

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

October 14 - 17, 2007

Youth with Special Health Care Needs (CYSHCN)

DAVID L. WOOD: I'm happy to be here to present our transition model, medical home for transition; medical home being kind of the theme of this session. I have the key collaborators down here. I'll start at the bottom: Children's Medical Services is the Florida Title V program. And this project would not be in existence if it weren't for the, I think, close collaboration and funding from that program.

In the Jacksonville area, Jacksonville is about a million people, 1.2, in the bigger metropolitan area, and we brought all the pediatric or children's health leaders and take holders together several years ago, three years ago, and did a planning process and asked what are the critical issues facing children in our community.

And the two big issues that came up was transition and mental health services, which mental health is no surprise to anybody, I don't think. But that's what kick started our

transition program. And we decided we'd look at models out around the country, look at what issues they had incorporated into their models and we came back through a community planning process with all the stakeholders, which are very important stakeholder was the American Academy and our local chapter, which is quite active. As well as other providers of services for children. And we came up with Jacks HATS. Jacksonville Health and Transition Services. I'm most proud of the name. Everybody loves that. We used to have the party hat, but the PR people got rid of my party hat.

Anyway, this is the definition of transition. The top is the Society for Adolescent Medicine. The bottom is Healthy People 2010, which I like better because it goes beyond health care services and ensures that youth with special needs receive services necessary to transition to all aspects of adulthood.

I think that's a very important aspect of our model is all aspects. While we're getting prepared to do healthcare, most youth and most people don't do, don't take care of their health just to take care of their health they take care of their health to participate in other aspects of life.

I think what we see in the youth when they're goal directed and they have some employment or vocational goals or real reasons to get up in the morning, then their adherence to medical care is much better.

I think one of the aspects of this program is that it's a collaboration between pediatrics internal medicine. There are many ways to do this. And I think like Tip O'Neal said about all politics is local. All healthcare is local.

You have to look at your local resources and decide who your partners are going to be. I'm in the university and I looked around the university and there's a variety of reasons why we situated in the university. The major one of which is there's no barriers to seeing Medicaid individuals. Adults or children. So it's a nice network that accepts Medicaid.

So we partnered with internal medicine. We could have partnered with family medicine but I think the partnership with internal medicine was critical because they're the ones with the linkages to the adult specialists much more so not that family medicine don't have those linkages but the internists really have the linkages and have many of their specialists in their departments. So it's been a really critical link to link with internal medicine.

Why transition? I'm preaching to the choir here. You guys know that all of the diseases that used to have very limited life span now have life expectancies into the 50s and 60s and 70s. So sickle cell disease is just one. CF is a great story. But almost every one of these conditions that we now screen for at birth or treat even the very complex ones have life expectancies well into adulthood.

And I gotta tell you although we've known this for 20 years, our healthcare training has not caught up to this. The adult providers are not trained to take care of cerebral palsy or spina bifida, they just aren't. And that's been a fun part of the project is to work with the adult providers and bring them some training.

We did grand rounds a month and a half ago on the care for the adult with cerebral palsy. And they loved it, because they really hadn't gotten that much. There are now more adults with cerebral palsy than there are children with cerebral palsy. There are now more adults with congenital heart disease than children with congenital heart disease. This is an issue that's going to get bigger and bigger and bigger, and I think our education system has to be kind of radically revamped to address these issues.

Spina bifida is another one that's a very complex disease. We're very fortunate that we have a urologist who is particularly interested in spina bifida. And we have a number of other adult specialists that are interested in taking care of our patients with spina bifida.

These are the -- again preaching to the choir. You know the statistics on the number of youth with special healthcare needs. About half a million children -- there's debate about that number -- age out, become adults with special needs every year.

Locally, I think the smaller number that need really fairly intensive transition services, so instead of 12 to 15%, maybe three to five percent. If you look across the transition age span, in our area, as many as 4,000. That might be a little bit large, but across that transition age range, a fair number of children and youth and young adults emerging adults is a new term, need, I think, some special transition services to be able to make the transition.

Well, how are we doing with transition? There isn't a lot of data on this. But the National Survey for Children with Special Healthcare Needs had some questions about that. The previous speakers alluded to this. Are pediatricians talking to their folks? Actually their data came from medical homes. This was a national survey.

So I think the national survey they found fewer that actually had discussed transition with their pediatrician. About half, only about 15% had some plan. Not necessarily a written plan but some plan on how they're going to go from adult services to adult services.

My experience is people talk about it. They give suggestions to the family but even in very complex diseases it's up to the family to negotiate that. It's a very complex issue because when they go into adulthood, the insurances change, providers and what insurance they accept change; the pediatric system really knows nothing about the adult healthcare system. The pediatric endocrinologists will know who the adult endocrinologists are and may point them to them, but they don't know what the adult system of care is for children with diabetes, for example.

All they do is do some general education. Our children services Title V care coordinators they stay with them during that time frame. So oftentimes they're the only ones giving them more guidance about where to go.

On the adult side, there's been very few studies looking at how do people do after transition. This is one study that was actually done in Canada. And they've -- in

cardiology is one area where they've actually done a lot of training of adult cardiologists in caring for congenital heart disease.

So I think it was because they got to be adults and then the adult surgeons had to operate on these people and they were really scared because they didn't know what to do with them.

So they had certification programs in congenital heart disease for adult cardiologists. Anyway, this study looked at how many of these folks that they followed in these special heart centers made it to adult special heart centers. And only about half of them made it to the adult special heart centers over the course of one to two years. They had some positive and negative factors. Basically the folks that were pretty compliant or adherent to their treatment, adherent to visits and the ones that had other problems that would put them at higher risk like using drugs were less likely to make that connection. But this is even with a special connection program, only about half got to that special adult transition program.

What are the barriers? ...

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