami Dade

"Jana Spalding" <Jana_Spalding@sheriff.org> - Broward area

"Jean McPhaden" <brevarddropin-jean@yahoo.com> - Daytona/Orlando area

"Patrick Hendry" <patrick_hendry@dcf.state.fl.us> - Sarasota/Fort Myers/Naples/Tampa area

"Elvira Sears" <break_9@hotmail.com> - Broward County area

It was agreed that choice and editing of material was the responsibility of the editor, who would confer with authors and committee members as needed for each submission. Overall approval from Board of Directors and the newsletter committee would be sought on policy issues. All material submitted to the newsletter should be sent to the editor, who would, in turn, submit edited material to the website coordinator. Dawn suggested that it might be helpful for Keith to create a “back end portal” (i.e. a folder which the Newsletter editor can drop articles in) that he can then upload to the website. This could expedite postings to the web page news section as well as make it very simple for the editor. It is important that meaningful communication be established between newsletter and webpage coordinators.

Saturday December 10, 2005

Gayle led discussion summarizing Friday's activities and reviewed the agenda for Saturday. All of the discussions were conducted with the large group. Key topics included:

- Membership Strategies
- Membership Conference
- List of FPN Successes
- Funding/Fund Raising
- General discussion

Membership Strategies

The following is a list of key points made by participants as part of the large group discussion:

- FPN needs to be clear about who we are and who we represent
- We are peers but represent broad interests.
- Should set a goal of 500 members by June 1, 2006.
- List of successes is an important selling point.
- Person is required to self-disclose to belong.
- Contact information web site of steering committee?
- Volunteer programs are important.
- FPN should visit drop-in centers using a PowerPoint presentation to provide orientation.
- Goal to visit every drop in center with other members over the next two months.
- Consider sending regular e-mail newsletters.
- Consider having a first annual statewide conference in the middle of 2006.
- Have links to other organizations.
- Consider having Drop-In Center memberships.
- Each person attending today will review the membership application.
- Track and post progress in membership numbers.

Membership Development Tasks:

- Drop in Center memberships-develop corporate membership: Bill to complete in 1 month - will work with Dawn.
- Visits to drop in centers – Gayle, Elvira and those in close proximity to centers.
- Power Point development – Gayle/Bill/Jana.
- E-mail news Sally.

- Web site committee- Nelson, Dawn, Patrick,
- PDF file with list of accomplishments: Gayle and Dawn – ongoing.

Membership Conference

Susan Lang described idea for an information conference for new FPN membership. The challenge is getting funding to support travel for all those who would like to attend. Patrick indicated that Dr. Rod Hall said funds might be available for consumer issues. Need a clear plan of goals and purpose for the meeting. Gayle may be able to bring Kathy Muscari from CONTAC in WV, for training in leadership.

FPN may be able to partner with DCF for district regional meetings, working with DCF personnel on issues such as supportive housing, employment. FPN can identify the deliverables, acquire funds, and deliver the services. FPN could focus on skills that support transformation and can offer our ability to deliver services and supports in achieving system's goals.

Issues to address: leadership, housing, benefits, education, drop-in center, and clubhouses.

Question: Should it be a general membership conference? Would require large funds.

FPN will ill set up an ad hoc committee, with Patrick Hendry leading. FPN should consider bringing consumers to Tallahassee. Dave Money stated that our job is to help consumers get motivated to help each other.

List of FPN Successes

1. First retreat June 29 and 30, 2005.
2. Circulated report to a wide constituency
3. Developed and revised OCA job description
4. By-laws – Articles - Incorporation
5. Peer specialist training
6. OCA meeting with Rod Hall (2 face to face meetings)
7. Web site
8. Membership
 - a. Application
 - b. Welcome letter
 - c. Membership card—(Dawn presented membership cards to the group for approval)
9. Mission statement development
10. E-mail newsletter
11. Beginnings of credibility in the State
12. SAMH corporation – PowerPoint on Peer Specialists

Funding and Fund Raising

- FPN has many talented grant writers.
- Funding is already a priority issues in every board meeting.
- Nelson's recommendation: Invest in QuickBooks.
- Dave: FPN should develop a grant writing committee: Nelson, Neal Bush, Dave, and Sally all have experience.
- FPN will send out letter to membership and ask members to join the committee.
- FMHI may be able to provide technical support.
- Nelson: after 501c 3 work is completed, we need to start thinking about financial statements and using QuickBooks for non profits.
- Bill will be opening a bank account on behalf of the network soon.

General Discussion

Pat Robinson identified the need to acquire resources to support all of the tasks that need to be addressed. She suggested focusing on specific domains such as organizational structure, financing, membership, and transformation activities/relationship to state efforts.

It's important to account for a division of labor so that everyone does not have to do everything. The group agreed that there is a need for more person power.

Website: Board will vote on web site issue. The report of this meeting will be posted, along with a Proclamation Document (Clint), and a group picture.

The board will need to address how management and leadership responsibilities will be handled after Gayle's departure in early 2006.

Funding to support travel to meetings throughout the state is an important issue that needs to be addressed to ensure consumer participation.

“We can only be the voice of our people if they feel comfortable and are able to comfortably voice their concerns. That will help to make this a transparent organization.”

The retreat concluded with a moving Open Microphone session that allowed each person five minutes to share their impressions of the meeting, express last minute thoughts and ideas, and artistic expression in song and poetry by several individuals.

(Open Mic. ending of meetings is a special time and is recommended for inclusion in all dialogues/meetings of this type.)

See Attached Guest List:

Dayspring Retreat

Bill Schneider	Fort Lauderdale
Bluebird, Gayle	Fort Lauderdale
Carolyn Wilson	Miami
Clint Rayner	Pensacola
Dawn Rix	Miramar
DeLoach, Heather	Tampa
Donna Jenkins	Coco Beach
Estes, Steve	Fort Myers
Jean McPhaden	Melbourne
Jim Winarski	Tampa
John Massolio	Tampa
John Nelson Kull	Orlando

Guest List

Michael Stevenson	Jacksonville
Money, David	Tallahassee
Patrick Hendry	Fort Myers
Sally Clay	Lake Placid
Sherri Trahin	Fort Myers
Susan Lang	Fort Myers
Tom Lane	Fort Pierce
Toni Beard	Pensacola
Clyde Kobayshi	St. Petersburg
Neil Bush	Tampa
Elvira Sears	Ft. Lauderdale

Guest Speakers

Farmer, Dana	Advocacy Center, Tallahassee
Neal McGarry	Florida Certification Board, Tampa
Patricia Robinson	FMHI, Tampa
Patrick Glynn	FMHI, Tampa
Anne Rollyson	DCF, Tallahassee