

Florida Peer Network, Inc.

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

CHOICE & ACCESS

Expansion of Choices in the Mental Health System
Access to Services for Individuals Without Benefits
Access to Medications
Self-Directed Care

Summary Report
Statewide Teleconference
May 16th, 2006

Submitted to
Florida Department of Children & Families
July 2006

CHOICE & ACCESS

Executive Summary

The Florida Peer Network (FPN) is concerned about the direction of DCF policies regarding services funded from general revenue vis-à-vis Medicaid changes. Recovery-based programs funded by DCF would not be available for clients on Medicaid who want a less restrictive level of care. In effect, under these new plans, rather than *Expansion of Choices in the Mental Health System*, consumers might face fewer choices. DCF will have to pay more for services to serve people without Medicaid. Two pilot programs in South Florida were set up by the Agency for Health Care Administration (AHCA) to test the changes under the Medicaid waiver. FPN members observed that this state agency, in contrast to DCF and SAMH, has not yet supported consumer initiatives. For example, FPN suggested that consumers be hired as “choice-counselors” for the pilot programs, but AHCA did not accept. It is recommended that a dialogue be set up between AHCA and the Florida Peer Network to create a working relationship.

Regarding *Access to Services for Individuals Without Benefits*, it was feared that because Medicaid will not cover recovery and resiliency programs, existing programs would become diluted and even cut because more persons will need them. Faith-based services can provide some recovery-based services, but they are overwhelmed by increased numbers. Programs that treat co-occurring disorders often follow a substance abuse model, not a mental health model. Although community resources such as AA are available for substance abuse survivors, mental health consumers are neglected. People without mental health providers have trouble getting benefits. It was observed that peer-run programs are recovery-based and help people link to benefits; these programs should be supported to replace services lost through Medicaid changes.

Discussion around *Access to Medications* centered on difficulties encountered in navigating the Medicare Part D program. Speakers were concerned that many clients cannot advocate for themselves without assistance. People who are most in need experience discrimination in this program, which targets seniors and overlooks people with disabilities. In many cases, people who had received medications at no cost now must struggle even to obtain their prescriptions. *Self-Directed Care* is a successful program in two districts by which people choose the services most beneficial to them. The Florida legislature has approved the expansion of these services into more districts next year, although there is no new money to fund new programs. It was recommended that money from existing programs be transferred to Self-Directed Care, and that key brokers and employees of these programs be consumers, especially those trained as Peer Specialists and Counselors.

Projects recommended for the Florida Peer Network include support of Self-Directed Care, meetings with AHCA, improved communication with local FPN members, additional FPN teleconferences, outreach to homeless people, and dissemination of information about programs around the state. FPN should continue to monitor difficulties with Medicaid Part D and with barriers of discrimination and neglect when they appear. These discussions and recommendations are further detailed in a matrix on page 12 of this report.

Introduction

Board Vice-President Patrick Hendry facilitated this second 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 1:30 pm to 3:30 pm on May 16, 2006. Eight speakers participated:

Jan Anastasato, Consumer Support Project Director, Nine Muses Art Center
Sally Clay - Editor, *On Our Own, Together*, Lake Placid
Alison Goldberg – Employment team, Advocacy Center Office
Sharon Hamilton - Florida Health Partners, Orlando
Patrick Hendry - Vice President, Florida Peer Network; Consumer Affairs District 8
John Massolio - Florida Health Partners, Value Options in Tampa
Dawn Rix - Executive Secretary for the Florida Peer Network
Peter Steelman – New Horizons, Treasure Coast, Stuart

Expansion of Choices in the Mental Health System

Consumer/survivors in Florida are facing changes with Medicaid and with the ways that services to individuals are funded by DCF. A new plan currently under consideration is that mental health services funded from general revenue will become totally exclusive of Medicaid. In other words, DCF will no longer serve people who are served by Medicaid. This new policy would change and even reduce choices for persons on Medicaid whose services are now paid for by DCF. As we go to the capitated rate for Medicaid, there will be fewer dollars available for recovery-based services like supported living, supported housing, and supported employment for folks on Medicaid. If we lose those services, then outcomes are not going to be good. Since DCF has not yet actually chosen this change in philosophy, now is the time that consumers need to speak up.

Peter said that he was particularly concerned because many people in their supported living program at New Horizons receive Medicaid. He observed that this would be a problem for clients who want a less restrictive level of care and will not be able to take part in some services currently supported by DCF. John agreed that there would not be much left for Medicaid recipients, who are at the bottom of the pecking order as it is. “If you take those things away, you are going to have more people homeless and on the street, and more people decompensating,” he said. He wondered whether Medicaid recipients could get some kind of “indemnity program,” some alternative by which they could get some dollars towards some services.

Jan said that in South Florida there is a pilot program for the two counties that are trying out the new Medicaid plan. The Agency for Health Care Administration (AHCA) in Tallahassee provides choice counseling for Medicaid customers. Nine Muses had hoped that consumers could be trained to do the choice counseling, but that did not happen. “Using another agency to do this just adds another layer of administrative cost,” Jan said, and this can even prevent someone from getting Medicaid. Patrick said that AHCA has not brought consumers into the conversations in any meaningful way, and it seems to be the one state agency where we have had the least voice. The Florida Peer Network (FPN) did a presentation a few months ago to the Substance Abuse and Mental Health Corporation (SAMH) on the need for consumers to be brought into all of the AHCA discussions about changes to Medicaid services. One of our major points was that consumers need to be a part of AHCA’s choice counseling process. We have the

Summary Report, Statewide Teleconference May 16, 2006

support of SAMH and the DCF program office, but not with AHCA. “Perhaps that is an area for the FPN to focus on.” It was suggested that the executives of FPN could schedule a meeting with representatives of AHCA. Jan suggested that that the issue might be a good topic for a future teleconference call, and that we might contact Alan Levine, the AHCA Secretary. Patrick said that another needed topic of discussion with AHCA is the Peer Specialist program. AHCA has to change its language in order for Florida to allow those services to be billed through Medicaid. If we are to get AHCA to change their language, we need to start that process.

Another issue in expanding choices is the availability of mental health providers. Right now if a consumer receives fee for service from Medicaid, there is usually not a single private psychiatrist who will accept it. People now in day treatment are worried that they cannot stay in the program. Already in some places, visits to day treatment have been cut to two or three a week. “There are some folks,” he said, “who might become severely ill without the services that they have now.”

Several of the speakers expressed concern that the FPN teleconferences have not connected as well with consumers at the ground level as with the leaders who have participated so far. We also need to have Clint Rayner of the Office of Consumer & Family Affairs on the calls so that we will have the ear of the program office. Patrick agreed, and responded that we had rushed these calls because of deadlines from the program office. However, we invited anyone to participate. We invited people through all of the drop-in centers, and emails and phone calls went out to all everybody who is already on our mailing list. The FPN has the money to do more calls, and we need to do a better job at getting the word out. Sally suggested that FPN could use more marketing techniques. She said that two or three people in Highlands County have joined the Peer Network, but in order to participate they need something to visualize or some action that hits their heart, that affects their actual situation. The topics for these calls are good, but they are vague and general, and people who never have been involved in peer advocacy may not know how to relate to them. “As an example,” Sally asked, “What is that the people want to choose? What choices in particular do we have or not have?”

Patrick said that that people could interpret the topics however they wanted. For example, choice is a huge question, and there is not a community in this state where people feel that they have anywhere near sufficient choice in where they get their services and what services they get. John said, “Let’s face it, if the only doctor who takes Medicaid is filled up, or if you don’t happen to like the doctor, then you are stuck. You are not going to have a choice.” Peter said that in Stuart, people on the FACT team have access to their doctors, and others are able to get private physicians. However, the people in their supported living program and supported housing program are Medicaid clients. Jan wondered what would happen to all of these people when the new plan goes into effect and, they are no longer eligible for some services because they have Medicaid. Peter wondered what was going to happen to the revenue of the community mental health center, which depends upon revenue from these programs.

Patrick said that this is an area where consumers really need to make our feelings known, and we need to get much more consumer input. With so many people on Medicaid, rehabilitation services will become fewer and fewer, and less available to people, and people will end up on the streets and in hospitals again. This costs the state money, and it hurts people dramatically.

Summary Report, Statewide Teleconference May 16, 2006

Sally said that we ought to publicize this issue, and yell and scream a little bit. Jan said that perhaps DCF Secretary Lucy Hadi could suggest a couple of ideas for us. Patrick commented that people at the state DCF feel that, as Medicaid narrows its focus away from recovery and resiliency, DCF will have far more people dependent on these other services. The state needs to protect dollars in order to serve the people who do not have Medicaid. However, if they dilute services too much to serve a bigger population, then there will be fewer services for people.

Peter said that it is seen as easier just to provide services to people who are not on Medicaid. However, that does not make sense because the people on Medicaid are those who are in the most need. There are many people who may be Medicaid eligible but have no one to help them link to benefits. Street people in particular may not receive SSI and Medicaid. This could be another push of FPN as a consumer organization, and as concerned citizens, just to make sure that folks who are eligible are getting the benefits that they qualify for.

Access to Services for Individuals Without Benefits

Consumer leaders deal with a lot of people in drop-in centers and other elsewhere who do not have benefits. Faith-based communities take care of a lot of people who are not on Medicaid, and they are looking to the state for more dollars to help them.

Peter said that although mental health providers in his area receive funding and help people receive benefits, the people who aren't involved in those programs have trouble getting benefits. A lot of them end up with problems with the law, and they often go to jail. Sometimes they deliberately do a misdemeanor, so they will go to jail and get a place to sleep. Metropolitan Ministries in Tampa help a lot of these people, but there are lot of folks in jail who are not receiving benefits. One drop-in center traditionally helps people to find a way to access benefits. Unfortunately in Stuart some individuals in the mental health system are charged a fee for service. Fees for service are charged on a sliding scale for individuals who are working and do not qualify for Medicaid, but still do not have the finances to pay the fee.

Peter observed that in his area, most of the folks charged a fee for service are substance abuse clients, not strictly mental health. However, Jan commented that with the preponderance of resources that go to people with dual diagnosis, the emphasis is really on substance abuse, and not with just plain mental illness.

Sally said that in Highlands County the largest agency is Tri-County Human Services, which used to deal totally in substance abuse, but now includes mental health. She worked on the Triad Project, which included three issues—substance abuse, mental health, and trauma. The idea behind the Triad program was that all three issues should be addressed. However, what she found in practice is that mental health issues get short shrift. Most dual diagnosis clients prefer to say that they are an addict rather than a mentally ill person, and most treatment programs follow a substance abuse model, which is quite different from a mental health model.

Peter said that in his experience with dual diagnosis, a large part of the therapy does deal directly with mental health issues, and he participates in a combination of both. He said that that about 75% of people with mental health issues also have substance abuse issues, so he felt it is valid to spend dollars on dual diagnosis. Jan said that in Broward there is a co-occurring disorders group that meets every month, and what they are working on is called “no wrong door,” so that

Summary Report, Statewide Teleconference May 16, 2006

anybody presenting themselves at any one of these agencies can get treatment. The substance abuse people are learning more about mental health issues and vice versa. Patrick said that if an agency purports to treat co-occurring disorders, and they refuse to treat an individual who does not have a substance abuse problem, that would be an issue.

In Florida there is a new program called Access To Recovery that operates from a federal grant covering seven or eight districts. It is a substance abuse program that also deals with co-occurring disorders, and it works like a Self-Directed Care program. You get a substance abuse assessment in which you identify your issues, and then you are given money that you can spend for your treatment. If you have mental health problems, you can use some of those dollars for that. However, this program, too, gives a strong preference to substance abuse treatment rather than mental health.

John said that almost every community in Florida has a lot of AA and NA groups, and most of them meet at churches. But you very rarely find mental health support groups, and people do not pay a lot of attention to folks who just have mental health issues. "All you have to do is stop in any center and you can be referred to maybe fifty AA meetings going on every day of the week in that area. The plain vanilla folks who are just mentally ill find help more difficult to find."

Peter said that part of the equation is that the churches have more space available for meetings than do for profit and not for profit agencies. He said that he is familiar with two faith-based organizations for substance abuse in his area. These organizations funnel clients who enter New Horizons into benefits, but he has not come across a faith-based organization that deals strictly with mental health.

John said that Catholic Charities are the only organizations around Tampa that serve the Hispanic populations. They take people if they can afford a dollar for a session, and they have small affiliate agencies that send a therapist into the communities once a week or work in the migrant-worker section. They are making some effort, but they are totally overwhelmed. When people contact them, they refer them to services with other community providers.

Patrick said that a lot of this is fairly new stuff for the FPN as a consumer organization. Some peer advocates have been involved in organizations in other states that were far more proactive in providing services than in Florida. He suggested that there be a far larger role for consumers to bring people into the system, whatever part of the system they want to be brought into.

Sally said that she is looking for the Florida Peer Network to help consumers understand what is going on. When she worked in Fort Lauderdale, she knew what was happening in Broward County but had no idea what was going on anyplace else. Living in Highlands County, she does not hear about other areas. If more people participate in teleconferences, we can hear what is going on in each part of the state. She would like to hear of more services that are available to people. What do people need the most and aren't getting, and how they can they be hooked up?"

Patrick said that right now DCF contracts with mental health providers throughout the state, and all the large community mental health centers provide services especially for people who do not have benefits. When someone is not yet on benefits, or are not eligible for SSI, their services are paid for by the center's contracts with the state. District 8, for instance, contracts with about

Summary Report, Statewide Teleconference May 16, 2006

twenty-eight different services, ranging from outpatient services and med visits to case management, supported living, supported housing, and supported employment. People who do have benefits go to the same places, but their programs are paid through their benefits. As it stands, Medicaid will now pay your doctor and your therapist. However, if you want to take part in a supported employment program, Medicaid will not pay for that, and you must use funds from the DCF contract. That is why there are caps on how many people can use these programs at one time. The funding is always limited, and it never increases. Florida allows the mental health budget to become less and less each year just through inflation. Now state officials are talking about separating those two groups even more. They are saying, "If you have Medicaid, Medicaid is responsible for all the services you receive, and if Medicaid doesn't pay for it, you're not going to get it."

Sally observed that consumer-run drop-in centers provide a lot of the non-Medicaid services such as supported employment. She wondered how the Medicaid waiver and AHCA's new suggested regulations would affect peer-run drop-in centers. Patrick said that currently Medicaid does not pay for any drop-in services, and because of the cuts in funding and the restructuring of programs, DCF wants to realign funding and is emphasizing clubhouses. At the AHCA meeting, officials put some funds back into DCF, but even though they shifted some money, none of it was allocated to the programs that have been cut for the Medicare and Medicaid population.

Patrick said that most drop-in centers now receive some funding from DCF, either through a contract under their own 501C3, or through another group like the Mental Health Association, NAMI or a community mental health provider. Operating the drop-in centers is largely paid for by the state, but a lot of drop-in centers try to raise independent funding. They work with their county governments, apply for grants, or run consumer-operated businesses. Theoretically, the Medicaid changes will not affect the drop-in's, but more people will need these programs if they have fewer recovery services available to them. If any of the recovery supports that we have built over the last ten years are cut, then more people will be in need. Consumers will turn to alternative services provided by drop-in centers, including peer-run supported employment, housing, and general case management services that the community mental health centers will not or cannot provide. The consumer-run drop-in centers will not get any more money; they might just get more people coming.

Access to Medications

One of the ways that changes in Medicaid will affect the mental health system is access to medications. Medicare Part D has introduced another large group of people eligible for Medicaid and Medicare, and their life has changed drastically.

Sally said that in Highlands County there used to be a program that provided support to consumers and that negotiated with the pharmaceuticals for free or affordable medications. For some reason the introduction of Medicaid Part D put this alternative service out of business. Now many of people who used the service are eligible for benefits under Part D, but they have found that receiving medications and support has become a nightmare. A friend of hers got a notice that she has spent her limit for medications, and now has to pay for them. Recipients are allowed \$2250 in benefits, but when that is used up after three months, the benefits cease. From \$2250 to \$5000 they have to pay 100% of the cost unless they are dual Medicaid/Medicaid eligible.

Summary Report, Statewide Teleconference May 16, 2006

Some people say that Medicare Part D benefits some people, because if you were only on Medicare before, medications were not covered at all. But it is the people who fall in the middle who are in trouble because now they have this limit to contend with. Most have been charged for medications that previously were free. Some are about to reach their transition limit of benefits and now must pay a huge amount from their own pockets. John said that he has seen several people who have to rely more and more on the pharmaceutical companies to get their supplies directly. They have to work hard in a lot of ways to get medication, because they have such tremendous bills—\$1,100, or \$1,200, or \$1,400 a month is common.

Sharon said that she had benefits under Medicaid when she first moved from Michigan to start her new job. However, when she arrived in Florida, she was switched to Part D and thrown into a program that covered none of her medications. Fortunately, she was able have her sister pick up samples from her doctor in Michigan. Otherwise, she would not have had medication for the first three months of her employment. She called Medicare about these issues, only to learn that, with Medicare Part D, the pharmaceuticals had cut out their needy meds program because they said that Medicare was picking up the cost of drugs. Sharon added that she is now on private insurance, but because she is still Medicaid eligible, she is still trying to navigate the plan. It is advertised that you can go to the website, and it will match you up with the proper plan. She has not yet been able to accomplish this.

Patrick said that it supposed be possible to sign up for Medicare Part D within one thirty-day period, but he does not know anybody who has been able to do it. The people getting switched from the medically needy and from dual eligible Medicaid and Medicare are having trouble getting their meds. Jan said that people in Part D have what are called small co-pays, but when a consumer has to take have several medications the cost becomes prohibitive for them. When they went to Medicaid before, it did not cost them anything. Now they have to pay \$25 or \$50. Sharon noted that a lot of retirees have private medical plans, and it is people with disabilities who are most adversely affected, especially people who were strictly on Medicare. She was on Medicare for the last eight years, but did not need it until her husband was laid off and they longer had insurance. At that time she qualified for Medicaid. “Then when it switched over to Medicare Part D, I went to the pharmacy and gave them my card, and they came back with a bill, saying that none of my medications were covered—not one, not even my blood pressure medication.”

Patrick said, “We have got a whole group of people who go back to work, but very often have to work in marginal jobs that do not have benefits. And we are only allowed to keep that safety net of Medicare or Medicaid for so long” Jan said, “Or, you don’t even try to go back to work because of your fear of losing that safety net of Medicare. Many people are afraid that they will make over the \$800 a month. If you make a dollar over that, you fear for your benefit. They thought that the Medicare Part D was going to be a great thing,” she added, “but in reality it harmed the people who could least afford to lose their coverage.” She said that she knew of people who still have not been able to get the medications that they need. Some people have had to use their credit cards to buy medication at full price. “Some of these problems have been straightened out,” she said, “but you really need to be able to advocate for yourself to straighten that out. Not everybody can advocate for themselves.”

Patrick again reminded the group of the people who have no benefits at all. The state funds the indigent drug program (IDP), but that program is limited, and only so many people get enough

Summary Report, Statewide Teleconference May 16, 2006

help. “We end up with folks on the street who might want to take medications, but because they have not been linked to benefits they are out of luck.”

Jan said that that the public needs to consider why people do not take their medication. One reason is that it is not affordable, so they self-medicate by smoking marijuana, for example. She said that she has worked for twenty years and has experience navigating the system, “but if you cannot advocate for yourself, and you don’t know the system, how can you do this? People do not have access to the Internet, and to providers that will assist them. I know one lady who just did not have it in her to continue to fight to get services; it was just too much for her. So far she is managing, but managing is not the same as recovering. What’s ironic is that they talk about all these programs—what Medicaid is going to do, and what DCF is going to do—when the truth of the matter is that the people who need help the most are getting dropped by the wayside.”

Sharon said that when a representative from Medicare Part D told her how wonderful the program was, she pointed out that all of their advertisements were geared strictly towards seniors. There was no advertisement that said, “Are you on disability? Then you can come in and sign up with us.” Patrick agreed that discrimination pervades that system. For years, people on Medicare through disability have not been eligible for the additional coverage a retired person on Medicare can purchase, and mental health consumers have co-pays for services. Some doctors drop the co-pay—if you can find a doctor that takes Medicare. Sally commented that government programs like Medicare contribute to the invisibility of poor and disabled persons because the public does not hear about how the program works for persons with mental illness. The public does not know, and even consumers do not know, what’s going on in the rest of the state. The only way to get around that situation is to talk to each other and bring it out in the open. She suggested that the role of the FPN is to make us visible.

Jan said that she felt that consumers in Broward were fortunate to have a supportive program office that is consumer focused and has always listened to the consumer voice. However, John said that this is not the case in a lot of areas of the state. There are providers who have been in the mental health system for a long time and do not see recovery as a possibility. Until you get such people to see recovery, they will continue taking their clients for granted. They need to understand that if people get better, they will not run out of clients, because the market is not decreasing. The job of FPN is to beat down these barriers. FPN members are examples of people who have gotten better through trials and tribulations, and who have reached the point where they can participate on this call. “A lot of our peers are not yet at that point, but as we go along we can get more people talking about these issues.” Sally said that the FPN should continue working to find sympathetic voices. It is important to get the real truth out about Medicaid Part D. Many people have been helped, but the people who are benefiting the most are the pharmaceuticals, the corporations, and the people on Medicare who already have resources. The people in the most need are not being heard—they are rendered silent.

Self-Directed Care

Patrick said that the original Self-Directed Care program was started in Jacksonville, and he is the coordinator for Self-Directed Care in his district, where they have been doing it for a little over a year. The Jacksonville program was designed by a group of consumers and family members. It had some growing pains and some problems with the state legislature because some people looked said, “You can’t let mentally ill people decide how to spend their own money.”

Summary Report, Statewide Teleconference May 16, 2006

But it has been an amazing success, both in Jacksonville and in District 8. Using Self-Directed Care is simple. People figure out what services they need, work on their own treatment plan, and do a life action plan. They decide what they want to accomplish, and they choose activities that will increase their quality of life and help them recover. Each person is given a budget based on their choices and their benefits. If they have Medicaid, they will get a budget just for recovery supports. That they may choose to go to school, or they may join a gym or go to Weight Watchers. They can define their program in almost any way, so long as that they can make the case that this will help in their personal road to recovery.

The program was set up by looking at the services people already received and calculating an average cost per person. Services that were paid by the state and not Medicaid averaged a little less than \$4,000 a year, not counting crisis visits, hospitalizations, or residential programs. Approximately 50% of that money is earmarked for traditional mental health services such as doctors, counselors, supportive employment, or supported living. The other 50% is used as enhancement money to support personal expenses such as school, rent, or paying the light bill. In each case, the client describes why the service will help them to recover and works out a schedule for how to pay for it within the budget. “It is very simple,” Patrick said. “People do best when they decide what they need for themselves. This is where a lot of mental health care needs to go. Hopefully the state will agree.”

Patrick said that District 8 wants to double and triple their Self-Directed Care program so that more people are eligible for it. The legislature has approved the expansion of Self-Directed Care into more districts next year. What is needed now is for DCF people on the local levels to go to Tallahassee and say, “We want that in our district.” There is no new money for this program, but it can be accomplished by transferring money from existing services. In the beginning providers may fear that they will lose money from their programs—but if a provider does a good job, the client comes back and continues to purchase services. For instance, most people who start Self-directed Care continue to see the same doctor. They get more confident as time goes by and they see that they are making good decisions. Part of the process is learning to make these decisions for yourself. There is no case management or resource coordination involved in Self-Directed Care—you are your own case manager. You do have access to a “Life Coach,” who works with you from the beginning to answer your questions and help you figure out your own plan and to make good choices. “People need to be able to fail sometimes in order to succeed,” said Patrick, “so you let people make decisions, and they learn from their decisions. Part of the recovery process is becoming empowered to understand what you are doing.”

Self-Directed Care could be the natural progression for mental health services. Ideally, 50% of all services should be offered through Self-Direction, where people choose what they want and how they buy it. Everyone who is eligible for mental health services could be eligible for Self-Directed Care. However, they need to be able to develop their own treatment plan and action plan. That is a tedious process in the beginning, because a person has to do a lot of self-analysis to be ready for that step. Nevertheless, in District 8 some people come directly from FACT teams or from case management, and some people come who have not had any services in awhile. There are people from virtually every level of the recovery ladder doing Self-Directed Care.

Some people need more help than others. For instance, if a client in Self-Directed Care has an emergency, they can purchase crisis services for a period of time with part of their budget. Most

Summary Report, Statewide Teleconference May 16, 2006

people are at their most vulnerable when they just have gone through a crisis, so they may choose to have a case manager for a limited period of time. This really depends on the individual. Self-Direction is a flexible, simple kind of concept that makes sense.

It is recommended that the Peer Network support the expansion of Self-Directed Care across the state. The FPN is in a good position to do this, because a key to success is that the group that runs it cannot be a service provider. Brokers acting as life coaches need to be truly independent of operating funds so that they will not have a conflict of interest, and the best independent broker is a consumer-run organization. When District 8 set up their local program, two of the three people hired as life coaches were consumers who had worked as Peer Specialists with FACT teams and as Peer Counselors. Peer Specialists can work effectively as coaches. With the type of training that they have had, it is a perfect progression in their careers.

Conclusions

John remarked that many mental health providers would be apprehensive initially about consumer-operated services because they would feel that their own funding was threatened. They might feel that they know how to do things, and that there is no other way to do it. Further, the state has to figure out how Self-Directed Care fits in. Officials might think, “Hey, we have a little Self-Directed Care, a little clubhouse, a little drop-in center, a little day treatment. Can’t we have just one thing?” However, the more choices people are offered, the better off they are. The state needs to recognize that not one size fits all. To learn what consumers need, they need to listen to those who use their services.

Jan said a program in Broward County called AmeriCorps trains volunteers work in different drop-in centers. It is like Self-Directed Care, she said, because they try to help a consumer to set a goal, and they help them try to achieve it, no matter how crazy it sounds. Patrick mentioned a program in District 8 called Personal Outcome Measures that is a satisfaction program. A consumer is interviewed from one to two hours, using twenty-five indicators about quality of life. People are asked about whether they have goals, and what their goals are. A number of the first candidates trained to do the interviews were professional mental health counselors. When one of them asked a consumer, “What’s your goal?” the person said that his goal was to move to Australia. The mental health counselor said, “I can’t support his moving to Australia. He doesn’t even have enough money for toilet paper!” The counselor was told that he missed the point. The job coach can help the client with other issues if he chooses to be helped, but his goal is to move to Australia, and you cannot change that for him.

John said that other states do not have the same issues as Florida, and most have more money. Patrick commented that Florida is a tough state since there are vast rural areas where people have to travel for miles just to get services, and there is no community transportation. Transportation is an issue that will always up the top of the list. Florida is also difficult because of its geography and its many different cultures. In the future FPN will address cultural diversity and how to accommodate that within the consumer movement. On another call we should talk about FACT teams—what’s good about them and what’s not working, and how they can become more useful to people. Patrick asked everybody to join the next call at 3 o’clock on Friday afternoon.