

HRSA/MCHB 2007 FEDERAL/STATE PARTNERSHIP MEETING

Building Blocks for Promising Practice Models

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Deficit Reduction Family Style:

Understanding the DRA, the FOA and the \$\$\$ for Families

DONENE FEIST: Basic health services. Usually, depending upon where you live in that big rural area, sometimes it can be an hour drive to some of the urban areas for healthcare. Or it could be up to a four- to six-hour drive, depending on power, if families are going to Bismarck or Fargo. When my son got burned, we were going to Minneapolis, so that was a five-and-a-half-hour drive.

Also in North Dakota, SSI isn't an automatic Medicaid eligibility because we're a 209-B state like 11 of the other states in the country.

Children and youth with special healthcare needs in North Dakota, the prevalence rates are very similar to the national rates by age and gender. And that came from the CSHCN survey. We have a pretty diverse culture in North Dakota. We have five American Indian reservations, two Air Force bases, a couple of religious communities like the Brethrens and (inaudible) which are of German origin.

Then we have a pretty large transient migrant population that basically comes because of our agriculture; and then we do have a large refugee population, which is just increasing all the time. And most of that is on the western half of our state.

Western? Eastern. Sorry. We have quite a large labor force with working moms. We're the second highest in the country of women working two jobs. And I would happen to be one of them. So South Dakota is first in the country. So that's kind of that pull yourself up by the bootstraps kind of thing.

Families of children and youth with special healthcare needs have had to quit their job, 28.1%. Some of them didn't have to take a job or not take a job or greatly changed their job.

And then I think this statistic actually is higher for North Dakota than it was in some of the parts of the country, was that most of -- 24% of our children live in poor or near poor families. I think that was a little bit higher.

30% of employment was affected for our kids in North Dakota. 60% missed one or more days of work. And 50% of the families had no paid sick leave or family leave. So those are some of the impacts that we had in North Dakota.

31% of our families have public health insurance, which SCHIP is really not adequate. And we did hear a lot during our legislative session of well what do these kids need this for, they have SCHIP.

On, I think it was, the Senate floor, that claim out loud and clear but it passed anyway. 12.9 had no insurance at all in the last 12 months. 19.1% needed special health services, equipment or other adaptive things.

24% of the families experienced financial problems. And that's the one I think is higher in North Dakota than the national average. And 22% of families were not able to pay for their financial costs for their child's health needs.

Similarly, and you can get all that information for your states off the county and the surveys as well. We used a lot of the national surveys with almost all of our publications to make sure that policy makers were understanding why families needed this bill.

A couple of stories, quick stories, is Jen and Allison are on the left. Allison has a metabolic disorder and was quite a champion for us in the legislative session.

She gets an IV infusion a couple times a month, which costs just about, I think it's like almost \$7,000 a month that Blue Cross/Blue Shield is now picking up. But Jen's biggest worry is that's going to stop at any time because they can and she won't -- they're over the income guidelines for any other types of assistance.

In North Dakota, we only have our DD waiver, and we have a TBI waiver. Other than that, there was no options for families, really. In our last legislative session, and I'll talk about that in a little bit, we did get a Medicaid waiver passed. However, it didn't come attached with any money. So we also had to work to get that as well.

And on the top picture, one of those little skiers up there passed away during the legislative session, so we'll talk about her later. And on the bottom is Missy Bronco's family they float between SCHIP and Medicaid. And one of the oldest one just got -- she's no longer eligible for the DD waiver. So the worry was who was going to pick up the pieces for these families?

So what would it take to get the Family Opportunity passed in North Dakota? We started -- when Family Voices started early on. So we were pretty much on board as far as the educational pieces and what we needed to do as far as fact sheets and all those kinds of things.

But the first thing was to get others interested. So there was a group, I'm part of a consortium of disability advocates from children's advocates all the way to adults advocates, and that was one group that we pulled together. We pulled together family leaders, consumers, some providers. We went pounding doors, this group of us, to see who we could get to sponsor the darn thing if we were even going to get one.

Of course joining forces with our partnerships like the Department of Human Services, Medical Services Division, Children with Special Health Services, North Dakota Disabilities Advocacy Consortium, Children's Caucus, Protection and Advocacy, we all kind of worked together to join forces to get some of the message out there.

And then we found our bill sponsors, which was -- they're listed there, not like you know who they are, but I listed them anyway.

The other thing was that, our Department of Human Services, the big thing was that the Governor's budget was coming out, and to get this piece of legislation as an optional request on the Governor's budget was a huge piece, and that took a lot from our members from the Department of Human Services. And Tammy is here with our Medicaid directors. And I can't thank them enough.

So that was a huge piece right there. And then the big thing was to stay on the radar for families and legislators and the public in general.

The one thing that one of the legislators, he joked a lot, quite honestly, about he'd say Donene, did you send out another e-mail on your listserv? Yes, I did. But in 2003 we had legislation that kind of set the stage a little bit for the Family Opportunity Act.

It was House Bill 1148 personal care services more for adults and home and community-based services in our '03 session. But a lot of the testimonies that families

and other advocates provided, the mention of the Family Opportunity Act was mentioned repeatedly over and over again. You know like prepare, because it's coming, kind of an educational piece.

And then our legislative session is only every two years. So that makes it a little difficult at times. And then in our '05 session, we had a family that had a little one with Russell Silvers syndrome. She was falling in the gaps. Once she left the early intervention system, there was really no options for them as a family.

So she went to a legislator and they wrote a bill. And I'll be darned it passed. But we kind of thought that was a little bit of -- worried that it was going to open up a Pandora's box. So we added language to that bill so that -- that's where our Medicaid waiver came in so we could get some extraordinary, we could get a waiver for our children with extraordinary medical needs who may otherwise need hospitalization.

And then we also, we thought while the going's good let's ask for a study with children with special healthcare needs because everybody was looking at our population of kids differently. And I was hoping that that would be a little more successful than it was and that we would look at everything a little more broadly, but it didn't happen that way, but maybe in the future we can.

But with this, we were able to keep talking about the family opportunity act in the interim legislative session. So that they kept hearing it a little bit.

So again making the case, we used a lot of state data. Insurance (inaudible) from the Catalyst Center. We used the National Survey from Tammy and Data Resource Center. We used the Title V needs assessment and also while not just the Title V needs assessment, but we got pulled together because of the waiver we pulled together information from Blue Cross/Blue Shield and Medical Assistance to identify what was needed for our Medicaid waiver as well.

And then we did, Family Voices of North Dakota did what do families think about healthcare in North Dakota to identify some of the family unmet needs and costs. And we put together that as a publication as well.

It was really important to provide them with the information to identify that these families were not -- uninsured was not the problem but that they were underinsured. So we put together some fact sheets. One of the confusing pieces was that the Medicaid waiver and our family opportunity act were in one bill.

So our legislators couldn't tell really what was the difference between one or the other. So we put together a fact sheet that identified the difference between the two. In your booklets, you also have one of the other publications that we did was our Family Stories booklet. We tried to get as many stories from across the state as we could. I think we ended up with 30.

But with pictures and put a face to what the issues really were for these families. With the data from Tammy on the back of it so that you have not only the data to support it, but you've got the stories to go along with it.

We did a lot of promotional materials and we did an awful lot of informational alerts as well. And then families really came out and did a lot of testimony. There was quite a group of us that did testify. And Tammy says it was organized but actually it was unplanned organized. When one would say something, somebody else would pick up the other thing that might have been missed. And I don't know how we did that, but it just kind of flew by the seat of our pants. It really wasn't too organized, but...

So this is kind of the roller coaster of up and down that we went through because we only had from really December until March, the day of the vote, for it to pass.

So in December we got it on the governor's list. By the beginning of the session we had -- well, actually we didn't have all the bill sponsors the day of the first day of the session. And then it started, as testimony started about the end of January and we did a little media blitz. You can kind of see how it kind of went.

But at the end of March we had a disability awareness day, which was really quite neat, because a couple of the senators were reading books to the kids. We had some kids at the Capitol, and it was a good media day.

And so they talked about the Family Opportunity Act too with the media. Some of the families.

So the outcome was that our bill passed and signed on April 11th, 2007 at 200%. The bill also passed. We passed the bill for a waiver the previous session. The money came in this session.

And we'll need to do a lot of monitoring. I'm hoping that the Department of Human Services will track the denials and income of the families so that when we go back and identify that to try to get up to 300%, we'll know how many that we're looking at.

And the Catalyst Center actually was really good about identifying how many families we actually had in North Dakota. So it was a huge effort on everybody's part, really.

And then the education and outreach, the department is putting to the a fact sheet for providers. We'll put together a fact sheet for families and it's just going to be a lot of ongoing education. A lot of grassroots about the program, how it's going to work, what the process is, that kind of thing.

So some advice for the and hindsight for tips for our Title V leaders I think if you can duplicate Tammy all over the country that would be a great thing, Tammy? Because consumer leadership organizations are your allies, whether it's Family Voices or who your consumer leaders are. And when you do your annual needs assessment, do check

the pulse of the community level by tracking (inaudible) and emails and things like that to really access those families at the community level too to see what their thoughts are.

And like I said already, informed consumers are really terrific allies, and I think we're very lucky in North Dakota that we're a small enough state and everybody works together, but I can't say enough about our Title V directors, that they truly get the meaning of family professional partnership and they work hard to do that.

And keeping a face on the issue, the short impact stories with pictures. And what's the return on investment really for families? We all pay taxes and what that's going to mean for families.

Some of the other implementation considerations is they had to come up with a name. And I think it's going to be Our Children With Disabilities Program, am I right? And one of the things that's always been a little confusing for families is our SCHIP program is Healthy Steps. Our EPSTD program is Health Tracks. So many that sound alike, so we left it simple.

And after the session it takes time to hire and train staff while others carry the workload. So there's a lot going on right now.

And in North Dakota they added a new MMIS system. So to that they're going to have to have a new eligibility group. So those changes to the system are going to take a little bit of time.

Then there's also after a session multiple competing issues that can really make implementation difficult, but I think implementation right now is expected to happen in March of '08.

So ongoing communication really needs to transpire with family organizations and amongst staff before and after an implementation to ensure that everything is working properly.

On the left -- right. Is Theresa Caseman while one of the days of the testimony they buried her little girl because well she got sick and passed away. But Theresa was going to come and testify that day, and with her is Governor Holebin one of our bill sponsors Judy Lee. But that was quite an emotional day.

If nothing else, all of us wanted to carry that banner for that one right there. And that's it.
Any questions?

(Applause)

[END OF SEGMENT]