

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

October 14 - 17, 2007

**State Medical Home Promising Practice Models: Partners in the
Medical Home for Children and Youth with Special Health Care Needs (CYSHCN) in
Pennsylvania and Florida**

DAVID WOOD: You know, good luck. And they just did not have any good -- a way to transition to adult therapists and that sort of thing.

So there are some -- there is a lot of issues around barriers that -- there are many different barriers for transition. Here is a list of them, and I think the list of barriers nicely summarizes kind of the approach that we are taking. We try to address these barriers with our program, our Medical Home for Transition.

The poor hand-off is we are trying to educate pediatricians and get information into their hands about how to make a referral, a very specific referral, so that you can make a good hand-off. We need to get to the point where we have like kind of like a countdown for like

a year before, two years six months before, give special information. We are not quite there yet. But we need to improve the hand-off. We need to improve our adult healthcare system as I've alluded to. There's lots of barriers there.

The youth themselves and the families are not prepared for transition developmentally, we'll talk a little more about that. There are a lot of challenges in this age group, especially if you have a complex disease, but letting go of their pediatric system, getting into the adult care system, is a culture shock. I'll address that a little bit more. The organization of care is very different in the adult side. And like I said, the developmental level, we'll talk more about that.

Limited access to support services. Many different diseases funded through federal programs or state programs have lots of support services for children with sickle cell, with other special healthcare needs. And when you hit 21, those go away, they just stop. And there are some innovative programs around the country that have picked up where those programs have ended, but not very many. We're having a discussion now in Jacksonville, we have a large sickle cell population, a large African American population, there's no program -- we have a wonderful sickle cell center, and great coordination, and social services, and special primary care, and special integrated specialty care, and then when

they hit 21, there's nothing. There is no primary care providers that specialize in this, there's no coordination, and we are trying to organize that. So there really is a lack of support services once you get into this young especially the 21, but even starting at 18.

And I think you've all probably seen some of these articles that compare the culture of pediatrics to adult care. That's part of the barrier. I think it's a barrier for a variety of reasons. Sometimes the pediatric culture is -- holds people back from transitioning. And independence, we really work on independence in our program and that's really not -- you know, the pediatric program, I should say culture, is more to work with families. And sometimes when they come into our program we have to say, Well, we have to ask the patient permission to share it with the parents what the issues are, because they are in control once they are 18, they are independent adults. So there is a little bit on both sides.

The adult healthcare system is basically pretty much you're on your own. If you don't show up to an appointment, you won't get a phone call from a nurse care coordinator saying, "Why didn't you show up? We are worried about you." So.

Insurance barriers are huge issues. This is a huge policy issue we need to address. At 18 to 24 years of age is the highest uninsurance rate for people under 64. You can see the insurance rates, 30 to 40 percent uninsured for this age group. And interestingly, if you have a special healthcare need, it doesn't necessarily go down, your insurance is about the same. So you may have a very serious disease and have no insurance. We have diabetics, many, a number of children, youth and adults, with diabetes that have no insurance. And fortunately there are some drug programs with the companies that we can get them insulin and supplies, but it's really quite difficult.

The reasons for loss of insurance are kind of complicated. It has to do with whether you're on public or private insurance. But parents, your eligibility if your parents' insurance oftentimes depends on if you're in school full time. Many youth nowadays are not doing school full time, only about a quarter of youth are doing school full time. They do part time work, work for a while, go to school for a while. It's a very different trajectory now for even folks that are quite functional due to the fact that school is very expensive now. So they may lose their insurance because they are out of school for a while.

Public insurance, Medicaid ends at age 18, Title XXI at 19, our Title V, special insurance which we in Florida call Safety Net ends at 21, and we really depend on that. Sometimes

they can get Medicaid and keep it if they're SSI eligible. The SSI rules change at 18, so that you go from a functional criteria, if you have diabetes or asthma under 18, you can qualify for SSI, but after 18, it's extraordinarily difficult to stay on SSI if you have diabetes, even if you have very severe diabetes, because they have this any gainful activity clause which means if you can work at all, you will not get SSI. And therefore you'll lose your link to Medicaid.

So there's a lot of reason insurance is ending, but the other big reason is that youth at this age, if they are employed, they are working at jobs that don't have benefits. We have many youth in our program that are working 40 hours a week. One for a company that our mayor owns, and he has no benefits. He's working 40 or 50 hours a week and he has no benefits. I didn't say that. You didn't hear me say that.

Anyway, so -- and I think one of the interesting things about transition -- thank you very much -- is there are really interesting trajectories through transition. All these things complicate it, obviously. But they are I think the three -- we are just thinking about this now, so we don't really have any deep, profound thoughts about this. But the youth that have one organ system disease, it's pretty easy for the adult system to take care of, like

asthma, insulin-dependent diabetes. They are relatively easy, but they may be complicated by other factors such as social and insurance.

The health conditions that kind of arise in childhood like cerebral palsy and spina bifida. Those are more complicated, and the adult healthcare system really is not prepared to take care of them. Cystic fibrosis solved this by the foundation forming a huge foundation and funding centers that now provide lifetime care, but that really happened outside the healthcare system. We really need to look at what cystic fibrosis did and do that in many different diseases. And they've not only created systems of care across the lifespan, but really, quality of care measures and all kinds of great things, 90 percent of which happened outside the healthcare system, holding our system accountable.

And I think a special case and a particular interest of mine is developmental disabilities, people with intellectual disabilities, just because of the systems they access, because of the supports that they need, their ability to interact with the healthcare system, they have a different trajectory. We work with families when they are 22, 26, and obviously they are oftentimes dependant on their families for the rest of their life, many of them, not all of them. But they do require special services. And I think again, our adult healthcare system, there are some good examples around the country, but generally speaking they are not ready to take care of those folks as well.

And I think one of the most fun thing about transition is the developmental challenges that the youth themselves experience. You know, developing social skills, doing a history with someone who's in transition really depends -- how much you get out of the history depends on what developmental stage they are in. And the developmental stage doesn't necessarily relate to age very well. So you can have someone in early adolescence, very concrete who is 19. I'm still in middle adolescence myself, so. Late adolescence, you know, late adolescence, they start to take a lot more responsibilities for their actions. They start to see the connection between using insulin and getting sick and saying, "Oh, gee, I've got to do something about that." A lot of times we'll get them from the pediatricians who've just kind of thrown up their hands and said, you know, "What are we going to do with him because he's totally noncompliant or no adherence," that's the proper term. And we've gotten them after a couple of years of very difficult health problems. When they get the transition, and usually they come to us late because they are not very adherent and they are not very compliant. They're starting to realize, "This is going to have a very serious impact on my life. If I don't get my act together, then I can't get to school, I can't get a job, I can't do these things." And we have oftentimes the real fun opportunity to help them learn self-management when they are at the end of that developmental kind of change. If you're in the middle of it, you just have to wait on them.

You know, we have a no-show rate in our clinic that sometimes approaches 30, 40, 50 percent. We talk about it and go, you know, do we tell this person you can't come back because they are using up some resources of ours, or do we wait for them to keep developing? And so we have that debate. Anyway, it's a very interesting discussion.

I won't -- this is the same slide you've seen several times today, I won't go through it, but it is our model. And I think the more I've thought about Medical Home, the more I like this model, and we won't go through it. But we do try to apply this model to transition, and all of these issues are quite important. And they have different spins on them. In the resources in the community, we access the junior college heavily. They are a terrific resource for us. They'll help us to do educational assessments they help people who have left school and help them get a GED, and a lot of times they give kids a direction in life. And also about vocational rehabilitation and these sorts of things that other pediatric services might not access, we use in the community. And the delivery system design is quite different because we are kind of bridging the two worlds, and so we are actively -- with any given person in transition, they may be accessing a pediatric specialist and an adult specialist at the same time. It don't all happen at once, the cardiologist will hold on to them until they are 25 or 30. Many of them will release them at 18. So it really depends. So our delivery system design is quite different.

The decision support is quite interesting in that most guidelines are written for either adults or kids, but the guidelines don't necessarily agree. And one example is sickle cell. What do you do with a person who is 18 or 19 who is on chronic transfusion therapy? You know, the data is not there to say, here is the guideline for that person. The adults don't do it. The pediatricians do it. And when do you stop it? Nobody knows. So when you're in that transition phase, setting decision support and setting up guidelines, what we've done is we bring the pediatricians and the internal medicine specialists together and say, "What do you think we should be doing?" How do we review the literature and decide, because we want to make sure taking-- the pediatricians want to make sure we are going to do what they did, and the internal medicine specialist want to make sure we're going to do what they want to do, so we have to kind of coordinate the care, and it just adds an interesting dimension to it for care.

Here are the family goals -- I mean the goals for transition. We break them down into three basic areas: Managing their own health, and this -- I kind of rewrote this slight, but this is my older slide, but I think managing their own health is one area. Managing their health care is a second area. And then other vocational goals and objectives are the third area that we are starting to break it down into these three areas. Jack's Hat is a medical

home, we provide these services. I won't read them. We provide the primary care, we provide the care coordination, we have a nurse care coordinator, we have a social worker who actually acts as our project manager as well, and we plug them into services across the different systems of care. And we actively encourage them to set goals for their transition, whether it's vocational goals, educational goals, independent living goals. We have had family conferences where we talk about where is so and so going to live? How are they going to transition out on their own? And what will that mean for their health and healthcare?

Here is a list of patients, just to give you a feel for the variety of patients that we have, and we are trying to set -- kind of look at the plan of care and how the transition trajectory should work and how you make the system work. And a lot of it is fairly disease specific. There's a lot of cross-disease as well. And those are a little bit older numbers, we have more now, but the --

Again, this is a multidisciplinary clinic within internists, a nurse care coordinator, program manager. We are actually using an Americor volunteer and that's a terrific addition. All the phone calls, all the things, they are a fairly inexpensive person, she's learning a

tremendous amount and she's actually almost the age of our patients, so she can relate to them in ways we can't.

We act as a liaison between the two worlds. We act as a broker oftentimes. I found that the adult specialists that are reluctant to take a patient, when they know that we are going to stay involved, that we are going to be the first line of defense, that we have 24-7 call coverage, they won't be called first, they are usually pretty interested in taking them at that point. So we oftentimes have to make that link and that broker.

We also, as I said, link clients to outside services and have an advisory group that has all of these different DD related advocacy groups so that we are trying to link them into the community as well.

We do a formal kind of readiness assessment, and that's something that we are in the process of developing. We educate them on disease self-management, and we have a questionnaire that assesses where they are. How much do they understand about their own disease, the medicines they are taking? How much do they understand about how to interact with the healthcare system to talk to doctors by themselves, nurse, make their own appointment, keep their appointment, get to the appointment, that sort of thing. So

we use that transition health assessment tool. We actually score it. We looked on the web and we looked at other programs, we didn't find anything that was really validated, so we are kind of in the process of really validating our own tool. And I'll show you just really quickly, I think this slide says it: Disease self-management, independent healthcare utilization, and progress toward life goals. Those are the three areas. We look at them as kind of a stages of change model which is, I don't know if you're familiar with that behavioral theory, but it's been used in smoking cessation and lots of other things. It basically has these five levels where you're not even thinking about making a change, you're contemplating making a change, you're preparing to make the change, you're doing something about it, and then you're maintaining your change. And this was first used with addictive behaviors, but it's used for a lot of things now in terms of promoting behavior change. And we kind of think of this transition period using this behavior change model. The ones on the far right are kind of the responses that we've used. And we've ask them, Do you know how to use your medications? This -- I don't need to do this, and sometimes they say that even though they do, so they are kind of not even aware of the need. I don't know how to do it, but I intend to learn. I'm learning how to do this. I've started doing this. And I always do this when I need to.

So we ask them a bunch of questions about, you know, how familiar are they with their health and healthcare, and how directed are they in other life goals? And they kind of rate themselves. This is our questionnaire, here is the question, it's accessing medical care is one of the questions, and then they kind of put themselves on this continuum. And we try to look at that, how are they doing on that. We actually rate them independently without knowing their own score, and we then talk about them in a case conference and say, "Well, gee, this person is doing everything. They are coming to the appointment on their own, they know how to manage their own health issues, they have insurance and they know what it's for and they know how to keep it, so let's send them off." So that's kind of when do you send them on for transition is basically based on this kind of assessment. We are open to other ways to think about this, but this is the way that we've come. This is an extremely busy slide, but it's kind of our logic model for this. But it's just meant to point out that there's two levels working on the client level, client family and then the system level. And we kind of have process measures we are working on the client level. We are also trying to work with the systems and make them work, and ultimately that will lead to good healthcare utilization, good outcomes, health outcomes and other life outcomes, and then optimal health. It just kind of keeps us focused.

This is our website if you're interested, it's in your handout. Please check it out. It's a work in progress. There's a lot of interesting websites being developed on transition by the way.

I want to turn this over to Phyllis Sloyer who has been tremendously supportive of our program. And again, without funding from the Title V agency, we would not be doing what we are doing.

(Applause.)

(End of Segment.)