

Interview with Improving the System of Care: Florida Epilepsy Team

Title V Director, Phyllis Sloyer and Project Leader, Judy Clauser

Question 1: At the beginning of the Learning Collaborative, what did you hope to accomplish?

Judy: “Initially, one of the goals of the LC was to improve communication between primary care providers and specialists. But, here in South Florida, the majority of the families that we serve lack primary care for their children due to the fact that they lack health insurance. 12.5% of Florida’s children lack health insurance, which is higher than the national standard. The goal that we recognized as our local need was to help these families access health insurance so they could provide primary care for their children.

The Epilepsy Foundation in Florida is unique in our provision of services. We provide direct medical services through clinics—we have children who are our clients, so they get very good neurological care, but they were going to the Emergency Room for primary care.

Another factor to consider was that a great many number of the families don’t have legal status. 30% of the children do not have legal status. And that was a huge problem for us.”

Phyllis: “Our goal is to make sure that children have access to services, however that needs to be accomplished. Children receiving services from the Epilepsy Foundation are part of a bigger delivery system—and should have access to that system. We know how it is organized and how to plug people into it. Our work is all about connecting the dots.”

Question #2: You’ve done an incredible job increasing access to (Title V- CMS) insurance. How were you so successful?

Judy: “I think we were fortunate that we established a really good working relationship with our state Title V director, Phyllis Sloyer, who understood our problems and who was very interested in actively working with us to provide insurance to this target group. We were able to establish this connection from early on and everything else trickled down from the top. She came here to Miami (several times), set up meetings with the regional nursing directors to create our program.

Many of the families would qualify, but were unaware that the opportunity existed and the enrollment process was cumbersome. It was very difficult to navigate the system. We did tests of change- when we first met with the CMS people, we gave them a list of people that we thought were eligible. In the past, we had case managers try to enroll these families, but the families were denied. Collaborating with CMS, we gave the list to the CMS eligibility determiners—who reported back to the EF when they were unable to contact families. In turn, our office was able to provide the outreach component, and invite families into the office to deal with eligibility. The clients felt more comfortable coming to our office dealing with people that they know. We learned that the most successful way to enroll families was to invite a CMS determiner into our office once a week to conduct the enrollment process. Many of the families are Spanish speaking, so the case managers are part of the process as well.”

Question #3: One of your greatest accomplishments is the implementation of USB flash drive—by the end of April 2009, 100% (114 children) will have access to care notebooks and flash drives containing their pertinent information? Have the flash drives been well received in the medical community? What are the barriers of implementation? How does this form of information benefit these children/youth?

Judy: “Our original case load was 77 kids, 20 of whom were our tests of change. We now have 125 children enrolled and 13 waiting for appointments. The success is attributed to the outreach that we’ve done with this program. We have 47 completed care plans, including test results that have been downloaded on the flash drive. It is very time consuming process, but we’ve received all positive feedback. We learned that care plans have been used in schools—even in the cafeteria. A care plan listed an allergy to a certain food to alert the mom because it was in something that was going to be served. We are hoping to start surveys next month.

As we are starting connecting families to a medical home, the parents take the information from the flash drive and give it to the primary care provider. The care plan provides a history of the child for a starting point. These are kids who have no medical record- only neurological. One parent reported using it in the ER. Our biggest fear was: would providers be willing to put a personal flash drive into their clinic system? So far we haven’t had any physicians or facilities that have refused to put the flash drive into the system.”

Follow-up to Question #3: How are the flash drives presented to the providers?

Judy: “On one side they say “Epilepsy Foundation” and the child’s name.

We go out and do presentations on our program, and everyone says, ‘What a great idea! I want to do that!’ It is useful for everybody to have. For us it was the simplest way to provide the information to primary care providers. We knew improving communication between primary and specialty care would be a huge challenge. The care plans are a simple way to share information. The process of coordinating the information is time consuming, but a simple idea that works. That’s something that I love about the Learning Collaborative- it’s about the simple things, once you have the concept.”

Question #4: Please tell us about your experience working with your State Title V Director, Phyllis Sloyer. What role did she play in the success of your team?

Judy: “Without the engagement of Title V at the state level, we wouldn’t have been able to make the changes that we made. We are able to implement system-wide changes; sometimes an idea is great, but if you don’t have the buy-in from the top level people you can implement, but here it worked and we were able to make such positive changes in families’ lives.

We have open lines of communication—we were fortunate that Phyllis gave us her time and attention. She made time for this, and the fact that she came down and met with the local level leaders—it is so important for communication to trickle down from the top.”

Phyllis: “After the second learning session, I said to Judy, ‘Let’s have a dialogue; I need to come and talk to you.’ I actually flew to Miami. When discussing what the lay of the land is, I really prefer face to face discussion. To be honest, I made the effort: Florida is a big state! Frankly, it was nice to meet the local folks as well. In other states, the Title V Director, may not have any relationship—and there may not be a local Title V person. And if that relationship does not exist, it is crucial to find connections in the health department, and bring those people to the table. I knew the system well enough to recognize that these kids should have access, I knew where they could get their primary care – and I wanted to make sure it happened.”

Question #5: In your collaborative experience, you’ve done an excellent job of engaging parents in the work. Why is parent empowerment so important?

Judy: “Nobody knows their child’s needs as well as their parent. The parent is the primary care giver, and we need to provide them with as many tools as possible so they can do their job well. I can relate, because I was the care coordinator for my son. He needed to see so many specialists, and they never spoke with each other. When this program came along I thought- they really get it, they get what parents needs.”

Question #6: With Learning Collaborative B gearing up, what are you looking forward to? What do you hope to accomplish in the next round

Judy: “In year 1, 98% of the families were of Hispanic decent. Now we are really looking to outreach to the Haitian community. We are starting a series of presentations to the Haitian Physician Organization in the area (made up of 20 Pediatricians). We are hoping that they will invite us back to facilitate discussions and presentations on epilepsy. It is our hope to gather feedback, and develop a great working relationship. Ultimately, we would like to successfully outreach to all of the other community health centers in Miami. It is important to reach children who aren’t already part of our clinic, and to provide the same services to them (access to primary and specialty care).”

Phyllis: “Eventually, they want to be able to go beyond Miami-Dade, or go farther out with the foundation. My goal would be to assist Judy in whatever fashion she needs my help in. Connect in counties, bring more providers in...”

Question #7: Tell us about your experience working with NICHQ.

Judy: “I learned a lot in this first year. I was unfamiliar with many of the processes; the Learning Collaborative was new to me; the term medical home was new to me (and everyone in Miami!); the change package was new too, and certainly PDSAs were foreign to me. Even though I felt that I was so knowledgeable about the needs of families with children with epilepsy, when I read the measures, it made me aware of things that we never thought of here.

Through the extranet, learning sessions, and monthly calls it facilitated wonderful networking with other projects around the country that are doing similar things, so we are able to learn from one another. We took a lot of materials from previous grantees and adapted them to our population. I am grateful to

those who went before us. For example, the sharing of one adolescent behavioral check-list that was made available in any language that you could ever want, has had a huge impact. We started implementing the tool with our case managers. This checklist made it easy for the neuropsychologist on staff to uncover any possible issues—and we were able to refer kids for further evaluation. It is a very simple tool that is very effective. NICHQ has been so helpful with providing simple tools to implement – and they’ve made a huge difference in the outcomes.

What we are doing is making such a positive impact in families lives; it makes staff feel so empowered. Half the staff is coming to the meeting on a Saturday night because they love this program. We are hoping to be able to sustain and replicate throughout all of our offices. That is our hope in spite of drastic funding cuts.

One of the things that was helpful to me was name-dropping, “HRSA, NICHQ”, it has made a huge difference and it opened doors for me. A federally funded program being done around the country, and people know those names and they listened.”